



Chinese Diaspora Communities' Knowledge of and Engagement with Advance Care Planning: A Systematic Integrative Review

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Words of Welcome

Dear Colleagues and Friends,

On behalf of the Board of Directors and as President, it is my pleasure to welcome you to the 18th EAPC World Congress in vibrant Rotterdam. After three years in the virtual congress reality of a world suffering from a devastating pandemic, we have finally returned to meeting in person! The last time we met in 3D and live was in 2019 in beautiful Berlin, which was the most successful EAPC congress ever. Palliative care is based on face-to-face interaction and this is also true for us peers. Meeting old friends, presenting and discussing new data, developing new ideas, networking and making new friends is much easier when we perceive each other with all our senses and not only as avatars in rectangles. However, we have learned a lot since the beginning of the global contract restrictions in terms of disseminating knowledge and our congresses. We are trying to save some of the lessons learned for Rotterdam and future congresses, for example, by making more content available online for after the congress.

It has been my great honour and pleasure to work with a dedicated group of colleagues who have worked tirelessly to make this Programme a reality. We are also very grateful to you for your continued support. We understand the challenges many of you face in your clinical work during a global pandemic, and we would like to thank all those who submitted one of the over 900 abstracts around which we designed the entire Programme.

There are many other people I would like to thank for their help in making this event a reality: the Board of Directors, who were brave enough to take the risk and opt for a face-to-face meeting during the period of great constraints, in the hope that in 2023 such an event would then be possible again. Special thanks go to the Scientific Committee and in particular our dedicated Chairs Sandra Martins Pereira and Agnes Csikós, and EAPC Scientific Coordinator Claudia Sütfield. They all deserve our thanks for their hard work and dedication over many hours, many of them in their spare time. More personal thanks, of course, go to the EAPC Headquarters team, Julie, Christine, Cathy, Joanne, Catherine, Carla, Fódhla Patricia and Guillermo for the logistics, organisation, and managing all the other EAPC demands while putting on a World Congress. Now I wish us all a wonderful congress reflecting on equity and diversity in palliative care!



Professor Christoph Ostgathe
President, European Association for Palliative Care

Dear Colleagues

As co-chair of the scientific committee, I would like to welcome you to Rotterdam for the 18th EAPC World Congress. With my co-chair Sandra Martins Pereira, it has been my pleasure to be a part of this enthusiastic and committed Scientific Committee. I would like to thank all of them for their hard work over the last two years. Working together, I believe that we have developed a diverse and interesting programme that will appeal to all delegates. We were most happy to see the diversity of topics and themes that has been submitted. Much of the programme has been developed around the submitted abstracts and the proposals for parallel sessions, these reflect the work of a wide range of clinicians, researchers, academics and others from Europe and beyond. Our plenary speakers, EAPC group meetings, and other events will make this a very special event. We are very pleased that so many people have registered and are attending. It has been four years since the last in-person congress in Berlin and now it is time for us to all be together again. To meet face to face gives us opportunity to share not just knowledge but personal experiences and good practices and to network. I wish a fruitful and enriching congress to all participants.

I look forward to seeing you in Rotterdam

Dr Ágnes Csikós
Co-Chair of the Scientific Committee, Hungary

Dear Colleagues, dear Friends;

It is a pleasure to welcome you to the 18th World Congress of the European Association for Palliative Care in Rotterdam. This 2023 congress is the first face-to-face congress organised by the EAPC since 2019. Like other EAPC, this congress is the result of two years of planning, organisation, meetings, reflection, and decision-making. Finally, here we are!

It has been our honour to co-chair the Scientific Committee of this congress together with my colleague Agnes Csikós. For the first time, as far as we remember, the Scientific Committee, composed of a dedicated group of colleagues (thank you Alberto Alonso, Augusto Caraceni, Fin Craig, Jeroen Hasselaar, Martin Loucka, Wendy Oldenmenger, Christoph Ostgathe, Danai Papadatou, Nancy Preston, Audrey Roulston, and Rainer Simader), was co-chaired by two women who have the particularity of living in the South and Eastern parts of Europe.

Under the theme “Equity and Diversity in Palliative Care”, the EAPC 2023 congress focuses on understanding health inequities and diversity in palliative care. Through a rich and diversified program, this congress draws attention to the utmost need and goal of creating equity of fair access, opportunity, and advancement in palliative care for all people in need of this care, within a context of diversity.

We will have the opportunity to reflect on ways to better understand why and how inequities in palliative care occur, develop strategies aimed at reducing those inequities, and identify which challenges and policies could help to improve equity in palliative care. That is why, determining the prominent factors in the production of inequities in palliative care and deciding which ones are most amenable to change is paramount.

As an operational definition of equity in palliative care, we adapted the definition proposed by the International Society for Equity in Health. Equity in palliative care is the absence of systematic and potentially remediable differences in one or more aspects of palliative care outcomes across socially, demographically, or geographically defined population groups. There is no basis for expecting a single characteristic or set of characteristics to be most influential in causing inequities in palliative care. Evidence suggests otherwise.

To complement the understanding of health inequities in palliative care, we need to take diversity in palliative care into account. The definition of diversity encompasses variety and the condition of being different or having differences. Rarely are diverse influences simultaneously explored in the literature to better understand and tackle plausible explanations for inequities in palliative care. Sometimes, diversity is used as a euphemism for “outside the majority” or “different from the dominant group”. Yet, as human beings, diversity is part of who we are. We are inherently diverse, and evidence shows that when reflecting on and discussing palliative care, there is no “one size fits all”.

Are we promoting equity in palliative care? If not, why are we failing on equity in palliative care? Do we spend inadequately or inappropriately on palliative care provision? Why in a world now much more aware of the impact of the social determinants of health are the world’s most vulnerable persons still missing out? Why are we still failing in providing increased or augmented palliative care services for socially, demographically, or geographically defined population groups with greater palliative care needs? How can diversity help to understand and tackle inequities in palliative care? These are just a few examples of questions that will certainly become “food for thought” during our days together in Rotterdam. And, we are so grateful to all and each one of you for your contributions to the scientific programme.

The 18th World Congress of the European Association for Palliative Care gives us the opportunity to reconnect and share all the exiting work that is being developed within our worldwide palliative care community. These days together offer us the amazing chance to meet colleagues and friends, to be inspired and inspire others, and to re-energise ourselves to face the future challenges for palliative care.

Promoting equity and taking diversity into account is not only the theme of the 18th World Congress of the EAPC. They should also be at the heart of palliative care practice, organisation, research, education, advocacy, and policy.

I wish you a wonderful and exciting congress and look forward to meeting you in Rotterdam.

Prof. Dr. Sandra Martins Pereira
Co-Chair of the Scientific Committee, Portugal

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A Innovation and e-Health Solutions
B Challenges in Symptom Management
C Caregivers
D Palliative Care for Older People
E Education and Advocacy
F Ethics, Policy and Law
G Diversity and Disparities
H Psychological and Cultural Challenges
I Paediatric Palliative Care

1. Sessions

1.1.1 Plenaries

PL 1 Inequities in Palliative Care

PL 2 Wish to Hasten Death: Implications to Palliative Care

PL 3 Palliative Care – Technology and New Media

PL 4 Advance Care Planning: What Do We Know and How to Move Forward

PL 5 Building Leadership in Africa to Promote Equity in Palliative Care

PL 6.1 Clinical Impact of New Developments in Opioid Analgesia

PL 6.2 Evidence of Symptom Control for the Dying Phase

1.1.2 Best Abstracts

1.1.2.1 Deaths at Home, Area-based Deprivation and the Effect of the COVID-19 Pandemic: An Analysis of Mortality Data across Four Nations

1.1.2.2 International Consensus of Occupational Therapy Interventions for People with Palliative Care Needs: A European Association for Palliative Care Group Concept Mapping Study

1.1.2.3 Validation of the EAPC/IASP Diagnostic Algorithm for Neuropathic Cancer Pain: Preliminary Results

1.1.3 Researcher Awards

1.1.4 Parallel Sessions

PS 1 - E Palliative Care in the Context of Emergency Medical Services

PS 2 - G Neither Seen nor Heard: Identifying and Meeting the Needs of Minority Ethnic Patients and Families

PS 3 - G Challenges and Opportunities of Providing Palliative Care for People with Intellectual Disability

PS 4 - E Civic Contributions to End of Life Care: Understanding Compassionate Cities in Action

PS 5 - G Palliative Care in Conflict Affected Settings

PS 6 - F Ethical Challenges when Conducting Research in Palliative and End-of-Life Care in Clinical Settings: How to Address them Successfully?

PS 7 - G Challenging the Inequities in Palliative Care Provision for People in Prison: Policy, Research and Practice

PS 8 - D Improving Palliative Care for Older People: Innovative Care Approaches

PS 9 - A Biomarkers in Palliative Medicine

PS 10 - G Poverty and Deprivation at End of Life

PS 11 - F Enhancing Healthcare Teams' Ethical Decision-Making in Palliative and End-of-Life Care

PS 12 - G Using Big Data to Understand and Address Inequity in Palliative and End of Life Care

PS 13 - H Management of the Wish to Hasten Death in Europe

PS 14 - G Palliative Care and Bereavement Needs and Experiences of LGBT+ People: Lessons Learnt, Recommendations for Practice and Next Steps

PS 15 - H Understanding Care Experiences: the Challenge of Conducting Transnational Qualitative Research

PS 16 - A Monitoring Technologies in the Last Phase of Life for People with Communication Difficulties

PS 17 - F Rethinking Palliative Care in Cultural Traditions to Optimise Equity and Diversity

PS 18 - B The Use of Proportional Palliative Sedation to Manage Refractory Symptoms

PS 19 - F The Lancet Commission on the Value of Death: Future Actions for Palliative Care

PS 20 - H Gratitude in Palliative Care: a Promising Beneficial Source for Patients and Professionals

1.1.5 Breakfast with. . . .

A Challenges in Randomised Controlled Trials in International Studies in Palliative Care

A EAPC Research Network Junior Forum

A From the Theory of Change to Recommendations for Clinical Practice

A How to Best Overcome Pitfalls in SWRCT in Palliative Care

B Pain and Opioids

C Are our patients' children their next-of-kin or their carer?

F OECD Publication "Better Care at End of Life"

F "Palliative Care During the War"

F Video Presentation: A Film Exploring Different Experiences Surrounding an Assisted Death in Switzerland

G Using Experience-Based Co-Design to Implement Palliative Care Research with Vulnerable/Underserved Groups

1.1.6 Free communication Sessions

FC 1 - B Advance Care Planning

FC 2 - F Ethics, Policy and Law
FC 3 - H Communication, Care Discussions and Shared Decision Making
FC 4 - F Health Services Organisation
FC 5 - E Education and Advocacy
FC 6 - H Grief and Bereavement
FC 7 - B Challenges in Symptom Management
FC 8 - B End-of-Life Care and Decisions
FC 9 - G Diversity and Disparities
FC 10 - A Innovation and E-Health Solutions
FC 11 - B Experiencing the COVID-19 Pandemic
FC 12 - C Family Caregivers
FC 13 - D Palliative Care for Older People
FC 14 - B Palliative Care in non-Cancer Conditions
FC 15 - H Psychosocial and Cultural Challenges

1.1.7 Paediatric Palliative Care Day

1.1.8 Workshops

W 1 - B Skills Workshop : The Compassionate Breath - Breathlessness Anxiety Management
W 2 - H Miscommunication with the Media
W 3 - H We Are Also Going to Die
W 4 - A Designing and Implementing Virtual Palliative Care Courses
W 5 - D Strategies to Provide and Measure Palliative Care Delivery for People with Dementia in Long-Term Care Settings
W 6 - H Workshop World Grief Café

1.1.9 Special Events

1. Public Understanding and Discussion of Dying
2. Palliatief meeting (In Dutch)
3. About Books and Communication
4. Digital Legacy Conference

1.1.10 Open meetings

OM 1 - APHN - Collaborative Opportunities in Research and Education in the Asia Pacific Region
OM - 2 G EAPC Reference Group Palliative Care and Intellectual Disability
OM - 3 D EAPC Task Force Advance Care Planning in Dementia
OM - 4 G EAPC Task Force Improving Care for LGBT+ People
OM 5 - C EAPC Task Force Social Work
OM - 6 E EAPC Task Force Innovation in Nurse Education
OM - 7 F EAPC Reference Group Public Health and Palliative Care
OM - 8 B EAPC Reference Group Primary Care "Towards Primary Care Providing Universal Access to Palliative Care Worldwide"
OM – 9 YOGA in the Morning
OM 10 - A - Update on European Union Funded Research Projects'
OM - 11 A EAPC Research Network Junior Forum
OM 12 - I EAPC Reference Group Palliative Care for Children and Young People
OM 13 - H EAPC Task Force Bereavement
OM 14 - G EAPC Task Force Palliative Care for People in Prison
OM - 15 B EAPC Reference Group Neurology and Palliative Care/European Academy of Neurology (EAN)
OM - 16 E EAPC Reference Group Education and Training in Palliative Care
OM - 17 A EAPC Task Force Leadership in Palliative Care
OM - 18 H EAPC Reference Group Spiritual Care
OM - 19 YOGA in the morning
OM - 20 Eastern Europe/Central Asia Meeting

1.1.11 Closed meetings

EAPC Board Meeting
EAPC Core Group 2025
EAPC National Associations Presidents and Chairs Meeting
EU Funded Project - Pal-Cycles
Kaderopleiding Palliatieve Zorg
New EAPC Task Force European Union Projects
WHPCA Board meeting

1.2 Abstracts

PL 1 Plenary Inequities in Palliative Care

Kelli Stajduhar

Victoria (Canada)

While increasingly recognized as a human right, access to palliative care is still not a given. Indeed, access to the services involved, from medical to social to psychological to spiritual, is uneven across the Global North. Even though palliative care as a concept seems to be unanimously supported, that is what it remains: an idea that only becomes reality for fewer than half of the people who might benefit. Those who do benefit from palliative care services tend to also benefit from high socio-economic status and family support, as opposed to those people facing the end-of-life who also face inequities like homelessness, poverty, isolation, racism, and stigma.

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. In this presentation I will argue that our ongoing desire to legitimize our field to promote "palliative care for all" has led to the creation of "blind spots" that have allowed us to privilege some in need of care, and render 'others' invisible. In doing so, we run the risk of dismantling (albeit unintentionally) the very root structure from which palliative care originated.

PL 2 Plenary

PL 2 Wish to Hasten Death: Implications to Palliative Care

R. Voltz¹

¹University Hospital Cologne, Palliative Medicine, Köln, Germany

Background/aims: As in many countries, currently also in Germany, palliative care is confronted with our societies' growing wish for a liberal handling of ending one's life, including assisted dying. For many in palliative care, this challenges long held ethical positions. On the other hand, trying to fulfill all patients' wishes and not abandoning them is also a key feature of palliative care. What are the implications of this situation for our field?

Methods: This personal reflection overlooking nearly 40 years of hospice movement will take a differentiated view:

Results: First, implications for whom: How good is my personal communication competence? What is the aim of our conversations with patients? How do we in our teams deal with this topic? Do we have institutional SOPs? Have we as a field neglected this situation in our teaching curricula? How do we position palliative care in political discussions?

Second, implications for which question along the patient journey: How do we handle the clinical routine situation? How is a further diagnostic step organized? How actively do we participate in assisted dying: Do we stop care, tolerate it passively, or actively participate?

Conclusions: Based on the clinical, research and teaching experience in our department on this topic over 15 years a clear roadmap for possible answers to these questions will be presented which will hopefully in the future lead to a more relaxed positioning of us individually and as a field.

PL 3 Plenary

PL 3 Palliative Care - Technology & New Media

M. Taubert^{1,2}

¹Cardiff University, School of Medicine, Cardiff, United Kingdom,

²Velindre University NHS Trust, Cardiff, United Kingdom

Background/aims: In this plenary past, present and future trends that can enable patients, carers and healthcare professionals to make good use of emerging technologies are explored. Media such as video, virtual/augmented reality, artificial intelligence (AI) and even the humble QR code, have already had a significant impact in our quest to make aspects of palliative care more understandable and transparent.

Methods: Working with patients, carers and students at a tertiary cancer centre has led to several studies and QI projects involving new media, including the use of AI. For instance, a virtual reality 360 degree radiotherapy experience is now available on the hospital trust's own YouTube channel, and is very highly accessed. But even day-to-day technologies, such as digital remote video consultations, have quickly led to new challenges regarding how we best communicate when using technology. Advance & future care planning can be demonstrably enhanced when outpatient or bedside video technology is used to help people understand complex topics like Do Not Attempt CPR (DNACPR) decisions, and we have used QR codes to link to trusted resources. Digital legacy planning has quickly become an important topic of conversation for healthcare professionals, social workers and welfare rights officers.

Results: New technologies offer exciting possibilities for patient/carer engagement in all the multiple areas that palliative care covers. New media are now frequently used by patients for information gathering. People will not always read the paper information leaflets they are handed, but instead will enquire on social media, YouTube and more recently on AI platforms such as chat GPT to find answers to their questions and problems. The areas that can be covered by technology are vast, and may allow clinicians to focus more on the interhuman aspects of communication, whilst technology 'does the rest'.

Conclusions: Rather than just *consider* new technologies in our field of expertise, we need to accept that they are already firmly established in patients' homes and on smartphones, frequently used in an unstructured way. Setting up local systems, including the AI project we have in use in our hospital trust, can be beneficial. But it can also be cumbersome, for instance when having to feed thousands of possible question/answer scenarios into the software. Therefore, collective approaches, ideally with mass participation, will ensure that such new media and technologies can be peer-reviewed and evidence based.

PL 4 Advance Care Planning: What Do We Know and How to Move Forward

I.J Korfage¹

¹Erasmus MC University Medical Hospital Rotterdam, Public Health, Rotterdam, Netherlands

Background/aims: The potential of advance care planning is appealing to many. Who does not want care and treatment to align preferences of patients and their relatives? However, meeting expectations is proving challenging.

Why is this and what can we possibly do about it?

In my lecture I will discuss the evolving concept of advance care planning, look at recent research on advance care planning, and conclude with some recommendations.

Methods: See section above

Results: See section above.

Conclusions: See section above.

PL 4 Plenary Award Session

PL 5 Building Leadership in Africa to promote Equity in Palliative Care

Z. Ali¹

¹NCD Alliance Kenya, Nairobi, Kenya

Background/aims: Africa faces a double burden of infectious and chronic diseases. The burden of disease due to NCDs and injuries, measured by the proportion of total disability-adjusted life-years (DALYs), has increased from 37.8% in 1990 to 66.0% in 2019 in the African Region. Most countries are seeing an increase in numbers of years spent in poor health, even though both life expectancy at birth and healthy life expectancy has improved in the same period.

Although there has been significant improvement in accessing palliative care in Africa, there remains a substantial need. It is estimated that more than 80% of people in urgent need of palliative care live in low- and middle-income countries (LMICs) where basic health care is less well-developed. This includes the African Continent, where Palliative care is needed the most. In Africa, approximately 80% of newly discovered cancers are no longer curable at the time of diagnosis, and access to basic palliative care and medication-based pain relief is extremely limited. It is estimated that in LMICs 20 million people die each year with severe pain that could have been alleviated with morphine. For another 28 million patients who did not die, morphine to combat severe pain was not accessible. Only 3.6% of available opioid painkillers are available in LMICs and only 0.03% in low-income countries. In the near future, the total number of patients who require palliative care at some point in their lives will grow significantly and is likely to double. Although palliative care as a discipline in high-income countries is maturing, it is still relatively in its infancy in sub-Saharan Africa an area where it is needed the most.

Methods: Although palliative care as a discipline in high-income countries is maturing, it is still relatively in its infancy in sub-Saharan Africa an area where it is needed the most. This session will focus on the importance of interdisciplinary palliative leadership in key areas: research, education, policy/advocacy, and integration with health systems, using Kenya as an example.

Results: Plenary session

Conclusions: Palliative care in Africa needs to be prioritized, hence effective leadership is important

PL 5 Closing

PL 6.1 Clinical Impact of new Developments in Opioid analgesia

P. Sjögren^{1,2}

¹Rigshospitalet - Copenhagen University Hospital, Section of Palliative Medicine, Department of Oncology, Copenhagen, Denmark, ²The Danish Cancer Society, Copenhagen, Denmark

Background/aims: Since its development in 1986 the World Health Organisation three step analgesic ladder has been a worldwide guideline for professionals treating cancer-related pain. Despite the widespread use of this ladder principle, unrelieved pain continues to be a substantial concern in one third of patients with malignant diseases. Recent guidelines based on systematic evidence-based grading including European Society of Medical Oncology (ESMO), National Comprehensive Cancer Network (NCCN), WHO and American Society of Clinical Oncology (ASCO) guidelines have further clarified the level of evidence of different opioid management strategies in moderate-to-severe pain related to cancer or active cancer treatment.

Methods: Nowadays, patients with cancer have exhibited longer life expectancy and higher survivor rates due to advances in the diagnostic methods and treatments, which may also prolong the opioid treatment for cancer-related pain. At the same time, the palliative care needs of patients in early stages of cancer trajectories are increasingly recognized and addressed, including the need for opioid management. Thus, besides the classic adverse effects of opioids, emerging evidence suggests that patients with cancer might be at higher risk of opioid addiction than previously thought. Contemporarily access difficulties to opioids due to interventions to combat overuse and misuse may constitute barriers for people with cancer in some societies.

Results: Therefore, it should be underpinned that the distorted patterns of global opioid availability and accessibility is a sensitive and complex issue. There are high income countries in opioid crisis fighting against the iatrogenic opioid over-use and a global pain crisis with many middle- and low-income countries with limited access to opioids. A balanced approach including regulations on prescribing opioids and adequate public information and training of health care professionals among others, is recommended to improve the access to pain treatment with opioids.

Conclusions: Considering the changing trajectories of cancer diseases and the increasing inclusion of non-cancer organ failure in palliative care programs worldwide, a continuing revision of the palliative care opioid guidelines should take place implementing safe management and evidence-based prescribing of opioid analgesics.

PL 6.2 Evidence of Symptom Control for the Dying Phase

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¹The University of Texas MD Anderson Cancer Center, Houston, United States

Background/aims: In the last weeks and days of life, patients with advanced diseases often experience a myriad of distressing symptoms such as delirium, dyspnea, pain and excessive respiratory secretions. The objective of this presentation is to discuss an evidence-based approach to the management of delirium, dyspnea, pain and excessive respiratory secretions in the last weeks and days of life.

Methods: For each symptom, we shall review the assessment, non-pharmacologic and pharmacologic approaches.

Results: The principles of symptom management based on studies conducted in patients earlier in the disease trajectory are often generalized to patients in the last weeks and days of life. It is important to recognize that suffering is multidimensional and that it is essential to address the physical, emotional, spiritual, social and informational aspects of care for effective symptom relief. At the same time, there are several unique considerations in patients in the last phase of life. First, clinicians need to weigh the risk and benefits of diagnostic tests and therapeutic interventions in the context of a limited prognosis. Second, as patients experience rapid decline in their bodily function, they may also lose their ability to participate in non-pharmacologic measures or swallow medications. Third, symptom assessment, communication and decision making may be compromised in delirious patients. Fourth, there is often limited time to introduce/titrate therapy. Fifth, caregivers have a particularly critical role in this phase of life and caregiver support represents another dimension of care. Sixth, some symptoms, such as excessive respiratory secretions, do not appear until the last days of life. Understandably, research in the last weeks and days of life can be particularly challenging. Although only a few randomized clinical trials have been conducted in this setting, these studies showed that it is possible to conduct research even in the last phase of life and provided some evidence to guide clinical practice.

Conclusions: More high quality research is needed to inform clinical practice and improve symptom management in patients in the last weeks and days of life.

Conflict of interest: Consultant for Eton Pharmaceuticals.

Best Abstracts

BA 1 Validation of the EAPC/IASP Diagnostic Algorithm for Neuropathic Cancer Pain: Preliminary Results

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of Palliative Medicine, Edinburgh, United Kingdom, ⁵Oslo University Hospital, Department of Oncology, Oslo, Norway, ⁶Università degli Studi di Milano, Department of Clinical Sciences and Community Health, Milan, Italy

Background/aims: In 2014, a Delphi expert survey report, resulted in the proposal of the EAPC/IASP algorithm for the diagnosis of neuropathic cancer pain (NcP). To date there is no clinical information on its application and accuracy. Our aim was to determine the accuracy of the EAPC/IASP algorithm compared to the NeuPSIG grading system and a standardized bedside neurological examination as gold standard.

Methods: This is a cross-sectional observational study of diagnostic accuracy conducted in a palliative care and pain management clinic. Only patients with cancer pain of intensity ≥ 3 (NRS 0-10) in the past 7 days and last 24 hours were considered eligible. The treating palliative care physicians implemented the EAPC/IASP algorithm during the visit, while an independent investigator applied the NeuPSIG criteria and evaluated sensory profile following a standardized bedside assessment. Accuracy for the algorithm was measured in terms of sensitivity and specificity.

Results: 81 patients were enrolled from August 2020 to December 2021, out of 100 hundred planned, as estimated by the sample size calculations. Mean age was 62.5 years. Mean pain intensity in the last 24 hours was 6.2. Prevalence of NcP as assessed by the EAPC/IASP algorithm and NeuPSIG criteria was respectively 39.5% (95%CI 28.7-50.3) and 35.8% (95%CI 25.1- 46.5). Sensitivity and specificity for the EAPC/IASP diagnostic algorithm compared to the NeuPSIG criteria integrated with the standardized bedside test was 84.4% (95%CI 67.2-94.7) and 95.9 (95%CI 86 -99.5) respectively.

Conclusions: The preliminary results indicate a very good performance of the algorithm in diagnosing NcP. More patients are needed to confirm this result and its generalization.

BA 2 International Consensus of Occupational Therapy Interventions for People with Palliative Care Needs: A European Association for Palliative Care Group Concept Mapping Study

M. Sampedro Pilegaard¹, E. Ejlersen Wæhrens², D. Morgan³, K. la Cour², K. Doyle Lyons⁴, M. Lozano Lozano⁵, M. M.R. Prado De Carlo⁶, G. Rezende⁶, EAPC OT task force

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Background/aims: Engagement in occupation is a priority for people with palliative care needs. The term *occupation* describes meaningful and/ or purposeful doing in everyday situations. While evidence shows that occupational therapists can play a key role in the care of those at the end of life, more knowledge about effective occupational therapy (OT) interventions for this group of people is needed.

Aim: To identify, organise and prioritise effective intervention components within OT for people with palliative care needs from the perspectives of clinicians, managers, and researchers.

Methods: A Group Concept Mapping study was conducted representing a mixed methods participatory approach. Participants were occupational therapists across Europe and worldwide working as clinicians, managers and/or researchers with people with palliative care needs.

The participants brainstormed on the following focus prompt: *In my experience an effective intervention component within OT interventions for people with palliative care needs is*. This was done online using the Concept System® Groupwisdom™ software where they also sorted, labelled and rated each generated statement. A validation workshop was conducted online. Multidimensional scaling analysis and cluster analysis were applied.

Results: 72 occupational therapists from 15 countries participated in the study. 117 statements were identified and organised into five clusters: 1) Being client-centered, 2) Promoting occupational engagement to optimise quality of life, 3) Involving the social, and relational environment, 4) Enabling occupations, and 5) Facilitating occupational adaptation.

Conclusions: Five OT intervention components were found to be effective when supporting people with palliative care needs. Future research should use this knowledge to inform future interventions for people with palliative care needs.

Financial support by the Danish Association of Occupational Therapists.

BA 3 Deaths at Home, Area-based Deprivation and the Effect of the COVID-19 Pandemic: An Analysis of Mortality Data across Four Nations

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Background/aims: The number and proportion of home deaths in the UK increased during the Covid-19 pandemic. It is not known whether these changes were experienced disproportionately by people from different socioeconomic groups. We aim to examine the association between home death and socioeconomic position during the Covid-19 pandemic, and how this changed between 2019 and 2020.

Methods: This is a retrospective cohort study using population-based individual-level mortality data. All registered deaths in England, Wales, Scotland and Northern Ireland were included. The proportion of home deaths between 28th March and 31st December 2020 was compared with the same period in 2019. We used Poisson regression models to evaluate the association between decedent's area-based level of deprivation and risk of home death, as well as the interaction between deprivation and year of death, for each nation separately.

Results: Between the 28th March and 31st December 2020, 409,718 total deaths were recorded in England, 46,372 in Scotland, 26,410 in Wales and 13,404 in Northern Ireland. All four nations showed an increase in the adjusted proportion of home deaths between 2019 and 2020, ranging from 21% to 28%. In all four nations, the increase (2020 compared to 2019) was lowest for people living in the most deprived areas (compared to the least deprived areas) (England: IRR 0.89, 95% CI 0.87 to 0.91; Scotland: IRR 0.93, 95% CI 0.86 to 0.99; Wales 0.88, 95% CI 0.81 to 0.97; Northern Ireland: IRR 0.92, 95% CI 0.81 to 1.04). There was evidence of a significant deprivation gradient in the increase in the proportion of home deaths in England.

Conclusions: The Covid-19 pandemic exacerbated a previously described socioeconomic inequality in place of death in the UK. Further research to understand the reasons for this change and if this inequality has been sustained is needed.

Funding: Marie Curie, grant [MCSO-20-102] and UK Research and Innovation (CovPall-Connect study, grant ref MC_PC_20029; HDRUK2020.145).

EAPC Early Researcher Award

Advancing the injectable anticipatory medication evidence base

Ben Bowers, UK

Is having access to injectable end-of-life anticipatory medications always helpful and reassuring? The prescribing of injectable anticipatory medications ahead of possible need has become established good practice in controlling distressing symptoms for patients dying in the community. The intervention aims to optimise timely symptom control, provide reassurance for all involved and prevent crisis hospital admissions. However, in signifying the imminence of death, anticipatory medication carries great symbolic and emotional impact. Ben's research has investigated current care and patients', family carers' and healthcare professionals' perspectives, with unexpected results and implications for practice.

What is the acceptability, clinical and cost-effectiveness of this common end-of-life intervention? What research is needed next to best inform clinical practice? Ben will outline the major scientific findings of his work to date.

Dr Ben Bowers is an Honorary Nurse Consultant in Palliative Care and Wellcome Post-Doctoral Fellow with the University of Cambridge. His Twitter account is @Ben_Bowers__

EAPC Post-Doctoral Researcher Award

How communication heals and harms in serious illness

Liesbeth van Vliet, The Netherlands

I study how communication can heal and harm when patients are confronted with a serious, life-threatening illness. To do so, I combine insights from communication & palliative care & placebo-and nocebo-effect research.

In this presentation, I'll briefly describe my research trajectory. Next, I'll present some of the research my amazing collaborators and myself have conducted in relation to which specific communication can help patients at which moment in time and which specific communication might cause harm. For example, we have conducted studies building the evidence-base behind clinician-expressed empathy from a patient perspective, while we recently have been working on a global project on when information-provision might actually harm.

I'll round off by sharing some research dreams, which can help us to further understand the evidence-based power of communication, to ultimately improve every patient's care experience at the moment this matters most.

EAPC Clinical Impact Researcher Award

The long and winding road

Sebastiano Mercadante, Italy

I started my work in different settings, including anaesthesia, intensive care, nutrition, pain therapy, other than palliative care. I was lucky, as I had the opportunity to meet and work with the best researchers in the world, also making friends with many of them. Some of them sadly are now retired or died. Thus, I have grown on the shoulder of giants in palliative care. The pathway to achieve the goal of successful research was not easy, it was a long and winding road, due to geographical and institutional issues. Despite these difficulties I produced many data on many different subjects, including cancer pain, breakthrough pain, opioid switching, the use of methadone, palliative sedation, bowel obstruction: more than 600 papers published in the best journals, more than 40 chapters or books, some thousands of conferences in the

five continents, teaching in many universities and hospitals. I worked for EAPC since the nineties, participating to many recommendations, launching the EAPC research working in Sicily, where the first meeting took place. I was the president of the congress of EAPC in 2001 in Palermo, and I was in various boards of many EAPC congresses. In the past I received many awards with the recognition of excellence in research in US and in Palermo, but not in Italy or Europe. Today I'm the recipient of "clinical impact award" of EAPC, a recognition worthy, I hope, of great attention for my long-term activity as a physician involved in teaching, research, but above all in clinical assistance in the real world in a department with two units with different profiles, unique in the world, for early palliative care in an acute unit for cancer patients, and in hospice where incurable cancer and noncancer patients are admitted.

I will continue to work for the next years to promote palliative care and help young investigators to improve the knowledge and experience with new ideas and projects. I'm grateful to EAPC for this award.

1.2.4 Parallel sessions

PS 1 - E Palliative Care in the Context of Emergency Medical Services

PS 1 - 1 A Paramedic-based Program Across Canada Supports More Palliative Care Patients to Spend their Last Days at Home

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¹Dalhousie University/EHS Nova Scotia, Halifax, Canada, ²Dalhousie University, Emergency Medicine, Halifax, Canada, ³Nova Scotia Health, Cancer Care, Halifax, Canada

Background/aims: People with advanced chronic disease often express a wish to spend their final days at home, and often prefer a home death, through a palliative approach to care. Despite this, people with palliative goals of care have multiple visits to the Emergency Department, often being transported by paramedics, in their last weeks and months of life. In 2014 in recognition of the mismatch between patients' wish to remain home and existing paramedic protocols, the Paramedics Providing Palliative Care program was launched, and expanded through a national spread collaborative in 2019. Essential elements include a protocol that enables a palliative approach to care, education, and access to goals of care, supported by diverse stakeholder engagement.

Methods: This program has been scaled up and spread in several Canadian provinces, with mixed urban-rural geographies. These are paramedic-based systems, with over 7000 paramedics at the primary and advanced care levels. Online physician support supplements clinical guidelines. A mixed-methods program of research is ongoing. Paramedic comfort and confidence, patient/family satisfaction, system metrics, have been evaluated as well as fit with paramedic professional identity, in the eyes of palliative care programs as well as paramedics themselves. Vulnerabilities such as rurality, frailty, isolation, poverty, have been examined for their interaction with the Program.

Results: Paramedic comfort with palliative care improved with the implementation of the program. Families report high satisfaction and comment extensively on the compassion and professionalism of paramedics. This is a fit with paramedic professional identity. The odds of hospital days in the last six months of life decreased by 37% with the program. Barriers include: low health literacy, lack of financial means, lack of private and public supports due to geography and/or capacity. Enablers are: eliminating healthcare siloes, peer champions, EMS and palliative care coaches, engagement of leadership, diverse, meaningful and early stakeholder engagement. Challenges were noted: sustainability, turf wars, privacy, communication and shared mental model among diverse and extensive stakeholder group.

Conclusions: The Paramedics and Palliative Care Program has spread across Canada. A mixed methods program of research shows benefit to

patients, families, providers, and the system. Challenges and enablers to spread and scale are noted, chiefly the importance of communication and stakeholder engagement.

PS 1 - 2 Crisis Decision Making; Lessons Learned from Palliative Care and EMS Collaboration

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¹London Ambulance Service NHS Trust, Clinical Directorate, London, United Kingdom

Background/aims: When ambulance clinicians manage a palliative and end of life care (PEoLC) crisis they battle a counterintuitive historical culture; address reversible causes, save life, convey to hospital. Natural dying can be interpreted as a reversible cause, often resulting in emergency department (ED) conveyance. With demands on the UK health service and a drive to reduce avoidable ED conveyance, how can this be achieved in PEoLC situations?

Methods: An improvement programme was established in the London Ambulance Service NHS Trust; a small team combining palliative care and pre-hospital expertise provided leadership, guidance and service development. Collaboration with PEoLC providers established referral pathways and patients' advance care plans were accessible on an electronic palliative care coordination system (EPaCCS).

Results: Service evaluation captured improvement in four key metrics, with learning embedded into business as usual (BAU):

Conveyance to the ED gradually reduced but refined data sources provided a more accurate picture, ED conveyance in BAU showing normal variance (average 29%), intriguing given an initial downward trend. Exploring transport decisions, 22% of an EoLC clinical audit sample were conveyed to the ED and based on clinical review, 42% were considered to be inappropriate.

The team consider the question of reversibility to be the most challenging issue ambulance clinicians face, greatest with the sepsis conundrum. Education now focuses on a framework to guide decision making but there is debate as to if such weighty decisions should be within their scope of practice. Further exploration with a specialist PEoLC car pilot identified no difference in ED conveyance (26.5%), when compared to a usual ambulance response.

Conclusions: A collaborative programme demonstrated numerous improvements but a decrease in ED conveyance was not sustained. There may be a particular level of hospital admission required for PEoLC patients and efforts to reduce it are not only futile but misplaced. Acknowledging limitations of service evaluation, the reversibility and conveyance question requires research to inform education and PEoLC collaboration strategies.

	Start of exploratory programme September 2018	End of exploratory programme December 2020	BAU August 2022
Staff confidence in PEoLC knowledge and skills *post specialist education	50%	65%	78%*
Advance care plan viewing on EPaCCS	35%	74%	-
PEoLC referral pathways	1	18	23
ED conveyance for known PEoLC patients **expanded data source	39%	21%	31%**

PS 1 - 3 End-of-Life Decisions in the Control Room. Can End-of-Life Situations Be Safely Identified in Emergency Call Processing?

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¹Prague Emergency Medical Services, Medical Dispatch Centre, Prague, Czech Republic, ²Centre for Palliative Care, Prague, Czech Republic, ³Charles University in Prague, 3rd Faculty of Medicine, Prague, Czech Republic

Background/aims: Emergency Medical Services (EMS) are often called to patients at the end of their life with an incurable disease. However, it is challenging to identify them as their prognostic awareness is often low. Project TIERA (Terminal Illness Early Recognition in Ambulance Settings) is focusing on early recognition of these patients within the EMS in Prague (230.000 emergency calls per year) by means of Rapid-PCST, a novel screening tool.

Methods: Rapid-PCST was derived from the validated Palliative Care Screening Tool. All emergency calls in Prague have been screened for Rapid-PCST since July 2021.

Rapid-PCST triage criteria:

1. Cancer (metastatic/recurrent) or advanced COPD or advanced renal disease or advanced cardiac disease or advanced neurodegenerative disease; chronic oxygen therapy or chronic dialysis;
2. AND recent multiple unplanned visits to emergency department;
3. AND recent deterioration in functional status or unacceptable level of symptom distress.

If all three criteria were met, the call was triaged as "palliative relevant patient". Patient's further trajectory within the healthcare system was tracked by review of medical records. Rapid-PCST was evaluated on the first 290 identified calls. Data were analysed using SPSS v. 25.

Results:

1. Majority (85 %; n=245) of Rapid-PCST triaged patients were correctly identified. Only 9 % did not meet criteria for palliative care. Trace of 6 % of patients was lost.
2. High proportion of triaged patients (42,8 %) were treated and released at home by paramedics.
3. Furthermore, 39 % of EMS-triaged patients were later redirected to specialised palliative care.
4. 73 % of triaged patients were not seen by EMS again. Subsequent repeated call occurred once in 14 % of them, 2 % twice, 1 % more than twice.

Conclusions: Rapid-PCST seems to be a feasible tool to indicate palliative care needs in emergency calls. Its use probably supports paramedics in the use of "treat and release" protocols and in future care discussions. Using Rapid-PCST has the potential to decrease hospital deaths and repeated subsequent EMS journeys, and improve palliative case access. Non-cancer patients are under-represented: 92 % of those triaged were cancer patients, although they only account for about 1/3 of predictable deaths, according to national registries. This could indicate low sensitivity of Rapid-PCST in non-cancer patients, or incorrect usage of the tool (e.g. reluctance to flag non-cancer patients as palliative). Additional data from different EMS systems would be useful.

PS 2 - G Neither Seen nor Heard: Identifying and Meeting the Needs of Minority Ethnic Patients and Families

PS 2 - 1 Palliative Care for Non-Western Migrants in Europe - a Systematic Review

J. Shabnam¹, H. Timm², D. Nielsen³, M. Raunkiaer¹

¹University of Southern Denmark, REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Nyborg, Denmark, ²University of Southern Denmark, Copenhagen, Denmark, ³University of Southern Denmark, Odense, Denmark

Background/aims: In light of emergent evidence of low use of palliative care services amongst non-Western migrants, it is critical to understand the factors that hinder palliative utilisation among this group. This study aims to identify and describe published research on barriers to access and use of palliative care among non-Western migrants living in Europe.

Methods: The systematic review of qualitative and quantitative studies was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines on the 26th of June 2020. Searches were carried out in four electronic databases (Medline, CINAHL, PsychINFO and EMBASE), google scholar, and reference lists to identify empirical studies published between 2011 and 2020. Search words were for example palliative care and ethnic groups. Studies were graded for quality and four main themes were identified using thematic analysis.

Results: Thirty-five studies met inclusion criteria, 29 qualitative and 6 quantitative. Study quality was good on average. The most frequently reported barriers were effective communication with healthcare professionals; poor knowledge and awareness among migrants; cultural and religious preferences of the patient; and the lack of resources at different levels of palliative care service provision. These mentioned barriers negatively influenced the palliative care utilisation among non-Western migrant patients and their family caregivers.

Conclusions: The results highlight several interrelated factors that contribute to the lower utilisation of palliative care among non-Western migrants. The focus therefore should be on improving palliative care service provision at the system, community and individual levels. Considering migrants as a heterogeneous group, the current practice needs to provide additional support based on their requirements in accessing and utilising palliative care services.

PS 2 - 2 Specialist Palliative Care Services Response to Ethnic Minority Groups with COVID-19: Equal But Inequitable- an Observational Study (CovPall)

S. Bajwah¹, J. Koffman², J. Hussain², A. Bradshaw¹, M. Hocaoglu¹, L. Fraser¹, A. Oluyase¹, C. Allwin¹, L. Dunleavy³, N. Preston³, R. Cripps¹, K. Sleeman¹, I. Higginson¹, C. Walshe³, F. Murtagh²

¹Cicely Saunders Institute, London, United Kingdom, ²Hull and York Medical School, Hull, United Kingdom, ³Lancaster University, Lancaster, United Kingdom

Background/aims: To develop insights into response of palliative care services caring for people from ethnic minority groups during COVID-19.

Methods: Cross-sectional on-line survey of UK palliative care services' response to COVID-19. Quantitative data were summarised descriptively and chi-square tests used to explore relationships between categorical variables. Free-text comments were analysed using reflexive thematic analysis.

Results: 277 UK services responded. 168 included hospice teams (76% of all UK hospice teams). Services supporting those from ethnic minority groups were more likely to include hospital ($p < 0.001$) and less likely to include hospice ($p < 0.001$) or home care teams ($p = 0.008$). 34% (93/277) of services had cared for COVID-19 patients or families from ethnic minority groups. 66% (61/93) of these services stated no difference in how they supported or reached these groups during the pandemic.

Three themes demonstrated impact of policy introduced during the pandemic, including: disproportionate adverse impact of restricted visiting, compounded communication challenges and unmet religious and faith needs. One theme demonstrated mistrust of services by ethnic minority groups, and the final theme demonstrated a focus on equal and individualised care.

Conclusions: Policies introduced during the COVID-19 pandemic may have adversely impacted those from ethnic minority groups making these at-risk populations even more vulnerable. The palliative care

response may have been equal, but inequitable. During the para-COVID-19 period, systemic steps are urgently needed.

We will use this parallel session to present our CovPall paper and launch our UKRI funded educational film developed to disseminate the results to health professionals.

PS 2 - 3 Spiritual Needs and Wellbeing for Terminally Ill People from Minority Ethnic Communities in the UK

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Background/aims: Research and policy increasingly emphasise the importance of spiritual care for patients at the end-of-life, but this is not always well provided. People from minority ethnic backgrounds in the UK are particularly poorly served in this area, partly because they are also under-represented as users of specialist palliative care services. This qualitative research project focuses on the spiritual well-being of people from minority ethnic communities living with a terminal illness.

Methods: The study is being conducted in three organisations providing care for people with terminal conditions across London, aiming to recruit 20-30 participants from minority ethnic communities across all these organisations.

Participants will complete the EORTC QLQ-SWB32 (SWB32) validated measure of spiritual wellbeing, and then take part in semi-structured debriefing interviews. The measure comprises 32 items, with 22 items in four scoring scales: Relationships with Others, Relationship with Self, Relationship with Someone or Something Greater, and Existential, plus a single-item scale: Relationship with God. Findings will be compared with those from the previous international validation.

Three to four months will be spent in each of the three organisations, and also involve ethnographic techniques, aiming to become familiar with the wider context and situations in which participants are living and receiving care.

Results: This presentation will discuss preliminary findings from the early stages of data collection, which is due to begin in March 2023.

Conclusions: This study's exploration of spiritual care and spiritual wellbeing of people from ethnic minority communities in the UK living with terminal illness, will contribute to research for this under-served population, and also to the wider, under-researched field of spiritual wellbeing and spiritual care in palliative care. Insights gained might assist in improving caregiving, and patient outcomes, for people in these communities, and more widely.

PS 3 - G Challenges and Opportunities of Providing Palliative Care for People with IDD

PS 3 - 1 Palliative Care and People with Intellectual Disabilities: Why It Matters (More)

S. Todd^{1,2}

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Background/aims: This paper will review data concerning death and dying in people with intellectually disabilities. The data will suggest that many of the deaths of people with intellectual disabilities are deaths that are typically disadvantaged, challenging and complex. That is deaths that are often not well anticipated and less often involve cancer. Furthermore many individuals with intellectual disabilities have communicative patterns that are challenging for professionals with little

expertise in the field. Many deaths of people with intellectual disabilities that are better or longer anticipated are the deaths of adults with Down Syndrome from younger onset dementia. Their condition may only have been identified at a late stage meaning there may be less time to develop high quality care with meaningful participation from the individual. Needs for effective and humane grief support to family, paid carers, and friends of a person with intellectual disability might not be routinely recognised due to the negative social value conferred upon this group. Intellectual disability deaths are amongst the most problematic deaths from an end of life care perspective.

There is much to be gained in researching and improving end of life care for this population for the potential benefit of all. Getting it right, at the right time and in the right place, for this population could suggest ways to improve the last weeks and months of life for all. Yet the patterns of death and dying of people with intellectual disabilities are largely overlooked in most research studies for diverse and complex reasons that will be explored here. The research that is done, whilst of good value, is often conducted by academics with a background in intellectual disabilities and often working in isolation from wider colleagues from other disciplines. Population based studies often do not include or identify people with intellectual disabilities.

Methods: n/a

Results: n/a

Conclusions: The deaths and the dying of the most vulnerable and disadvantaged members of our communities. There is much to be gained in researching and improving end of life care for this population for the potential benefit of all. Getting it right, at the right time and in the right place, for this population could suggest ways to improve the last weeks and months of life for all. Yet the patterns of death and dying of people with intellectual disabilities are largely overlooked in most research studies for diverse and complex reasons that will be explored here.

PS 3 - 2 Lessons Learned from PEPIC-19: An International Survey on the Quality of Palliative Care for People with Intellectual Disabilities

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Background/aims: People with intellectual disabilities lack equitable access to quality palliative care. In 2015, the European Association of Palliative Care (EAPC) Taskforce on Intellectual Disabilities published a White Paper containing 13 areas ('norms') that, when met, could reasonably be thought to facilitate excellence in palliative care provisions for this population. Insight into the quality of palliative care for this population and the influence of the COVID-19 pandemic is lacking. The aim of the current study was to gain insight into the challenges for different countries in meeting the 13 norms set out in the 2015 EAPC White Paper on palliative care of people with intellectual disabilities—both before and during the COVID-19 pandemic.

Methods: This is an explorative observational descriptive study, using an international on-line survey. An international research team targeted professionals working in health or social care services or academia and who had an interest in palliative care for people with intellectual disabilities.

Results: 726 respondents from 22 countries completed the survey. The consensus norms with the highest ratings were about access to hospital care, access to palliative care services, and involving informal caregivers in making end-of-life decisions. The consensus norms about involving people with intellectual disabilities in making decisions about their care, addressing spiritual care issues, training for staff working in services for people with intellectual disabilities, and training and support for families are worst met.

The COVID-19 pandemic negatively affected attendance of funerals, involvement of families, access to hospital care and needs support.

Conclusions: A baseline against which to compare future quality measurement efforts has been established in this study. The data here show that there is much still to be done to offer people with intellectual disabilities quality palliative care.

PS 3 - 3 "It Is My Own Death" - Involving People with Intellectual Disabilities in their Palliative Care

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Background/aims: Palliative care that is cognizant of the needs and wishes of diverse populations has been a goal of advocacy groups, clinicians and practitioners for some time. However, people with intellectual disabilities still tend to be treated less equitably than others when making their own end of life decisions. The principle of supported (instead of substituted) decision-making is therefore not implemented as the UN Convention on the Rights of Persons with Disabilities (UN CRPD) calls for. In this paper, we report on a research project exploring end of life care in disability services in Germany.

Methods: A survey concerning mortality rate, causes and places of death and the structures of palliative care for people with intellectual disabilities collected data from 152 residential homes, covering 79 individual death cases. Interviews with staff and managers explored how care was organized and how individuals with intellectual disability were supported to make end of life decisions. In a second survey, the Group Home Culture Scale was adapted to include items on end of life care during the COVID-19 pandemic. The survey provided data from 73 teams (486 staff members) of 29 residential institutions. Finally, qualitative workshops explored in depth how organizational culture was shaping resident-decision-making.

Results: The study revealed a broad spectrum of care in residential homes for people with intellectual disabilities. The types of care varied from a delegating paradigm, outsourcing end of life care to nursing homes, to best practice models with a high level of reflective professional attitudes. The second phase of the project indicated that aspects of organizational culture including ethical premises determine the involvement in decision-making procedures and the quality of care at the end of life. The degree of person-centeredness and the general willingness of the organization to allow the greatest possible participation are critical factors. Respect for the individual's status as independent legal subject as specified by the UNCRPD is crucial for the design of decision-making processes.

Conclusions: Trust in the legal capacity of persons with an intellectual disability is not yet as self-evident as policy and ethical guidelines demand. The professional attitudes and opportunities for reflection and shared decision-making (ethical case discussions) are important so that people with intellectual disabilities can decide for themselves about the conditions of their end of life care.

PS 4 - E Civic Contributions to End of Life Care: Understanding Compassionate Cities in Action

PS 4 - 1 A Tale of Three Cities: Insights from the Collaboration between the Compassionate Cities of Bern, Buenos Aires and Mendellin

S. Eychmueller¹, Swiss - South America compassionate city study group

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Background/aims: Communities invest in the CCs a lot of time, money, effort, and work. However, it is not known whether the CCs are having the effect they are expected to have, so it is not known whether it is worth continuing with these initiatives. An evaluation model that

emerges from the experience of a CC in a small city in a high-income country may not be transferable to a CCS in a large city in a low- or middle-income country. The purpose of the collaboration of the CCs in Buenos Aires (AR), Medellin (COL) and Bern (CH) is to explore outcomes that may be generalizable to all sites as well as specific conditions and factors for success for each environment.

Methods: A variety of methods ranging from an international expert workshop up to local focus groups with different target populations are used to gather insights in potential meaningful outcomes for all cities and settings.

Results: Recent results as well as open questions and challenges will be reported. Experiences from all cities may reflect considerations of many colleagues who are currently active in building compassionate cities. Opportunities as well as limitations of these programs will be discussed.

Conclusions: Conditions that are applicable for all cities are the shared vision and strong leadership of a local steering group composed by representatives from various groups and institutions as well as a clear commitment and personal exposure of local governmental leaders. Outcomes are dependent on strategic priorities and may be found in the domain of improved school education in regard of introducing end of life/ death literacy or in the domain of increased collaboration between city administrators, health care providers, volunteers and churches particularly while co-creating city events or programs dedicated to the topic of end of life.

PS 4 - 2 Building a Compassionate City: a Local Social Policy Perspective from Bruges (Belgium)

A. Boone¹

¹City of Bruges, Brugge, Belgium

Background/aims: With one in three citizens older than 65 by 2030, the city of Bruges faces a rapidly aging population. Consequently, an increasing proportion of citizens are confronted with end-of-life care needs. This evolution has made visible the societal lack of attention to the needs of all people experiencing serious illness, mourning and loss. In 2020, Bruges' city council decided to integrate end-of-life care in its local policy plan by becoming a Compassionate City. Compassionate Cities are new public health approaches to palliative care that aim to reintegrate the end of life in everyday life through a series of interventions in different sectors of society. Under the leadership of a local project lead, Compassionate Bruges has gained valuable experiences in enhancing qualitative end of life care on a city and neighbourhood level.

Delegates to this session will get insight into the process of developing a Compassionate City through a city's structures. Emphasis will be put on the transition from the theoretical Compassionate City Charter to a bespoke local development approach which shows how the city of Bruges supports local initiatives both at city level and within neighbourhoods. Lessons learned on how to integrate the end of life care within a broader social policy framework, as well as strategies to keep accessible end-of-life care on the political agenda will be highlighted.

Lastly, we will regard Compassionate Bruges' ambitions for the future and how other Compassionate Cities or Communities and researchers can support initiatives and cities in this endeavor.

Methods: Experiences and lessons learned in the process of setting up a Compassionate City network will be shared from a local social policy perspective.

PS 4 - 3 Compassionate Cities - Insights from Birmingham City and Brereton & Ravenhill Parish

E. Hodges¹

¹Compassionate Communities UK, Helston, United Kingdom

Background/aims: The Compassionate City Charter proposes thirteen standards designed to support a population based, public health approach, to palliative and end of life care. The approach aims to be fully inclusive creating conversations and opportunities for all parts of society, whether these be citizens or organisations to improve the experiences of death dying and loss in their communities. The two areas included in this abstract vary significantly in size, structure and their approach to demonstrating commitment and progress to the thirteen standards. Birmingham City has a population of 1.2 million and is a multicultural city with 50% of residents from ethnically diverse backgrounds. Brereton and Ravenhill is a Parish of 7000 residents with little ethnic diversity but with similar societal issues of increased older people, people living alone, areas of poverty and increased number of people dying.

Methods: Both areas completed a self assessment matrix ahead of a presentation to the Board of Compassionate Communities UK to determine whether accreditation could be granted. The self assessment includes a rating that utilises levels of community participation and ownership in order to support teams or networks to work towards and/or celebrate grass roots ownership, partnership or power sharing in the context of support for people impacted by serious illness, death, dying or loss. The self assessment requires specific examples of activity against the charter standards and also a recognition of what more needs to happen in order to achieve a whole population approach, co-designed and delivered with communities.

Results: The comparison of these two areas demonstrates the applicability of the Compassionate City Charter to different communities who can embed it in the way that is most appropriate for them. For Brereton and Ravenhill Parish some of the standards were less relevant. However each standard was considered within the specific local context. Birmingham were able to demonstrate and provide evidence of activity across all of the standards, however as expected as this point in their journey, next steps were often about inclusivity and accessibility at scale, balanced with local co-production. Both areas demonstrated the three components required for accreditation.

Conclusions: The Compassionate City Charter is adaptable to any size of place and can provide a useful framework in balancing a statutory and hyper-local response to issues relating to palliative and end of life care.

PS 5 - G Palliative Care in Conflict Affected Settings

PS 5 - 1 Pediatric Cancer and Palliative Care in Conflict Affected Area

T. Kutluk¹

¹Tezer Kutluk, Hacettepe University Faculty of Medicine and Cancer Institute, Ankara, Turkey

Background/aims: Turkey has a population of 85 million and also hosts the larger number of refugees with 3,7 million mainly from Syrian. Globocan 2020 data estimates 233,000 new cancer cases and 126,000 deaths due to cancer. By the end of the 90s, the palliative care (PC) services were very limited with lack of trained professionals, low awareness and limited access to opioids.

Methods: The investments from Professional organizations and government started mainly after 2000's but still limited. The first Cancer Control Programme was released by Ministry of health (MoH) in 2008, and implemented the Palliatürk project in 2011, targeting the pain control and community based PC model. PC directive was released in 2015.

Results: The International PC scale ranking named Turkey in group 2 in 2006, and moved up to group 3b in 2011, then in group 3a in 2017, which is the isolated PC provision. After the start of Palliatürk project in 2011, the investment continued from the MoH. The number of the beds for palliative care were increased to 5577 in 2021 which was very low in number before 2014. Turkey also implemented the Universal Health Coverage in 2012, >98% of the population are covered by UHC. In a short survey from the 21 Southern Turkey's major University hospitals, only 8 has palliative care services and 4 has palliative care exclusive staff

although providing the PC services. Twelve was also providing the PC services for refugees. The annual number of new pediatric cancer patients is estimated around 3000 per year, the palliative care services were mainly provided within the oncology services. There were 10 paediatric PC services with 119 bed capacity in 2021 for all pediatric patients in nation, not specifically for cancer patients. In a recent analysis of cancer in Syrian refugees living in the city of Konya, we reported the 3 year survival rates as 69.5 probably less in 5 years. We also found that the 5 years survival rates was about 30% in Syrian refugee children with cancer living in Southern Turkey. The five years survival rates for Turkish children is about 70%.

Conclusions: There is still a need of investment on palliative care services for pediatric cancer patients and integration of PC services to current cancer care is also essential.

PS 5 - 2 Cancer and Palliative Care in Conflict Affected Settings

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Background/aims: Cancer burden is significantly rising in low- and middle-income countries (LMICs), including countries in the Middle East and North Africa (MENA) region. The health care infrastructure was destroyed and fragmented due to war or prolonged arm conflicts in the war affected countries. On the other hand, in the conflict neighboring countries, the health care is negatively affected and strained due to increasing number of refugees and displaced persons. Cancer care among other NCDs was one of the major loser in this chaos throughout disease trajectory from screening and early detection through treatment and palliative care.

Methods: In our panel, we aim to 1- understand the landscape, challenges around cancer and palliative care in conflict affected MENA countries, 2- to understand the verity of national and immigrant patients and families' health related needs and concerns, 3- to acknowledge the need of equitable access to high quality of palliative centered care, 4-to highlight cancer and palliative care research capacity strengthening initiatives in the region.

Results: Understanding the regional contextual cancer and palliative care related needs, concerns, strengths, challenges, and capacity building initiative are crucial to enable improvement of equitable cancer and palliative care, for diverse national and refugee's patient population at professional, service and policy level.

Conclusions: Understanding the regional contextual cancer and palliative care related needs, concerns, strengths, challenges, and capacity building initiative are crucial to enable improvement of equitable cancer and palliative care, for diverse national and refugee's patient population at professional, service and policy level.

PS 5 - 3 Person Centred Care and Outcome Measures in Palliative Care in Conflict Affected Settings

R. Harding-Swale¹

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Background/aims: Universal Health Coverage identifies palliative care as an essential health service for all. Many families face advanced cancer

while displaced or seeking refugee status away from their homeland. Truly holistic person-centred care must anticipate and respond to their specific circumstances and needs. This programme of work has sought to identify the specific palliative care-related concerns of families facing advanced cancer including refugees, in Jordan and Turkey and to adapt outcome measurement to support assessment and care.

Methods: We conducted in-depth qualitative interviews in adult oncology services with 50 adult patients (of which 29 were refugees) and 20 caregivers (7 refugees). In paediatric services we interviewed n=50 children and young people with advanced cancer, n=30 of their family members and n=24 healthcare professionals. Following thematic analysis we conducted expert groups to concept map the data to an outcome measure and propose adaptation.

Results: Adults reported (1) Psychological distress and sustaining social support. Refugees often experienced unmet psychosocial needs. However, psychosocial support was reported either absent or limited. (2) Knowledge and uncertainty. Lack of information and poor communication between healthcare providers and patients caused significant distress due to uncertainty. (3) Family anxiety and support roles. Being away from the home country cut patients and caregivers off from their wider social support network, which added increased anxiety and responsibilities to caregivers. (4) Compounded trauma and poverty. Many refugees have experienced trauma related to war that may affect their physical and mental health. Children described psychological changes of maturation and serious illness, spiritual distress and hope for the future, and high financial burden of illness on families. Adult POS has proposed expansion to measure social support, and children's POS reflects the developmental and existential concerns of children.

Conclusions: Core measurement of symptoms and concerns must be adapted where necessary to reflect specific populations and settings. Refugee families articulate specific concerns and these novel items must be tested to determine their psychometric properties.

PS 6 - F Ethical Challenges when Conducting Research in Palliative and End-of-Life Care in Clinical Settings: How to Address them Successfully?

PS 6 - 1 Does the Ethical Principle of Vulnerability Prevent Equity and Fair Research Participation in Palliative and End-of-Life Care?

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Background/aims: Research ethics is the analysis of the ethical issues that may occur when conducting research. It ensures that research is performed with high ethical standards. Nevertheless, when conducting research in real world clinical practice, particularly in palliative and end-of-life care settings, many ethical challenges occur and need to be properly addressed. Patients in palliative care represent a vulnerable population deserving special attention when developing, implementing, and evaluating research. Due to their increased vulnerability, these patients are sometimes prevented from being included and participating in relevant studies, potentially leading to inequities and unfair participant selection. Aims: To provide an overview about the ethical principle of vulnerability, systematize different categories of vulnerability and discuss how these categories may affect participation in relevant research.

Methods: This presentation is based on different international research projects, combining theoretical frameworks with empirical research findings.

Results: Ethical frameworks with a pragmatic contour and implication are needed to protect vulnerable patients from potential harms and ensure their optimal participation in palliative care research. Important ethical challenges and issues in palliative care research occur due to patients' increased vulnerabilities. If handled thoughtfully, they will not pose insuperable barriers to research. If ignored, they can slow the research process, alienate potential study participants, and cause harm.

Conclusions: Ethical considerations in research involving patients in palliative care, particularly at the end-of-life, primarily concern the representation of their interests as participants and protection of their vulnerabilities and rights. Yet, preventing these patients from participating in relevant research due to their vulnerability might exclude them from accessing high-quality and evidence-based care and interventions.

PS 6 - 2 How to Enhance the Informed Consent Process in Persons Unable to Consent? Experiences from Different Contexts and Settings

P. Hernández-Marrero^{1,2}, S. Martins Pereira¹, Project DELiCare: Decisions, Decision-making, and End-of-Life Care: Ethical Framework and Reasoning
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Background/aims: Informed consent is the most scrutinized and controversial aspect of clinical research ethics. In palliative and end-of-life care, assessing decision-making capacity may be challenging. Patients, particularly those with cognitive impairment, deserve special attention when developing, implementing, and evaluating the informed consent process. Respecting patients' autonomy in research includes obtaining informed consent; facilitating and supporting patients' choices about research options; allowing patients to refuse participating in research; disclosing comprehensive and truthful information; and maintaining privacy and confidentiality. An autonomous decision requires that participants/patients have the capacity to provide informed consent. Aim: To explore how to enhance the informed consent process in persons unable to consent (e.g., persons with cognitive impairment, dementia, severe and persistent mental illness, and/or at the end-of-life) to increase equity and fair participant selection.

Methods: This presentation is based on a series of systematic reviews and international research projects. It combines theoretical frameworks and ethical principles with empirical research conducted in different contexts and settings.

Results: The informed consent process involves both consent and assent, which should be monitored throughout the research process. Informed consent must be an ongoing process of communication, understanding and decision-making that involves a wide range of key stakeholders (the patient and potential participant, possible surrogates, clinicians, and researchers) throughout the course of the study. Cognitive impairment, and other disorders affecting cognition, may have a negative impact on patients' capacity to provide consent to research participation. Also, stereotypes among researchers can contribute to failures in the informed consent process. This might prevent patients with limited decision-making capacity from participating in relevant research.

Conclusions: This presentation provides an overview of ethical frameworks and principles linked to the informed consent process and decision-making capacity in palliative care research, particularly in patients with cognitive impairment and/or limited decision-making capacity. A core set of ethical questions and recommendations is drawn to aid researchers, institutional review boards and potential research participants in the process of obtaining informed consent for palliative and end-of-life care research.

PS 6 - 3 Addressing Ethical Challenges When Conducting International Collaborative Research in Palliative and End-of-Life Care

N. Preston¹

¹Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

Background/aims: There has been an increase in international palliative care research including cross-country collaborations. In part this has been driven by grants from the European commission. However, systems for gaining ethical approval internationally differs, even across Europe. Differences can include what is considered research (rather than evaluation or practice development) and requires ethical approval. There are differences in what is considered appropriate at a country level and what ethical representatives from funders deem appropriate. Conducting research outside of Europe, especially in countries with fledging ethical approval systems, can be even lengthier and complex especially when the planned research is qualitative and the ethical review board have less experience in assessing such proposals.

Methods: International review of ethical approval processes

Results: After more than 10 years of European funded research, reflections are made to highlight these differences. Previous analysis of gaining ethical approval revealed that the UK had the most complex system which took the longest to navigate. Time to gain ethical approval across Europe for the same study ranged from 1 month to 12 months with a median of 6 months. The number of committees varied as did the type of informed consent (written or oral), and even whether consent needed to be recorded.

Conclusions: Based upon these reflections, recommendations are made about how cross-country research ethical approvals are prepared and gained.

PS 7 - G Challenging the Inequities in Palliative Care Provision for People in Prison: Policy, Research and Practice

PS 7 - 1 IAHC Policy Recommendations to Ensure Palliative Care in Prisons

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Background/aims: Few prisons in the world are set up to meet the complex health care needs of the growing global cohort of older prisoners. Continued incarceration, especially if it deprives inmates of appropriate health care, constitutes disproportionately severe punishment. The revised Standard Minimum Rules For the Treatment of Prisoners, adopted unanimously by the UN General Assembly, also known as the 'Nelson Mandela Rules,' stipulate that "prisoners should enjoy the same standards of health care that are available in the community." However, the quality of health care in custodial settings is frequently below the national average in most countries, and access to palliative care is even more limited. Older persons, many of whom suffer from chronic conditions are the fastest growing cohort of prisoners in high income countries.

Methods: Human rights laws, conventions, and guidelines were reviewed to discern any mention of prisoners' right to health and to palliative care. A literature review of articles concerning prison populations, especially where there is a high proportion of prisoners serving life or indeterminate sentences, was conducted to discern if there is any research on palliative care provision in prisons, particularly for older persons in high income countries. Reviews of articles discussing access to internationally controlled essential medicines in prison were performed. Reviews of compassionate release policies were also performed.

Results: Health conditions requiring palliative care are more prevalent in prison settings than in the outside populations. These include NCDs,

diabetes, HIV/AIDS, MDR TB, and dementia. Prisoners have little or no family support when they are ill, and prison medical staff are generally untrained in palliative care and use of controlled essential medicines. These conditions violate the right to health, which includes access to palliative care and essential medicines.

Conclusions: Policy recommendations include training prison staff in basic human rights norms concerning right to health. Prison medical staff should receive basic palliative care education and controlled essential medicines should be available in prison medical wards. Prisoners should be transferred to community hospices and if these are not available, hospice services should be available in prisons. Compassionate release protocols and procedures should be expanded and prisoners trained as volunteer caregivers to assist in ADLs and hospice care.

PS 7 - 2 Challenges to Providing Palliative Care in Prisons in Europe and Australia: Findings of a Qualitative Study from an EAPC Task Force

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Background/aims: The EAPC Task Force on Palliative Care for People in Prison was established in 2017; it completed and published the first part of its work in 2021. The current study is the second part of this Task Force project and, against a background of both rising and ageing prisoner populations and increasing numbers of deaths in custody, aimed to obtain insights into the experiences and views of key professional stakeholders about palliative and end of life care (PEOLC) provision in prison settings.

Methods: Qualitative individual and small group interviews were conducted with key professional stakeholders working in and with prisons across six European countries and Australia. Framework analysis of data was undertaken; the initial framework was created by the research team from the study objectives and was further developed through regular data analysis meetings of the country leads. Complex ethical and governance procedures were successfully completed in all participating countries.

Results: Data from more than 90 interviews from Australia, Belgium, England, France, Northern Ireland, Portugal and Scotland reveal stark differences between countries and their approaches to PEOLC in prison and highlight inequities within and between countries. For example, whilst some countries have developed tools that promote aspects of palliative care provision (such as advance care planning), in others this is non-existent. There are also wide variations in approaches to early release on compassionate grounds (ERCG) for those at the very end of life; in some countries ERCG is commonplace but in others it is extremely rare. However, the study also highlighted similarities between participating countries, for example regarding the need for training and support for staff engaged in this difficult and challenging work.

Conclusions: This is the first international study on PEOLC in prison settings and highlights complex challenges and multiple inequities within and between countries in providing palliative care to people in prison. There is great potential for shared learning between countries and prison systems.

PS 7 - 3 Palliative Care in Prisons: A Peer-Caregiver Model

L. Deal¹

¹Humane Prison Hospice Project, Atherton, United States

Background/aims: Worldwide prison populations are aging, especially in the United States, the country with the highest incarceration rate in the world. By 2030 approximately 1/3 of incarcerated people will be over 55. The aging population disproportionately suffers from serious illness and

complex chronic diseases including heart disease, cancers, dementia, and respiratory disease. The need for palliative and hospice care is acute, yet prisons are not organized to care for aging populations.

A US-based organization, Humane Prison Hospice Project, works to transform the way incarcerated people die through education, advocacy, and programs that train prisoners in compassionate end-of-life care and grief companionship. The aims of Humane's program are both to provide end-of-life care for the often-unforgotten people aging and dying behind bars, and to offer their incarcerated peers an opportunity to give back to another human in a profound and meaningful way – something many of them describe as a form of atonement for the crimes they committed.

Methods: In partnership with the California Department of Corrections and Rehabilitation (CDCR), Humane has developed a palliative care curriculum based on work they've done in San Quentin State Prison since 2017 and drawing on best practices from the only inpatient prison hospice program in California.

Humane's work is part of a larger system-wide effort to develop comprehensive palliative and hospice programs in California prisons and change prison culture to be more rehabilitation focused. Humane will implement its training program in four California prisons during 2023, with the goal of sharing the model throughout California and other states.

Results: Humane has been training San Quentin prisoners in peer supported compassionate end-of-life care and grief companionship since 2017, despite no formal hospice program at the prison facility. The men trained have described the work as transformative and empowering as they've supported and cared for their peers.

Conclusions: Prison-based hospice programs training incarcerated people as end-of-life caregivers are transformative for the person receiving care, the caregivers, the prison staff who witness this compassion, and the broader society when the peer support caregivers are paroled. Although the impact of these programs requires further study, several programs show a recidivism rate of near zero percent for inmates with compassionate end-of-life training and experience.

PS 8 - D Improving Palliative Care for Older People: Innovative Care Approaches

PS 8 - 1 EAPC White Paper: An Integrated Palliative, Geriatric, and Rehabilitative Care Approach for Frail Older People

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Background/aims: To date, there is no consensus on what optimal palliative care for older people with frailty should entail. The EAPC Reference Group on Aging and Palliative Care aimed to identify key domains and recommendations for optimal integrative palliative, geriatric and rehabilitative care in frailty, based on evidence and expert consensus.

Methods: International Delphi study (6 rounds, N=90) gathering the collective opinion of experts in frailty and palliative, geriatric and rehabilitative care, and experts by experience, while considering relevant empirical evidence.

Results: We identified 12 domains that define an integrative palliative, geriatric and rehabilitative care approach for older people with frailty and their family:

1. applicability of palliative, geriatric and rehabilitative care in frailty
2. holistic care focused on capacities as well as needs

3. goal-oriented care guided by values, priorities, and preferences
4. pro-active care, including advance care planning, parallel planning, emergency-response and out-of-hours planning
5. communication and shared decision-making
6. dying with comfort, dignity and choice
7. family as care provider and recipient
8. integrated, interdisciplinary care and access to services
9. professional competencies
10. context and culture
11. community and public health
12. ethical principles and frameworks

The importance of these domains and agreement with the recommendations for each domain will be scored by an international group of professional experts and representatives of older people and their families, with the aim of reaching consensus.

Conclusions: This work will lay the foundations for future research, practice, and policy, to ensure all older people living with frailty and their families receive the care and support they need to live and die well.

PS 8 - 2 Evidencing Community Palliative Care for Older People with Advancing Frailty in the UK: The PALLUP Study

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Background/aims: For most older people, the nature of living and dying in later life will be frailty and multimorbidity. Time-based approaches for referral to end-of-life/palliative care services are increasingly questionable. Rather, end-of-life care provision for older people should be focussed on a holistic formal assessment of need and tailored care. The PALLUP study uses mixed methods over 4 phases to evidence the specific end-of-life needs of older people with frailty and service response. This paper focuses on Phase 1

Methods: Phase 1- Consensus of core palliative care needs.

- **Scoping review** of evidence on the palliative care needs of community dwelling older people with severe frailty/multimorbidity. Data extracted and presented within palliative care need domains: physical, psychological, social, spiritual, practical. (N=28 papers)
- **Interviews.** and survey Participant led video interviews N=10 older people with severe frailty, N= 5 carers and paper survey N= 10 older people
- **Virtual-Delphi** – over 2 rounds with 256 participants across health, social care and voluntary sectors and family carers. And Online Facilitated Workshop to discuss needs consensus, service provision implications and forward Phase2 . N=18 from E-Delphi. Composite film of interviews led the discussion

Results:

Scoping Review - Existing evidence is superficial and mainly from care homes. Primacy in assessing and reporting given to physical needs. Social and practical needs often prioritised by older people

Interviews and survey - Participants expressed needs across all domains. Loneliness, persistent pain, medication help, mobility/ access to appropriate equipment and practical support common . Families often coordinated and carried out care

Virtual-Delphi - High level of consensus across stakeholder groups on needs. Top five needs 1)Trust in care providers 2)Not to feel lonely 3) Opportunities to discuss current practical and care needs and advance care planning 4)Daily Medications 5)Standing and walking. All respondents noted families as important in meeting needs . Facilitated workshop - highlighted that evidence of need is clear but poorly understood and communicated and the role of integrating families in care provision is ambiguous

Conclusions: Remodelling of palliative and end of life care services requires different ways of working, different partnerships and a sharing of power to enable a focus more on assessing and responding to the priorities of older people who are living and dying with frailty in older age.

PS 8 - 3 Development, Evaluation and Scale-up of the Nav-CARE Volunteer-led Community Navigation Intervention for Older Persons in Canada

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Background/aims: Nav-CARE (Navigation: Connecting, Advocating, Resourcing, Engaging) is a volunteer navigation intervention that has been developed through a decade of research. The program provides specially trained, mentored, and experienced volunteer navigators to work with persons living with declining health and their families to improve quality of life. More specifically, the program seeks to provide early support using a palliative approach to care, build volunteer capacity, optimize access to resources, and foster the development of compassionate communities by building social connections.

Methods: Nav-CARE has been implemented primarily through community-based volunteer hospice societies. Implementation occurs using a standard toolkit and has been studied using the Consolidated Framework for Implementation Research (CFIR). Volunteer navigators receive evidence-based training in which they learn to address quality of life concerns, advocate for clients and families, facilitate community connections, promote active engagement, and support virtual navigation. After training, they work one-on-one with clients in the home, in a supportive relational model, helping them with challenges related to the social determinants of health.

Results: Nav-CARE clients have reported statistically significant improvements in awareness of available services, confidence in making decisions, taking care of their illness, and communicating needs to healthcare providers. Over subsequent studies, clients report improved quality of life through tangible benefits that improve their illness experience. Volunteers report good self-perceived efficacy in navigation, satisfaction in their role, and enhanced meaning in their own lives as they develop reciprocal relationships with their clients. Organizational factors that influence the development and sustainability of Nav-CARE include adequate organizational capacity, effective leadership, strategic messaging of the program, and identifying a population in need in the community that is not served by other organizations.

Conclusions: Nav-CARE is an effective community-based program that can improve client and family quality of life while closing gaps in home-based care. It is important to note that Nav-CARE was designed to work in alignment with paid professional services, not to replace them. Nav-CARE is currently being scaled out across Canada using a Centre of Excellence hub and spoke model and is being adapted to support family caregivers of persons living with dementia.

PS 9 - A Biomarkers in Palliative Medicine

PS 9 - 1 How We Die from Cancer

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Background/aims: Predicting when a patient with advanced cancer is dying is a challenge and currently no prognostic test is available. Despite the fact that nearly 10 million people worldwide died from cancer in 2020 alone, little is known about the biochemical pathways that change as people die.

Methods: We hypothesise there are specific metabolic changes associated with dying. This talk will present the results of recent metabolomic studies on the urine of patients with lung cancer. Metabolomics

identifies new or changing metabolites from biological samples and can give an insight into changes in biochemical pathways.

Results: Data will be presented showing not only metabolite changes but also associated biochemical pathways. From these metabolites we developed a number of models predicting the dying process within the last weeks of life.

Conclusions: The metabolites identified are potential biomarkers of dying in lung cancer and could be used as a tool to provide additional prognostic information to inform expert clinician judgement.

PS 9 - 2 Narrative Review on Neurofilament Light as a Potential Biomarker for the Early Detection of Delirium in Patients with Advanced Cancer

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Background/aims: Delirium is a debilitating disorder with a high prevalence and morbidity near the end of life significantly impacting the quality of life of patients and their relatives. The exact underlying pathophysiology is unknown. Early detection can aid in prevention of delirium through the use of non-pharmacological interventions. Neurofilament light (NFL) is a protein present in nerve cells and detectable in bodily fluids. From neurodegenerative illnesses it is known that it is secreted when (axonal) nerve cells are damaged. There are some signs that it also may be a viable biomarker for early detection of delirium. We aimed to examine published empirical data on the potential of neurofilament light (NFL) as a predictive biomarker for delirium by way of a narrative review.

Methods: We conducted a narrative review with a focus on the biomarker NFL and delirium. Studies were eligible when reporting on NFL measurements in individuals that develop a delirium. Studies on healthy participants, neurodegenerative illnesses and non-English articles were excluded.

Results: Three studies were found that were conducted exclusively on NFL in patients with delirium. These studies demonstrated that high pre-operative blood levels of NFL predict the occurrence of delirium in post-operative elderly patients. One of the studies suggests that brain cell damage, reflected by an increase in NFL, occurs prior to the development of delirium symptoms. Levels of NFL peaked during the episode of delirium and was followed by a gradual decrease or stabilization of NFL.

Conclusions: Our review suggests that patients with pre-existing levels of brain vulnerability may be more likely to develop delirium. This indicates that NFL is a potential biomarker for the early diagnosis/detection of delirium in patients with advanced cancer. However, the feasibility and sensitivity of NFL as a possible biomarker must be confirmed in future prospective studies. Further research on this topic will likely provide insight into the pathophysiology of delirium potentially leading to early detection, novel therapeutic strategies, and improvements in quality of life.

PS 9 - 3 Transforming Growth Factor-Beta and other Biomarkers of Cachexia in Advanced Cancer Patients at the End of Life

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Background/aims: Cachexia is a multifactorial metabolic and immune system imbalance that represents one of the most detrimental side

effects of cancer. This so-called cancer-associated cachexia syndrome (CACS) is characterized by progressive loss of skeletal muscle mass and function (with/out fat loss). CACS impacts 50-80% of all advanced-stage patients, it cannot be reversed by nutritional supplementation, and is the cause of death in at least 22% of all cancer patients. Unfortunately, CACS is still an unmet medical problem, as we still lack biomarkers predicting muscle atrophy and CACS, and treatment opportunities targeting specific pathways in order to revert CACS. We provide an overview of the role of the TGF- β pathway, that is involved in the onset of cancer, as a molecular driver of CACS and as a potential target for therapy.

Methods: A narrative review was conducted. With a search string using simple search terms as well as MeSH terms we searched the electronic database of PubMed up to August 2022. Reference lists of included studies and relevant systematic reviews and meta-analyses identified in the search were examined for additional eligible studies. Only English language studies published in peer-reviewed journals were included.

Results: In the 42 articles that were included we found that the extensive crosstalk between TGF- β and the tumor microenvironment (TME) plays a central role in the onset and progression of CACS, for instance by remodelling of the extracellular matrix of adipose tissue. We also identified multiple players within the TGF- β -NOX4-RyR1 signalling pathway that could potentially serve as signatures to monitor and/or therapeutic targets to prevent CACS. However, only a few studies are ongoing to evaluate potential inhibitors of the TGF- β pathway to prevent or treat CACS. Thus far, no treatment has been found against CACS due to unacceptable side effects or the absence of clinical benefit.

Conclusions: In conclusion, TGF- β is known to be a major mediator in cancer-related processes and tumorigenesis. Although causative factors of CACS are not fully understood, the TGF- β family is implied in its onset and might be a useful biomarker to monitor CACS. Considering that the TGF- β family regulates several processes in cancer, it is necessary to identify all mediators involved for a better understanding of the crosstalk between TME and CACS. Lastly, a potential TGF- β -inhibiting therapy could hopefully prevent or attenuate CACS, thereby increasing the survival of cancer patients.

PS 10 - G Poverty and Deprivation at End of Life

PS 10 - 1 Dying in the Margins: Experiencing Financial Hardship and Deprivation at End of Life in Scotland

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Background/aims: This research aimed to examine barriers to, and experiences of, dying at home for people experiencing financial hardship and deprivation in Scotland. The project ran from 2019-2023 and has captured participants experiences during the pandemic and the current cost of living crisis.

Methods: The project used participatory visual methods, specifically photo-voice and digital storytelling, to enable participants to tell their own story in their own words and images. World-renowned Scottish documentary and portrait photographer, Margaret Mitchell, also worked with participants visually capturing their stories and emotions, all the while foregrounding their agency.

Results: The project has generated impactful imagery designed to inform the public conversation around end of life care improvement specifically for people experiencing poverty and structural marginalisation. Challenges faced include: insecurity of housing; materially deprived circumstances e.g. mould, damp, lack of general maintenance, lack of basic toiletries; cost of living e.g. utility bills, equipment running costs, taxis to hospital appointments; space e.g. room for other family members to co-habit; isolation (social and physical); lifetime experiences of hardship; health literacy/education; availability of care-giving; self-care.

Conclusions: There are currently no images in UK contemporary palliative care policy and literature, and therefore arguably the public

imagination, which speak to the experience of dying in circumstances of socio-economic hardship. Dying in the Margins has given people with direct experience of financial hardship the means to show, on their own terms, gaps in current support and potential strategies to improve their end of life experiences.

PS 10 - 2 Poverty at the End of Life in the UK: Prevalence, Patterns and Policies

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Background/aims: It has been estimated that someone with a terminal illness in the UK can experience a negative financial impact of up to £16,000 per year (APPG for Terminal Illness, 2019). However, while poverty at the end of life is recognised as a legitimate concern, its magnitude has remained unclear. This research aimed to produce a statistical profile to increase understanding of the risk and prevalence of poverty in the last year of life for people across the UK, and evaluate the potential costs of benefits of policy interventions to reduce poverty at the end of life.

Methods: The analysis was based on data for individuals aged 20 and older from the UK Household Longitudinal Study, Understanding Society. Mixed-effects binary logistic regression was used to estimate the probability of an individual being in poverty in a given year, based on their age, whether they were in the last 12 months of life, and the interaction between these variables. The estimates were used to produce a risk ratio that could be applied to population-level data on poverty rates and mortality rates. Using the same data, a cost-benefit analysis was carried out to estimate the impact of providing people of working age in the last 12 months of life with access to the state pension.

Results: The regression analysis revealed a statistically significant, positive association between being at the end of life and being in poverty. When combined with population-level data, the estimates suggested that in 2019, more than 90,000 people died in poverty in the UK. There was a significant interaction with age ($p=0.08$), with a stronger association between poverty and mortality for younger, working-age respondents. Giving people of working age with terminal illness early access to their State Pension was estimated to almost halve the rate of poverty across the UK in this group, lifting more than 8,600 dying people out of poverty every year. The cost of introducing this change, £114.4 million per year, would be just 0.1% of the current annual State Pension bill.

Conclusions: The findings show that poverty at the end of life is an extensive and wide-reaching issue that affects many people at a time when they are vulnerable and least able to deal with financial or material hardship. In policy terms, the findings indicate that giving working-age people with terminal illness early access to the State Pension would be an effective approach to reducing the risk of poverty in this group, and could be delivered at a minimal cost to the taxpayer.

PS 11 - F Enhancing Healthcare Teams' Ethical Decision-Making in Palliative and End-of-Life Care

PS 11 - 1 Relational Autonomy in Palliative and End-Of-Life Care: A Deeper Way to Enhancing Dignity and Respect

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Background/aims: Dignity and respect resonate with the practice of palliative and end-of-life care. They are pillars on which patient and family experience is based and good practice is judged.

The current discourse on autonomy in clinical practice would promote the ideal that dignity and respect are advanced when an individual's choices are considered paramount. People have the right to accept or reject clinical

options based on their personal views, wishes and desires. If such wishes and desires are supported, dignity and respect are, in theory, upheld.

However, this view of autonomy may not always fit well with the philosophy and practice of palliative and end-of-life care. A focus on the individual alone is contradictory to the nature of palliative care as a practice which sees the person within their family and social network, supporting and strengthening such relationships across transitions between living and dying.

Methods: Based on the work of Bergum and Dossetor (2014) and clinical case examples from palliative and end-of-life care, the importance of relational autonomy as a discourse rather than problem-solving strategy will be discussed.

Results: Relational autonomy does not deny the importance of autonomy but places it in the wider context of shared communication and the network in which people live their lives. A relational approach to fostering dignity and respect would not propose to find solutions to problems, but rather, to ask appropriate questions (and find solutions together) in order to place the person and their family or social network at the centre of care planning.

Conclusions: This oral presentation will consider how a deeper understanding of relational autonomy can enhance dignity and foster respect in meaningful ways for patients and families in palliative and end-of-life care.

PS 11 - 2 How to Improve Ethical Decision-making in Clinical Practice? Practical Models and Guidelines

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Background/aims: Clinical practice in palliative care is characterized by the need of making ethico-clinical decisions, particularly at the end-of-life. End-of-life situations are situations in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future, posing the need to make ethico-clinical decisions. Often, these decisions are difficult and challenging; the so-called "ethical challenges" emerge. Despite its ubiquity, there is no consensualized definition of this expression. Various terms are used interchangeably, e.g., "ethical challenges", "ethical problems", "ethical issues", "ethical dilemmas". Moreover, even though there is a wide range of ethical decisions that need to be made in palliative and end-of-life care, there is no unique model or guideline to help professionals and teams in making difficult and complex decisions. Aim: To explore practical models and guidelines that can be used in clinical contexts to improve ethical decision-making in palliative and end-of-life situations.

Methods: This presentation is based on the work developed within project DELiCare: Decisions, Decision-making, and End-of-Life Care: Ethical Framework and Reasoning. The overall project, its objectives, methods, results, and implications will be presented in an integrated fashion, including the application of ethical decision-making models and guidelines to specific clinical cases.

Results: End-of-life decisions are rooted in clinical, sociocultural, political, legal, economic, and ethical concerns. Several models and guidelines for ethical decision-making at the end-of-life coexist but are rarely used in clinical practice. These models and guidelines can be a relevant aid for healthcare professionals and teams. They can stimulate the debate around disputed and controversial issues, helping professionals to follow a well-informed and shared decision-making model in order to meet patients' values, wishes and preferences.

Conclusions: Decision-making processes underlying end-of-life decisions are influenced by and foster clinical, ethical, sociocultural, religious, political, legal, and economic concerns and debates. Healthcare professionals working in palliative and end-of-life care often perceive these decision-making processes as complex and challenging. The use of practical models and guidelines can enhance professionals and teams'

competencies and effectiveness in making ethico-clinical decisions at the end-of-life.

PS 11 - 3 Enhancing Ethical Decision-Making at the End-of-Life: Empowering Conditions or Team Empowerment?

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Background/aims: Healthcare professionals are increasingly making end-of-life decisions (ELDs), which have become an integrated dimension of contemporary palliative and end-of-life care. ELDs are medical decisions made at the end of life that may have a potentially life-shortening effect. These situations are very often moments of high vulnerability with a profound impact on patients' ability to exercise their autonomy. Healthcare professionals perceive end-of-life decision-making as complex, difficult, and stressful. Evidence shows that making ELDs is frequently associated with burnout and moral distress. Strategies need to be implemented to enhance ethical decision-making at the end-of-life.

Aim: To explore and discuss strategies on how to promote team empowerment within interdisciplinary teams to support and enhance ethical decision-making processes surrounded by uncertainty, risk, and asymmetry of information.

Methods: This presentation is based on the work developed within project DELiCare: Decisions, Decision-making, and End-of-Life Care: Ethical Framework and Reasoning. The knowledge, experiences, and evidence from different fields will be mobilized and integrated to build theoretical and empirical frameworks. The structure and processes that can enhance ethico-clinical decision-making processes and their effectiveness in palliative and end-of-life care will be explored.

Results: The need to make ELDs requires healthcare professionals and teams, as well as patients and family members, to embrace ethico-clinical decision-making processes under uncertainty, risk, and asymmetry of information. Shared decision-making is a cooperative process among healthcare professionals, patients, and families that enables a way of decision-making combining both the professionals' expertise and the patient's values, preferences, and goals. Shared decision-making processes should integrate information exchange, a deliberation period and making a decision. Communication among all stakeholders is paramount.

Conclusions: Shared decision-making processes helps teams to bring together information and views, anticipate scenarios, and prepare a joint and common approach to the decision that needs to be made. This team empowering strategy fosters the sense of both individual and teamwork meaning, a core dimension of empowerment. By fostering shared decision-making processes, professionals and teams feel more empowered and are more effective in meeting patients' values, wishes and preferences.

PS 12 - G Using Big Data to Understand and Address Inequity in Palliative and End of Life Care

PS 12 - 3 Can We Go Beyond Observing the Problem? Using Routine Data to Address Inequity in Palliative and End of Life Care?

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Background/aims: Researchers have been using routinely collected health and mortality data to study socioeconomic inequity in palliative and end-of-life care for three decades. Our review of this work found consistent evidence that in high income countries people with

low socioeconomic position die in hospital more (compared to home or hospice), have more hospital admissions in the last months of life, and access specialist palliative care less. We also find a social gradient in access to palliative and end of life care, demonstrating that inequality is a problem for everyone below those at the very top of the social strata, not only a problem for the poorest people in society.

Methods: The covid-19 pandemic generated a heightened awareness of health inequalities in particular area-based deprivation and ethnic inequality in covid-19 mortality. In the UK, the pandemic also accelerated access to routinely collected data for researchers and improved the way that data is linked. We used these data assets and found that in relation to place of death, the pandemic exacerbated existing inequalities.

Results: This presentation will consider future priorities for using routine data to address inequalities in palliative and end of life care including the urgent need to go beyond simply observing and reporting the problem. We will present examples of studies that have done this including: using data to understand intersectional inequality, data for quality improvement, in terms of monitoring, accountability and identifying exemplars, and using mediation analysis for understanding the causes of inequality.

Conclusions: The author has received research grants from the Dunhill Medical Trust and Marie Curie.

PS 13 - H Management of the Wish to Hasten Death in Europe

PS 13 - 1 Risk Factors and Protective Factors in the Wish to Hasten Death

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Background/aims: The Wish to Hasten Death (WTHD) is a complex and multifaceted issue that can have significant implications for patients with advanced illnesses, their families and health care providers. By identifying and addressing its risk and protective factors, palliative care professionals can help ensure that patients are making well-informed decisions about their end-of-life care. Additionally, understanding these factors can also help professionals to identify patients who may be at risk for wishing to hasten their death, so that they can try to provide appropriate support and resources to help them cope. To provide a more comprehensive understanding of the WTHD and its risk and protective factors, this presentation will synthesise the scientific literature over the past decade from both systematic reviews and original studies of various methodologies.

Methods: An overview of systematic reviews and extended literature review of original scientific articles.

Results: Eleven systematic reviews and 33 primary studies were included in the review. The wish to hasten death is not only related to the physical aspect of the illness, but also to the psychological, social and spiritual problems of the patient. Risk factors, such as depression or hopelessness, social isolation and spiritual suffering may make a patient more likely to wish to hasten death, while protective factors, such as social and spiritual support, may make them less likely to do so. Suffering can arise from a sense of loss of control, loss of independence, loss of autonomy, loss of self, as well as from a sense of burden for the patient and their loved ones, highlighting several targets for care that should be monitored proactively for each patient.

Conclusions: The relationship between the WTHD and suffering is complex and multifaceted. Palliative care professionals should regularly

assess patients for risk factors that may be contributing to their wish to hasten death, such as depression, hopelessness, spiritual suffering and pain. Addressing these risk factors may help to alleviate suffering and reduce numbers of patients with a WTHD.

PS 13 - 2 The Clinical Approach of the Wish to the Hasten Death in Europe

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Background/aims: The direct response to the Wish to Hasten Death (WTHD) remains with palliative care (PC) professionals that try to optimize the quality of care and quality of life for patients with advanced life-threatening illnesses. An analysis of the current knowledge and practices of PC teams in Europe is urgently needed to determine what preparation exists or is lacking for management of the WTHD in clinical practice. This study reports the results of a survey distributed to PC practitioners through the EAPC network as part of the objectives of our WTHD task force. An online survey was developed to obtain information regarding the frequency, intensity, causes, preventive and therapeutic initiatives to the WTHD according to perceptions of PC professionals in Europe.

Methods: A descriptive cross-sectional survey. A total of 20 multiple-choice and Likert scale questions were decided on and uploaded into an online survey platform.

Results: Participants from 20 out of the 44 countries in continental Europe responded with a total of 78 responses. The majority (60%) endorsed that it is difficult to extremely difficult to take care for WTHD issues, and admitted they lack guidelines to guide clinical assessment and response, despite a majority (55%) agreed to strongly agreed the WTHD must be assessed. Many other lessons learned will be highlighted.

Conclusions: Combined with a lack of guidelines reported by most respondents, clearly there is a need for preparation and guidance to assist formal and informal caregivers in the assessment and management of the WTHD. With this information, the EAPC task force aims to develop guidelines and to recommend standards for clinical practice to guide those working in palliative and end-of-life care to address this challenging topic.

PS 13 - 3 The Wish to Die and its Potential Links to Current Social, Ethical and Political Challenges

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Background/aims: The Wish to Hasten Death (WTHD) is increasingly relevant throughout Europe in the area of policy and public debate regarding patients' rights at the end of life.

Methods: By analysing the up-to-date legal and ethical frameworks surrounding assisted dying in different jurisdictions, this presentation aims

to expand our understanding of the WTHD in the context of the current challenges that our societies face.

Results: In our pluralist societies, attitudes towards death and dying vary enormously and are source of debate and division. They may also be intertwined with worldviews and our current zeitgeist in the context of multiple global crises. Ethically, wishes to die raise complex questions about the autonomy, solidarity, human dignity, and the value of life. Politically, jurisdictions around the world vary widely in their support for assisted dying, palliative care, and other responses to WTHD. Palliative care professionals may face ethical and legal challenges when caring for patients who express a WTHD. This adds to the difficulty in communicating about the WTHD with patients, their families, and other professionals.

Conclusions: The societal, ethical, and political challenges surrounding the WTHD for patients with advanced life-threatening illnesses are complex, and there is no easy solution. It is all the more important for health-care providers, policymakers, and citizens in general to develop an open attitude and a capacity to ethically reflect and appropriately communicate about the WTHD and forms of assisted dying.

PS 14 - G Palliative Care and Bereavement Needs and Experiences of LGBT+ People: Lessons Learnt, Recommendations for Practice and Next Steps

PS 14 - 1 Palliative Care and Bereavement Needs and Experiences of LGBT+ People: Lessons Learnt, Recommendations for Practice and Next Steps

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Background/aims: Background: Lesbian, gay, bisexual and trans (LGBT+) people face barriers to accessing essential healthcare, including: fears and experiences of discrimination, heteronormative and cisnormative assumptions, lack of recognition of relationships, and insensitive communication. Despite legal advances to protect LGBT+ people in healthcare, these barriers persist. A decade on from our first systematic review, we reflect on lessons learnt, recommendations for practice and next steps.

Methods: Methods and participants: Two systematic reviews, and four primary research studies conducted utilising: interviews and focus groups with LGBT+ people with serious or advanced illness (n=81), their informal caregivers (n=19) and bereaved informal caregivers (n=35), and health and social care professionals (n=39); and a population-based post-bereavement survey comparing outcomes of people bereaved of a same-gender (LGB) partner (n=233), and people bereaved of a different-gender partner (n=329). An overview of each study will be provided. Key findings from across the studies are presented below.

Results: Healthcare engagement and experiences for LGBT+ people are affected by the extent to which they feel able to disclose LGBT+ identities and important relationships to care providers, and the skills of those professionals to deliver person-centred care that responds to all elements of self. After the death of a partner, high levels of complicated grief are experienced irrespective of sexual orientation. However for bereaved same-gender (LGB) partners, there are higher levels of distress alongside that grief, and they describe experiences of reduced social support and isolation. While LGBT+ people fear discrimination, health and social care professionals mirror these concerns describing fears of making mistakes and causing distress.

Conclusions: Health and social care professionals are skilled at providing person-centred care, but need training, support at organisational level and appropriate infrastructure to enable them to provide LGBT+ inclusive care. Evidence-based recommendations for inclusive practice are presented. A systematic and coordinated approach to implementation

(between LGBT+ community networks, policy makers, and health and social care providers) is required to embed LGBT+ inclusive care practices.

PS 14 - 3 LGBTQ People's Experiences of Receiving Eldercare in a Swedish Context

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Background/aims Methods

Results: There is a general silence on gender and sexuality within eldercare contexts. This is due to structural factors where neoliberal effectivization of eldercare create pressed working conditions for staff, with little time for conversation or small talk in every-day eldercare situations. This is also due to heteronormative assumptions and ageist notions, where aging care facilities are coded as asexualized milieus. The responsibility to lift LGBTQ issues lie on the care-receivers. While some are not open with their sexualities or gender identities toward staff or other residents, other talk about being open as a strategy and a way to control the situation. Presence of supporting relationships and social networks vary among participants and shape their experiences of eldercare. However, the results point to how eldercare needs may also make it harder to participate in LGBTQ community activities. The lack of integrity also compromises the possibility for intimate practices.

Conclusions: LGBTQ people's experience from eldercare are shaped by discourses on gender and sexuality, heteronormativity and material factors such as ability, architecture, lack of integrity, blurring of private/public in one's home. Recommendations to affirming LGBTQ people within eldercare include moving from a equal-treatment-framework to a person-centered approach; facilitate integrity; enhance norm-critical knowledge on gender, sexuality, LGBTQ history and life experiences; and work toward better work conditions within eldercare which in turn may facilitate better pre-conditions for conversation in everyday eldercare as well as for increase knowledge and competence among staff.

PS 15 - H Understanding Care Experiences: the Challenge of Conducting Transnational Qualitative Research

PS 15 - 1 Developing an Advance Directive 'Communication Tool' Across Six European Countries. Insights from a Qualitative Process-Evaluation Study in the ACTION Trial

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Background/aims: The ACTION trial was a multi-center cluster-randomized clinical trial investigating the effectiveness of the ACTION Respecting Choices Advance care planning intervention in six European countries (Belgium, Denmark, Italy, the Netherlands, Slovenia, United

Kingdom). Patients with advanced lung or colorectal cancer were invited to have one or two ACP conversations with a trained facilitator. To document advance care preferences we needed an advance directive communication tool.

The aims of this talk is to describe and discuss insights from developing the advance directive communication tool 'My Preferences form' (MPF) within the international, multi-center trial, ACTION.

Methods: The MPF was developed based on a) discussions within the large group of consortium members (n=38), and b) with input from clinicians from participating hospitals (n=13) and the trained facilitators (n=13). A qualitative analysis of all textual data (emails, meeting minutes, feedback etc.) concerned with the development was conducted using framework analysis.

Results: In total, it took ten versions to develop the MPF. In the process, many modifications took place. The main rationales for the modifications were the need for the AD to be relevant in a cancer context and to comply with the clinical, legal and cultural practices within the six European countries.

Conclusions: The study showed that developing a common advance directive communication tool to be used across six European countries was both ambitious and challenging. The six countries participating in the trial were chosen to be diverse. Thus, we had countries with nearly no experience with advance care planning, and other countries who had quite extensive experience. Further, subtle differences between cultures had impact on the needs regarding the document in each country. Thorough processes are needed when developing cross-cultural interventions.

PS 15 - 2 International Cross-case Analysis: Insights from an Implementation Study in Nursing Care Homes Across Six Countries

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Background/aims: The purpose of the overarching study was to implement an intervention focused on advance care planning in nursing care homes for people living with advanced dementia. The study was conducted across a number of different countries, with both qualitative and quantitative data collection. The aim of this presentation is to explore the planning, process and outcomes of data analysis across six countries.

Methods: A multiple case study design enabled an understanding of the implementation process and the identification of the factors which determined how well the intervention worked as intended. Nursing care homes were enrolled across six countries (Canada n = 2 Republic of Ireland = 2, three regions in the UK n = 2 each, The Netherlands n = 2, Italy n = 2 and the Czech Republic n = 2) to reflect the range of characteristics in each national and local context.

Results: A range of processes were used to facilitate within and cross-case analysis including the development of theoretical propositions, a shared codebook and coding framework, and the development of case descriptions using an agreed template. The codebooks and the individual nursing home case templates informed the development of a cross-case template which was populated with findings from each case. Important considerations included the languages within which different processes occurred, how to maintain the nuance of findings across cultures and contexts, and the roles of individuals and the team in facilitating and leading within and cross case analysis.

Conclusions: Analysing qualitative data across highly different international contexts within a single study is challenging, but possible. Researchers need to be cognisant of the epistemological, ontological and methodological assumptions inherent in such analyses, focusing on what is possible and helpful to the consumers of such research.

PS 16 - A Monitoring Technologies in the Last Phase of Life for People with Communication Difficulties

PS 16 - 1 Non-invasive Monitoring Technologies to identify Discomfort and Distressing Symptoms in Persons with Limited Communication at the End of Life: A Scoping Review

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Background/aims: At the end of life, people often experience distressing symptoms while no longer able to express their discomfort. This review aims to provide an overview of available non-invasive monitoring technologies that may be applied to persons with limited communication ability at the end of life to identify discomfort or distressing symptoms, also reporting on psychometric properties.

Methods: In 2021, a literature search was performed in 9 databases, including PubMed and Web of Science. The search will be updated in 2023. Key search terms included non-invasive monitoring, distressing symptoms, and multiple terms relating to persons with limited communication. The manuscripts were screened by two researchers independently. We abstracted author, year of publication, language, country, participants, type of technology, model and brand of the technology, symptoms monitored, psychometrics (validity, reliability, sensitivity, specificity, responsiveness), and acceptability or feasibility of the technology.

Results: Before the updated search, 194 manuscripts were included. Twelve types of technologies were identified, covering actigraphy, polysomnography, respiration monitors, electroencephalography-based technologies, incontinence sensors, pressure mats, electrocardiography, electrodermal activity monitors, surface electromyogram, photoplethysmography, non-contact monitoring systems, and other multi-model systems. The main symptoms monitored were sleep, agitation, sedation, stress, pain, risk of pressure ulcers, and urinary incontinence. Psychometrics of well-established technologies, such as actigraphy and (portable) polysomnography, were mainly favourable. Acceptability and feasibility of the technology were rarely reported. Some new technologies are being developed to monitor the person without physical connection, making use of video, radar and sound.

Conclusions: This review identified 12 types of non-invasive monitoring technologies that may be applied to persons with limited communication at the end of life to identify discomfort or distressing symptoms. This overview may guide researchers to further investigate the usefulness and applicability of these monitoring technologies in end-of-life care settings and evaluate the acceptability among relevant stakeholders.

PS 16 - 2 Detecting Stress in People with Dementia: Requirements and Opportunities for a Garment-integrated Sensor System

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Background/aims: People living with advanced dementia are vulnerable to stress. Their communication impairments limit the ability to express their emotional state. Stress buildup can result in challenging behavior, which negatively impacts the quality of life of people living with dementia and increases caregiver burden. Technology can help caregivers detect stress in people with dementia. However, current stress detecting technologies are

often perceived as uncomfortable, less suitable for longer measurement periods or are not accepted by users. This study aims to identify user requirements and opportunities for a garment-integrated sensor system for early detection of stress in people living with dementia.

Methods: A qualitative design with online focus groups (n=9) and interviews (n=21) with persons living with dementia (n=4), family (n=10), and professional caregivers (n=9) was used. The participants took part in three focus groups or interviews within 6 months, allowing for each round to build on the findings of previous rounds. Qualitative data were analyzed using inductive conventional content analysis.

Results: User requirements could be divided into: (1) practical requirements (washable, no loose parts); (2) ethical requirements (privacy, autonomy, minimize stigma, permission of use); and (3) requirements to increase acceptance (user friendliness, customizable). Preferred designs for the sensor system were a wristband, sock or shirt. Participants could see the sensor system being used to detect stress, but also as a tool to identify triggers for challenging behavior, for diagnostic purposes or to evaluate effectiveness of interventions.

Conclusions: Participants were positive about the idea of a garment-integrated sensor system and even attributed several usages other than early stress detection to the system. One of the key requirements is the need for customizability to increase user acceptance. The next step is to develop and validate the garment-integrated sensor system in clinical practice.

PS 16 - 3 Feasibility of Using Technology to Monitor Awareness in Patients with Advanced Disease

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Background/aims: The delivery of care can often be challenging in people with advanced diseases as they are often unable to communicate their needs and experiences. Currently, most level of consciousness assessment tools rely on direct observations or patient behaviours, body language or facial expressions. However, relying on observer ratings of behaviours can be subjective, unreliable and prone to biases. There has been growing interest in the use of level of consciousness monitoring technology in people with advanced diseases. One such monitoring tool is the Bispectral Index (BIS) device, which was originally developed for use in surgery to measure levels of consciousness.

Methods: This presentation describes a research project that investigates the acceptability and feasibility of using the BIS device in care home residents with severe dementia. The project consists of three studies involving key stakeholders. Firstly, an interview study with family carers of people with severe dementia (n=13) was conducted to elucidate their views on the use of the BIS device in this group. Secondly, a two-round Delphi survey study was carried out to establish factors that are important when implementing the BIS device in a care home setting. Respondents who work with people with severe dementia (n=47) in a professional capacity took part in the first round, of whom 29 completed the subsequent round. Thirdly, 17 care home residents with severe dementia were recruited into a pilot study to examine the acceptability and feasibility of using the BIS device to monitor levels of awareness; 13 of whom tolerated the device and had their BIS values recorded.

Results: The three empirical studies reveal that it is generally acceptable and feasible to use the BIS device in care home residents with severe dementia. The results, including some preliminary analyses on the BIS data are presented. The implications of the findings as well as suggestions for future research are also discussed.

Conclusions: This is the first project that extensively explores the acceptability and feasibility of using the BIS device in people with severe dementia. The BIS device is able to offer additional information when used in conjunction with direct observations, especially in individuals

with communication difficulties. More research is needed to evaluate its clinical utility.

PS 17 - F Rethinking Palliative Care in Cultural Traditions to Optimize Equity and Diversity

PS 17 - 1 Reframing Palliative Care through a Global South Perspective

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Background/aims: The need for palliative care is greater in Low and Middle Income Countries (LMICs) because disease-specific treatment does not reach patients adequately or in time. 51 million people in LMICs experience Serious Health-related Suffering (SHS). Palliative care in these countries is required to go beyond symptom control, end of life care or specific disease groups. In these settings, mitigating SHS requires addressing the suffering of the whole family, in addition to the physical distress of the index patient. There must be consideration for the impact of illness on social, emotional, spiritual suffering, the assault on dignity and autonomy, and recognition that the illness of one person has a multi-generational impact.

The 2017 Lancet Commission Report on Access to Palliative Care and Pain Relief highlighted the “access abyss” and the alarming disparity in access to opioid analgesics. Yet, the majority of the guidelines emerge from the Global North. Decisions that most impact LMICs are arrived at with inadequate consultation with those that are most affected. This lack of representation stems from the inability of Global South representatives to participate for several reasons, including the geographic location of where meetings are held – High Income Countries where many don’t have diplomatic missions, or cannot afford to travel to unless sponsored. Consequently, current frameworks, while theoretically sound in terms of indicators for measurement of service delivery and quality, are rarely implementable in the countries that require comprehensive palliative care the most.

This talk focuses on the gaps and the possible frameworks to reimagine palliative care through a more equitable lens.

Methods: Not relevant as this is not a research presentation.

Results: Not applicable

Conclusions: We need to focus on well-calibrated, compassionate and smart regulatory systems, and fit-for-purpose frameworks for controlled medicines, while simultaneously providing the guardrails of training and evidence-based information about the safe use of opioids for pain relief. This must include partnerships between governments, professionals and civil society actors, with patient-centredness being the driver of appropriateness. We need to reimagine controlled medicines through a post-colonial framework. A vision informed by collective international action rooted in post-colonialist ethics and approaches to ensure equitable access, particularly for historically excluded stakeholders from LMICs.

PS 17 - 2 Rethinking Culture and Tradition at the End of Life.

Dying in Singapore

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Background/aims: Culture and Tradition are inexorably inter-twined with death and dying. It is unique and diverse in different countries around the world and needs to be respected and honoured by all who care for those with serious illnesses who are at the end of life.

In this talk, Dr Koh will share about customs, traditions and rituals surrounding death from an Asian perspective using Singapore – a multi-cultural and multi-ethnic country as an example. He will share about important topics like collusion, cultural beliefs and religious practices and how they impact care at the end of life.

PS 17 - 3 Cultural Perspectives on End-of-Life Care for Patient with Cancers in West-Africa

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Background/aims: In our African pediatric oncology environment it is frequent that resources become insufficient to cure some cancers or that the patient arrives to the unit at advanced stages of their disease. Therefore, the subject of death and dying frequently rises. It is essential to gain more insight on children’s awareness during this trying life period. The purpose of this study was to assess children’s ability to verbalize their perceptions and emotions on death.

Methods: In this study, qualitative methods (therapeutic groups) and case studies (individual therapy sessions) were used. We have addressed the subject of death and dying with a sample of 24 children aged between 5 and 15. In the therapeutic groups, we have read an illustrated fairy tale and used art therapy. Following the book reading and drawing, we have initiated a metaphorical debate allowing us to launch the subject of death. During individual sessions, we have created a space for children to vent their emotions and bring up their apprehensions and fears on the end-of-life.

Results: Although the word “death” was never pronounced during groups, the pediatric cancer patients clearly discussed the subjects of fear, end-of-life, saying goodbye and the afterlife. African children, from collectivistic cultures, were more concerned with the people left behind than with their own mortality. They were inquisitive about the “unknown place” they might be headed for. Having to leave life sparked a great debate that most participants joined in with a clear identification of their thoughts and feelings. Many wanted to prepare themselves by acquiring mystical protection, packing provisions, leaving instructions behind, taking photos with them and explaining their departure.

Conclusions: Frequently, doctors and parents’ own worries about death prevent them from addressing the matter with pediatric cancer patients. This study shows that children are capable of deeply discussing their thoughts and emotions on death. It is our experience that children who are at the end of life have a strong sense that something grave and unusual is happening within their body. It would be cathartic for them to have a medium to express their feelings about dying and prepare for their departure. Offering children the opportunity to vent their emotions freely at this stage is a very powerful enabling tool.

PS 18 - B The Use of Proportional Palliative Sedation to Manage Refractory Symptoms

PS 18 - 1 What are Appropriate Outcomes for Assessing Palliative Sedation? A Scoping Review

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Background/aims: Extensive debate surrounds the practice of palliative sedation (i.e. using sedative drugs to lower consciousness in patients nearing death) and its various complexities. Initiatives undertaken to date to evaluate palliative sedation are mostly focused on a single outcome domain unlikely to reflect overall sedation quality and thus leading to incomplete evaluations of the overall practice. There is a need for an agreed, standardized set of outcomes for palliative sedation, yet an overview of relevant or appropriate outcomes for palliative sedation is lacking. Therefore we set out to identify indicators that reflect the overall quality of palliative sedation reported in the wider academic and professional literature.

Methods: We performed a scoping review of the academic and grey literature from 2000 onwards, following a pre-developed protocol. The search string was developed in collaboration with an in-house

information specialist. Two researchers independently screened all abstracts and discussed disagreements on inclusion. Data were extracted using a pre-developed extraction form appropriate for the purposes of our specific research aim.

Results: Data collection and analysis was still ongoing at moment of abstract submission. Findings will be presented in full at the EAPC conference (June 2023).

Conclusions: The findings will provide a comprehensive overview of the various types of indicators that might determine the quality of palliative sedation, both in terms of the actual performance of sedation and in terms of circumstances surrounding the sedation, eg communication, attention to the family, etc. As such, the insights will constitute a sound basis and first step toward developing a core outcome set for the evaluation of palliative sedation in research and in clinical practice. This study is part of the COSedation project, funded by the Research Foundation - Flanders (FWO Vlaanderen, project G0A9622N, 2022-2026).

PS 18 - 3 Palliative Sedation: A Multimethod Approach from a European Project

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Background/aims: Palliative sedation involves the intentional lowering of consciousness in the last phase of life. The indication for palliative sedation is based on refractory symptoms, complex and severe distressing symptoms such as pain, delirium and breathlessness which cannot be treated otherwise. In such situations, palliative sedation may be applied in the context of a palliative care approach. There has been much international debate about terminology, ethics, and practices surrounding palliative sedation. The aim of our project is to study the practice of palliative sedation in an international context. For this aim, a multi method approach has been applied in a European study.

Methods: The project consists of several work packages, indicating the variety of methods that are used in the study. This includes amongst others a systematic investigation of the literature and an expert survey, a multicenter clinical study, a qualitative interview study, a delphi panel for a revised framework, an educational program, a policy workshop, and a moral case deliberation study. The methods will be highlighted in the context of the European study proceedings together with some preliminary results.

Results: At the abstract deadline, the multicenter study and the interview study are still ongoing, the literature reviews and the moral case deliberation sessions have been completed, whereas a revised framework for palliative sedation has been designed. The educational program and the policy workshop are still forthcoming. Throughout the proceedings of the project, much attention has been given to the harmonization of study protocols across the participating countries, which gave interesting process information on the application and acceptance of the concept of palliative sedation, and the need to adapt to local circumstances.

Conclusions: Palliative sedation is in general an accepted medical practice across Europe, but careful recognition of cultural and ethical dimensions of care is advised

Conflict of interest: The author is coordinator of a European (Horizon Europe) project. Parts of the abstract is related to that project.

PS 19 - F The Lancet Commission on the Value of Death: Future Actions for Palliative Care

PS 19 - 1 The Lancet Commission on the Value of Death: What are the Implications for Palliative Care?

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Background/aims: The *Lancet* Commission on the Value of Death draws together global perspectives on death, dying and grieving and argues that these experiences have today become unbalanced. The story of dying in the 21st century is a story of paradox. While many people are overtreated in hospitals with families and communities relegated to the margins, still more remain undertreated, dying of preventable conditions and without access to basic pain relief.

Methods: To rebalance these universal human processes, a 'realistic utopia' is presented, outlining the changes required throughout complex systems to transform how we live, care, die and grieve. The Commission recognises that rebalancing death and dying will depend on changes across 'death, dying and grieving systems', the many inter-related social, cultural, economic, religious and political factors that determine how death, dying, and bereavement are understood, experienced and managed.

Results: Examples of the realistic utopia in practice will be discussed, with implications for the role of palliative care services.

Conclusions: This session will explore the principles of the realistic utopia, the role of complex systems thinking in death, dying and grieving, and understand the role of palliative care services and approaches.

PS 19 - 2 Does Palliative Care Own Death?

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Background/aims: The Lancet Commission on the Value of Death explored global death systems that influence how people live, care, die and grieve, to develop recommendations for different audiences in society as to how to 'rebalance' approaches to dying, death and grief.

Methods: A multi-disciplinary global panel explored multiple perspectives - historical, ethical, social and biomedical via dialogue and debate. This culminated in the publication in February 2022 of the Commission report.

Results: A 'realistic utopia' underpinned by concepts to inform systemic change was described, including tackling the social determinants of death, understanding the relational process of dying, accepting that social networks must lead support of the dying, stories of 'normal' dying must be shared and death must be recognised as having value.

Currently it seems that death has been sequestered to palliative care in the northern hemisphere. Dying patients are often referred to palliative teams - with diminishing confidence of the community, primary care and hospital specialists to support their dying patients to their last breaths.

There is also a huge bio-medical focus, a rhetoric of risk and a stifling of compassionate practice. The network surrounding the patient is not explored - often just the 'next of kin' is noted. Quality of life, and what matters to people is not questioned. The person is reduced to be a recipient of services.

Conclusions: Palliative care does not own death, but others believe it does, and are abrogating responsibility. Small system changes could bring about a shift. These include new conversations, not just about advance care planning (which sadly focuses on the last heartbeat) but instead focussing on a greater understanding of community assets. Volunteers could play a significant role in companionship for the lonely dying, improving the relational and safety aspects of care. Stories of normal dying can start in school, to rebalance the stories of traumatic and intensive care deaths that populate the media. A debate is needed of how over-treatment at the end of life is not a story of biomedical success, but often of suffering and resource depletion. All medical disciplines and all communities share core principles of humane care for the dying - these imperatives need to flourish again. We need to learn from societies that have a gentler approach to mortality, where the community is seen as an equal partner in care, where power and trust lies in connections, not in medical industrial complexes.

PS 19 - 3 Suffering, Caring and Loss and the Role of Palliative Care in LMICs

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Background/aims: WHO defined health as “physical social and mental well-being and not merely the absence of disease or infirmity” in 1948. The palliative care movement is 58 years old. It is 14 years since the United Nations Special Rapporteur for Torture called denial of pain relief “inhuman or degrading treatment or punishment”.

Yet, in 2017, the Lancet Commission Report on Access to Palliative Care and Pain Relief estimated that around 51 million people in low and middle income countries (LMICs) in serious health-related suffering (SHS) have no access even to basic pain relief. Death and dying often demonstrate a cruel paradox in LMICs. As the Lancet Commission on the Value of Death (2022) pointed out, “while many people are over-treated in hospitals with families and communities relegated to the margins, still more remain under-treated, dying of preventable conditions and without access to basic pain relief”.

Part of the reason appears to be a form of ‘neo-colonisation’ by definitions and guidelines which are essentially based on available research, 93.5% of which are from 15% of the global population in Euro-American countries. The elements of suffering could be vastly different in LMICs and need to be elucidated.

Many conditions that may not cause SHS in high income countries could warrant palliative care in LMICs. Acute pains, chronic pain, major disabilities and substance use disorders are examples. When the paucity of primary, secondary, tertiary or rehabilitative care causes SHS, palliative care teams have no option but to fill the gap.

This talk looks at available literature covering this subject and offers a possible solution.

Methods: Not relevant as this is not a research presentation.

Results: Not relevant as this is not a research presentation.

Conclusions: We need a strategy specifically designed for LMICs with implementation frameworks that are adaptable based on individual countries’ needs.

Such a strategy must include participation of the community and must aim to integrate palliative care into the countries’ healthcare systems at micro, meso and macro levels. Definition of palliative care should not be restrictive and must encompass all serious health-related suffering. Futile and inappropriate treatment at the end of life can be avoided only by bringing death from the realm of hospitals back to the community. Action steps need to be created bearing in mind the possible implementation gaps created by paucity of resources and by resistance to change.

PS 20 - H Gratitude in Palliative Care: a Promising Beneficial Source for Patients and Professionals

PS 20 - 1 Presence of Gratitude in Palliative Care daily practice

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Background/aims: Gratitude has sparked interest in the world of health. In the field of social psychology, gratitude is considered a characteristic of the personality^{1,2}. The other perspective understands gratitude as linked to emotions^{3,4}. Considering the social association of palliative care with death and negative view and the context of end of life, it may seem unusual the existence of gratitude in palliative care.

Methods: This session aims to set the context of gratitude in palliative care considering the current evidence.

Results: Gratitude is very present in palliative care, from both professionals and patients and family’s perspective. A national survey

showed that 79% of palliative professionals almost always receive gratitude for the work performed. This coincides with an Italian study, in which 92.5% of patients’ and 97 of caregivers’ reports, included expressions of gratitude when asked about their experience of care with palliative care⁶. The quantity is not important⁵, but what is appreciated and the repercussion or effect of it. The latter being address on the following interventions of this workshop. Here we will discuss what is appreciated in the palliative care setting and how is expressed. Patients and family members expressed gratitude for: physical symptom management, emotional support, improving quality of life and wellbeing, improved attitude toward death, opportunity to die at home, better information, humanity, and the familiar environment⁵⁻⁸. In fact, a recent study suggests that all of this underlies an implicit recognition of having received an ‘objective good’ for the person, not just something that may be ‘just’ satisfactory, promoting a healing process in the person⁹. Expressions of gratitude are varied. They can range from letters, food, hugs. . . and there are cultural aspects related to its manifestation^{5,7,10}. Patients and family members often convey gratitude very vividly. They feel they need to convey it because it is important to them, and it remains unexplored what role it plays. Gratitude expressed to professionals may be important but also gratitude expressed among the dyad patient-family. Palliative care professionals receive gratitude, but they also feel gratitude toward the patients and families who allow them to share part of their lives.

Conclusions: Patients, families and palliative care professionals share gratitude, and feel good about it, and it seems that may have also a protective role and vice versa.

PS 20 - 2 Giving and Receiving Thanks: A Mixed Methods Pilot Study of a Gratitude Intervention for Palliative Patients and their Carers

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Background/aims: So far, few studies have considered gratitude in palliative care patients. Based on first exploratory study which found a significant associations between gratitude and quality of life and psychological distress, we designed and piloted a gratitude intervention where palliative patients and a carer of their choice wrote and shared a gratitude letter with each other. The aims of this study are to establish the feasibility and acceptability of the intervention, provide preliminary effects, and explore what patients express in their letters

Methods: This study adopted a mixed-methods, pre-post evaluation design. We employed questionnaires on quality of life, quality of relationship, psychological distress, and subjective burden, and semi-structured interviews. To assess feasibility, we considered patients and carers’ eligibility, participation and attrition rates, reasons for refusal to participate, modalities of participation, and barriers and facilitators. Acceptability was assessed through post-intervention satisfaction questionnaires. Inductive thematic analysis was used to explore participants’ letters.

Results: Thirty-nine participants completed the intervention. No statistically significant pre/post intervention changes was found for patients, a significant decrease in psychological distress was found for carers (median=13 at T0, 7.5 at T1, p=.041). Thematic analysis of interviews indicates that the intervention had: (i) multiple positive outcomes for over a third of interviewees (positive emotional, cognitive, and relational effects) (ii) simple positive outcomes for nearly half of interviewees (emotional or cognitive effects); (iii) no effect on two patients; and (iv) negative emotional effects on two patients. Feasibility and acceptability indicators suggest that the intervention was well received by

participants, and that it should adopt flexible modalities (e.g. writing or dictating a gratitude message) to ensure that it is feasible and adapted to individual needs. The content of 22 letters showed that patients were thankful for their relative's love, presence, unfaltering support, and kindness and generosity. Beyond gratitude, participants wrote about their life with serious illness.

Conclusions: Larger scale evaluation of this intervention is warranted in order to have a reliable evaluation of its effectiveness. At this stage, we recommend to propose a gratitude-based approach as a part of an individual therapy to offer the greatest potential for clinical usefulness.

PS 20 - 3 Palliative Professionals' Experiences of Receiving Gratitude: A Protective Resource from Patients and Families

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Background/aims: Providing palliative care can be both challenging and rewarding. It involves emotionally demanding work and yet research shows that burnout is lower than in other fields of health care. Spontaneous expressions of gratitude from patients and family members are not uncommon. They are highly valued although no systematic studies have been found on the characteristics of these expressions or on the importance they have for palliative care professionals. The objective was to understand the meaning and role that the expressions of gratitude from patients and family members have for the palliative care professional in Spain.

Methods: Combined methodology was used, specifically an explanatory sequential design. The first phase was quantitative, sending an ad hoc survey by email to every palliative care service in Spain (n = 272) by Survey Monkey. The second part was qualitative with a phenomenological approach using macro-thematic and micro-thematic reflection. Conversational interviews were conducted with 10 purposefully selected palliative care professionals. Two team members independently engaged in this reflection with an inductive approach.

Results: The expressions received provoke positive feelings such as satisfaction (94%), motivation (91%) and pride in their work (75%). Respondents said that gratitude increases their job satisfaction, is a source of support in times of professional difficulty (90%) and improves their mood (88%). In the phenomenological analysis from the interviews, three main themes and subthemes reflected the experience of the palliative care professionals who received expressions of gratitude: Recognizing expressions of gratitude as authentic (Benevolent, Deeply felt, Captures meaningful encounter); Internalizing and treasuring the expressions (Symbolism, Recognition of commitment, Recognition of uniqueness); and Using expressions of gratitude as a valued resource (Reflection, learning and transformation, Protection to continue).

Conclusions: Expressions of gratitude are significant for professionals working in palliative care. They are a powerful and deeply meaningful resource that they revisited over time. These professionals considered that those expressions offer multiple beneficial effects, giving them a protective role against emotional exhaustion and having a transformative role. They invited a stronger sense of the value of one's self and one's work that was motivational, particularly during challenging times.

1.2.6 Free communication sessions

FC 1 - B Advance Care Planning

FC 1.1 Advance Care Planning and a Structured Palliative Plan Decrease the Number of Cancer Deaths in Hospital: A Pre-post Intervention Study

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Background/aims: Advance care planning (ACP) enables patients to define goals and preferences, reflecting a person's wishes and current medical condition. Spending less time in hospital and not dying in hospital are advocated to be desirable outcomes in palliative care (PC). In 2017, 35% of cancer patients died in hospital and 13% died at home in Norway.

Methods: From 2015 to 2020 this pre-post intervention study included 151 cancer patients from the Romsdal region with or without an organized ACP conversation with a conclusive and structured palliative plan in primary health care. Seventy-six patients were included and observed before systematically implementation of structured palliative plans in primary health care in 2018, and 75 patients were included after the intervention. The patients were identified through their contact with the local hospital, cancer outpatient clinic or hospital-based PC team.

Results: During the observation period, 135 patients died. Of these, 74 patients had a structured palliative plan (the intervention) and 61 had not. Dying in hospital was significantly less common for patients with the intervention in primary health care (16,2% vs 34,4%; p=0.014; χ^2 (1, n = 135) = 6.00). These patients were more likely to die at home (33,8% vs 29,5%) or nursing home (50,0% vs 36,1%). Contact with the hospital-based PC team did not affect if patients died in hospital or home / nursing home (p=0.34; χ^2 (1, n = 135) = 0.92). There were no statistically significant differences between the groups with or without the intervention according to days at home, in nursing home or in hospital during the last 90 days of life.

Conclusions: Use of a structured palliative plan as a conclusive documentation after an ACP conversation with patient and relatives decreased the number of cancer deaths in hospital in our study. Interventions in primary health care can change the current care profile to a more outpatient care.

FC 1.2 To Talk or Not to Talk: What Are the Actual Needs and Barriers in Advance Care Planning Communication among Healthcare Professionals?

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Background/aims: Although the importance of advance care planning (ACP) is widely recognized among healthcare professionals, these conversations are not yet routinely implemented in clinical reality. We aim to identify healthcare professionals' needs and barriers to having ACP conversations to support the development of an online communication training.

Methods: We searched PubMed for potentially relevant records between January 2000 and July 2022, using broad search terms for barriers and needs in communication about advance care planning, palliative care and end of life with adult patients and their relatives in all healthcare settings.

Results: 2761 records were found, of which 229 articles were included as full-text. One review from 2016 was found, which focused solely on communication about serious illness in primary care. We identified 141 barriers and 28 needs and organized them into 9 themes: (1) societal values and knowledge of ACP; (2) patient factors; (3) coping strategy of patient and family; (4) family structure and dynamics; (5) ideas, concerns and emotions of healthcare professionals; (6) lack of skills, knowledge and support of healthcare professionals; (7) timing (who, where, when); (8) roles and structure of organization and (9) legal issues.

Conclusions: Perceived barriers and unmet needs cause healthcare professionals to delay or avoid advance care planning conversations. Surprisingly, our review is the first to explore these barriers and needs so extensively. Until these barriers are overcome and needs are met, it will remain difficult to implement advance care planning in routine clinical practice. This study provides useful knowledge to develop an online communication skills training in which these barriers will be tackled.

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FC 1.3 Barriers and Facilitators in Transmural Advance Care Planning for Older People in the Netherlands: A Qualitative Study

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Background/aims: Optimal organized advance care planning (ACP) for the growing number of frail older people is necessary to provide appropriate care in line with their wishes and needs. The aim of this study is to obtain insight into barriers and facilitators in transmural ACP for older people.

Methods: Five focus groups and four individual interviews were held, with three patient representatives and 32 healthcare professionals involved in ACP from the community, nursing home, ambulance and hospital services. Thematic analysis was used to describe themes.

Results: Four themes were identified. The main theme was transmural sharing of outcomes of ACP. Barriers are caused by privacy concerns and non-communicative digital care systems. The other themes were: lack of knowledge, the moment of ACP, and roles and responsibilities in ACP.

Healthcare professionals (especially physicians were mentioned) often have insufficient knowledge of ACP and alternatives in (palliative) care, specifically in acute situations. Furthermore, nurses often do not know the different possible disease trajectories and can therefore not anticipate, inform and guide a patient optimally.

A shift in roles is proposed by promoting a two-level ACP: a (district) nurse could start a ACP conversation in a familiar environment and a physician concludes on (medical) treatment that is in line with the wishes and needs. Participants think that timely ACP can prevent potentially inappropriate care, tensions with families and moral distress to healthcare professionals.

Conclusions: Digital sharing of the outcomes of ACP, improvement of knowledge on timely ACP and palliative care and a shift in roles in ACP can contribute to optimal transmural ACP for older people.

FC 1.4 Making ACP Work for People in Practice: Implementation of a Structured Advance Care Planning Intervention in Scottish Primary Care (4ACP)

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Background/aims: Advance Care Planning (ACP) for people with one or more progressive, long-term illnesses helps deliver personalised care, support wellbeing, and reduce the impact of healthcare crises. Our "Four Steps ACP" (4ACP) study implements integrated ACP in primary care in Scotland. 4ACP builds on our work in screening for advance care planning and adds an implementation including public information, professional education, electronic records and a national screening of nearly six million primary care health records.

Methods: A mixed-method, healthcare implementation study following StaRI guidelines implements the four ACP steps. National primary care datasets from approximately 5,800,000 GP-registered patients screened using the AnticiPal search conducted before and after ACP implementation case studies with 16 diverse GP practices in four Scottish Health Boards (study population approximately 100,000). Practice case study data include; AnticiPal screening outputs, GP 'Thinking Aloud' interviews of AnticiPal list assessments, patient-carer and linked GP interviews following ACP conversations, ACP plans recorded, screened cohort outcomes.

Results: Approximately 0.6% of GP registered patients in Scotland who had not previously identified for palliative care screened positive for ACP. Of these, 61.6% had no Key Information Summary or documented ACP. Practices found 4ACP straightforward to implement with potential to improve ACP for significant numbers of deteriorating patients known to clinicians who had not previously been identified for ACP or palliative care. Qualitative interviews with patients, families and primary care clinicians identified areas of acceptability and concern.

Conclusions: Effective ACP depends on implementation into routine practice of a feasible intervention acceptable to patients, families, and professionals alike. 4ACP provides robust implementation of national ACP programmes in Scotland and informs refinement and implementation at scale in the UK and internationally.

FC 1.5 Experiences of Advance Care Planning in Amyotrophic Lateral Sclerosis (ALS): A Qualitative Longitudinal Study with Persons with ALS and their Family Carers

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Background/aims: ALS is incurable and characterized by progressive muscle paralysis with an average survival of 3 to 5 years. Although previous research has shown that people with ALS and their families often think about their future and what they would prefer in terms of their future care and treatment, it is very unclear when and how these issues arise, how they change over time and through which dynamics.

Aim: To understand the experiences with advance care planning (ACP) for people with ALS and their family carers, and when and how these experiences unfold over time throughout the disease trajectory.

Methods: We conducted a qualitative, longitudinal multi-perspective study with nine dyads (persons with ALS and their family carers). We interviewed them every 3 months over a 9-month period. Via content analysis, we obtained an in-depth understanding of the data and conducted a coding list, resulting into overarching themes.

Results: All dyads had some experience with ACP, mostly contemplating about their future and future care, but only few talked about it. Over time, ACP experiences were influenced by: (1) the extent in which patients' declined physically (e.g. no longer being able to walk); (2) how they identified themselves as patients with ALS; (3) professionals initiating conversations about medical aspects of end-of-life decisions, even though participants experienced it as stressful or too early; (4) balancing between hope to remain stable and worry about what the future might hold; (5) protecting themselves and each other about the future; and (6) gaining information about diagnosis and prognosis and learning that everyone evolves differently which makes planning for the future difficult.

Conclusions: ACP experiences unfold over time and are influenced by different factors. Professionals should focus on what matters most to patients and family, on supporting them in ACP, and on explaining why these medical (end-of-life) decisions need to be discussed this early on.

FC 1.6 The Responses Study – A Qualitative Exploration into Psychological Responses to and Potential Influences of, Advance Care Planning Discussions for People Living with Advanced Illness

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Background/aims: Advance Care Planning (ACP) discussions can be beneficial to people living with advanced illness. While research has focussed on ACP barriers, outcomes and completion, little is known about how ACP discussions influence thoughts, feelings and behaviours.

Aim: To explore psychological responses to ACP discussions, and their potential influences on the thoughts, feelings and behaviours of people living with advanced illness.

Methods: Design: Semi-structured, qualitative interviews with purposively sampled adults receiving hospice care. Data were analysed using framework analysis. Reflexive journalling and discussion of coding framework and emerging themes supported rigour.

Results: 20 adults aged 30-93 with cancer (15) and non-cancer (5) diagnoses were interviewed. Participants described a range of responses to ACP discussions, including relief and satisfaction in expressing wishes, confidence in decision making, and appreciation of the support, acceptance, expertise and honesty of clinicians and relatives. A smaller number of negative emotions such as worry, anger, and doubt about achieving wishes were expressed. Existential responses included acceptance of their illness, hopes and fears for the future, and difficulty of facing mortality. Responses were tied to factors such as attitudes towards having a terminal illness, previous thoughts about ACP, personality, and previous experiences of death and dying.

ACP empowered participants, confirming previous end of life wishes, allowing them to address existential concerns, promoting openness with relatives, and encouraging them to make the most of time left.

Conclusions: Participants described positive, negative and existential responses to ACP discussions. When considering both how to approach and support people after ACP discussions, clinicians must sensitively navigate their potential impact, being aware that they encourage people to consider their future, and their own mortality.

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FC 2 - F Ethics, Policy and Law

FC 2.1 Do Patients Still Face Barriers to Writing Advance Directive

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Background/aims: Advance directives (AD) are promoted since more than 25 years in Geneva Switzerland. However, the number of patients that completed AD is still low and is not increasing despite the significant deployment of the advance care planning.

The objective of this study was to better understand the needs and the values related to AD of patients with an advance disease hospitalised in a palliative care unit. We will in this abstract only focus on the potential barriers evoked by the patient.

Methods: Qualitative study involving semi-structured in-depth interviews with patients hospitalized in a palliative care unit in Geneva, Switzerland. The data were analyzed using the interpretative phenomenological analysis method.

Results: 13 patients were included (average age of 70.3±4.2 years), mainly with advanced cancer. Eight had completed their AD. Barriers evoked by patients were related to (1) health professionals who not always seem comfortable during the discussion and the needs of patients to choose the timing and the health professional they want to discuss with, related to (2) patients who didn't want to think about the worst, or were worried to not be able to change their mind or on the contrary that their wishes were not respected, related to our (3) system as patients feel burden on the fact that information are collected several times in patient chart: advance care planning, AD, . . .

Conclusions: Barriers to advance care planning are still present even in a palliative care setting with a large experience and good health professional education in advance care planning. Innovative solutions must be found to continue to promote the autonomy of the patients.

FC 2.2 Updated EAPC Framework on Palliative Sedation: What's New?

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Background/aims: The European Association for Palliative Care (EAPC) acknowledges palliative sedation (PS) as an intervention for patients with life-limiting diseases experiencing refractory symptoms. The aim of this study is to revise the EAPC framework on PS (Cherny et al, 2009).

Methods: A 4-step Delphi consensus procedure among experts with different professional backgrounds (n=91, 39 ♀) from 28 countries was carried out (06/2019 – 09/2022) as part of the Horizon 2020 research project Palliative Sedation (funding no. 825700) supported by a literature search as well as input from other work packages. Quantitative and qualitative analysis were carried out using SPSS Statistics 27.0 and NVivo

R 1.61. The draft of the updated framework was submitted to the EAPC Board in 09/2022 for approval. Feedback is currently incorporated.

Results: The framework is now structured into 12 thematic sections and comprises 42 statements. As compared to the previous paper, it highlights that the principle of proportionality of sedation (duration and depth) according to the individual patient's situation should be taken into account and that the decision of PS and hydration are independent of each other. No specific period of remaining life expectancy has therefore been defined for indication. It stresses the importance of timely discussion of patient preferences and shared decision-making between patient and healthcare professionals. It also shows a shift towards a broader recognition of refractory existential distress as a possible indication, which led to the use of the broad term refractory suffering to include physical and psychological symptoms as well as existential distress.

Conclusions: This update provides evidence and consensus-based guidance to healthcare professionals involved in end-of-life care, medical associations, and health policy makers. It can be adapted in individual countries according to their specific legislation and culture to develop high quality local guidelines.

FC 2.3 Could Palliative Care Training Help Physicians Struggling with Personal Ethics When Deciding Whether to Maintain NIV at End-of-Life?

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Background/aims: Deciding to withdraw non-invasive ventilation (NIV) at end-of-life (EOL) in patients with chronic respiratory failure is a challenge. Recommendations advise not maintaining artificial therapies that could prolong life during palliative sedation (PS) at EOL.

Aims: This survey was to assess palliative care physicians' and pulmonologists' opinion on withdrawing or maintaining NIV in patients with chronic respiratory failure during PS and, in the case of NIV not being withdrawn, the reasons behind this action.

Methods: From April to May 2019, we performed a prospective survey among pulmonologists (n = 1545) and palliative care physicians (n = 631) with multiple logistic regression to determine the prevalence of opinion in favour of maintaining NIV and identify the factors associated with this choice.

Results: A total of 457 participants were enrolled comprising 202 pulmonologists and 255 palliative care physicians. Around 20% of pulmonologists and palliative care physicians declared an opinion in favour of maintaining NIV during PS at EOL. An opinion in favour of maintaining NIV was found in 88 (19.3 95%CI [15.7; 23.2]) physicians comprising 57 (28.2%) pulmonologists and 31 (12.2%) palliative care physicians (p < 0.001). The main factors associated with an opinion in favour of maintaining NIV were: a) spending time looking for advanced directives (AD) in the patient's file (odds ratio (OR): 6.54, 95%CI [2.00; 21.32], p = 0.002) and; b) personal ethics of physicians (OR: 17.97, 95%CI [9.52; 33.89], p < 0.001). When a decision was made in favour of withdrawing NIV, the factor associated with this choice was previous palliative care training. [(OR: 0.31, 95%CI [0.16; 0.60], p < 0.001). The main reasons in favour of maintaining NIV were emotional comfort for close relatives, reducing discomfort of dyspnea and anticipation of suffocation.

Conclusions: Palliative care training can stimulate reflection and help foster a change of opinion about practices.

FC 2.5 Everyday Ethical Challenges in Specialist Palliative Care Practice in Uganda: A Semi-structured Interview Study

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Background/aims: Background: Ethical challenges (ECs) arise daily in the delivery of specialist palliative care, but there is limited evidence regarding the range and nature of ECs, with no evidence from Africa. Understanding these ECs is crucial to inform education and training, and adequately support staff.

Aim: To explore and map the ethical challenges experienced by specialist palliative care practitioners (SPCPs) in clinical practice in Uganda.

Methods: Semi-structured interview study conducted with a purposive sample of SPCPs of any professional background practicing across multiple sites in Uganda.

Results: 36 interviews were conducted (17 nurses, 8 physicians, 5 clinical officers, 6 social workers) across at 7 sites. 25 different EC areas were identified and grouped into across four main thematic areas: inside the consultation (communication, best interest, autonomy and decision making, goals of care); bedside deliberations (challenging stigma, confidentiality, genetics); engaging institutions (policy and guidelines, prioritising institutional resources, working with colleagues); and navigating society (legal issues and human rights, fairness and justice, spirituality and care). The four main themes were impacted by four cross-cutting themes: gender, resources, working with families, and traditional health beliefs. Challenges were described in a highly contextual manner, rather than via ethical principles.

Conclusions: This study demonstrates the huge breadth of ethical challenges faced by SPCPs in their day-to-day practice, broader than current curricula. Secondly, the highly contextual way in which these challenges were discussed has implications for design and delivery of training materials that support SPCPs in daily practice. The institutional challenges are relevant to service leaders looking to support staff and design services, and societal level challenges provide possible targets for advocacy activity.

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FC 2.6 Attitudes of Patients with Advanced Chronic Illnesses towards Palliative Extubation in a Country where Palliative Extubation Is Illegal - Is it Time for a Policy Change?

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Background/aims: Palliative extubation (PE) is the cessation of futile mechanical ventilation in patients with a terminal illness. Although PE is an acceptable procedure in many countries, in several countries it is still illegal. Indefinite continuation of ventilation can create physical and emotional burden to patients and families, and increased cost to the healthcare system. Very few studies have evaluated the attitudes of patients with advanced illnesses towards PE.

Methods: We conducted a prospective questionnaire-based study enrolling consecutive patients with advanced chronic illnesses admitted to an internal medicine ward in a large tertiary hospital between October 2021-October 2022. Currently we are continuing to enroll patients. Patients did not require mechanical ventilation at the time of questionnaire filling.

Results: A total of 59 (42% Female, 71±11.0 years) out of 120 patients were included in this interim analysis. 23 patients had advanced malignancy, 14 patients had advanced heart failure with a NYHA of 3-4, 11 patients had Gold Class D COPD, 9 patients had ESRD, 1 patient had decompensated Cirrhosis and 1 patient had a previous CVA with significant disability. 85% of patients supported the concept of PE and thought

it should be made legal. Main reasons for supporting PE were to avoid pain and suffering (88%) and to prevent unnecessary emotional and financial burden from their loved ones (30%). Most patients thought that the decision to perform PE should be taken by the patient's physician and family (66%). Religious observance ($p=0.03$), but not the type of chronic illness, was associated with opposition to PE.

Conclusions: Most patients with advanced chronic illnesses admitted to an internal medicine ward in a country where PE is illegal support the concept of PE and support its legalization. Further study and a reassessment of the practice of continuing indefinite ventilation should be done.

FC 3 - H Communication, Care Discussions and Shared Decision Making

FC 3.1 'If Ma Became Ill, What Would She Want? Never Crossed my Mind' a Constructivist Grounded Theory to Promote Culturally Negotiated End of Life Conversations in African & Caribbean Heritage Families

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Background/aims: Adult children often play a key role as end-of-life decision makers for their parents. Family conversations about end-of-life preferences are rare in families of Black and minority ethnic heritage. Little is known about what people from African and Caribbean heritage feel about having end-of-life care planning conversations within the family.

Aim: To develop a substantive theory about the perspectives of adult children and their elders around end of life planning conversations in families of African and Caribbean heritage.

Methods: Using a constructivist grounded theory approach, data was collected via online and face to face focus groups. Adults of African and Caribbean heritage were purposively and theoretically sampled if they identified as being ≥ 60 or having a family elder ≥ 60 of the same heritage living in the UK. Analysis was conducted using initially line by line, focused and theoretical coding using a constant comparison approach, focusing both on content and interaction

Results: 21 people (f=19, m=2, adult children = 17, older people = 4) participated in 5 focus groups. A substantive grounded theory was developed comprising five themes; (a) We are planners of funerals but not of care; b) Talking about cancer and dying is taboo in our culture- Cultural traditions cross oceans; c) I am a London girl, things are different in Ghana- living and dying between cultures and traditions; d) There is culture, gender and personality – intersectional influences on negotiating family decision making; e) I talk with mum because her mum needs care now -Watching the death of another prompts conversations.

Conclusions: Conversations with adult children may be key to initiating family conversations around end of life. Exploring this constructed theory could help health care professionals to partner better with communities, patients and families to promote, initiate and navigate patient and family conversations to reach better culturally negotiated approaches to planning care at the end of life.

FC 3.2 "I Even Felt Relieved" – A Randomized Controlled Trial Investigating an Online Intervention to Increase End-of-Life Communication

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Background/aims: Despite many advantages, end-of-life (EOL) conversations with loved ones are often avoided in the general population. One reason can be negative expectations regarding these conversations.

Therefore, we developed a short online intervention challenging common negative expectations in this field. The aim of this study was to investigate its effect in healthy adults.

Methods: 272 participants (18 to 77 years) were randomized to three different video conditions (CG 1: Expert lecture not addressing EOL topics, CG 2: Persons reporting different attitudes towards EOL conversations, IG: Persons reporting positive outcomes of EOL conversations). Primary outcome was negative expectations, secondary outcomes readiness for EOL conversations and communication apprehension about death. After the interventions, all participants were invited to have an EOL conversation with a loved one in the following eight weeks. Data were collected before (T0) and after the interventions (T1) as well as eight weeks later (T2). Data was analyzed using hierarchical linear models.

Results: Between T0 and T1, the IG reported significantly more changes towards positive expectations than CG 1 ($b = 0.15, t = 2.08, p = .020$) and CG 2 ($b = 0.21, t = 2.94, p = .002$). The IG also reported more changes in readiness than CG 1 ($b = -0.16, t = -2.56, p = .006$). Across conditions, negative expectations decreased significantly more in participants having had a conversation between T1 and T2 ($b = 0.35, t = 3.54, p < .001$). This group also showed a higher increase in general readiness for EOL communication ($b = -0.13, t = -2.15, p = .016$).

Conclusions: In the short term and as a first step, online interventions can be useful to reduce negative expectations and increase readiness for EOL communication. In the longer term, having a live conversation with a loved one seems to be most effective in challenging negative expectations and improving readiness for further conversations.

The study was funded by the German Research Foundation (DFG).

FC 3.3 Goals of Care Discussions among Patients with Life-limiting Diseases and COVID 19 - A Prospective Cohort Study from the COVID-19 Palliative Care Registry

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Background/aims: COVID 19 pandemic has exposed the need for more frequent goals of care discussions (GOCd) in patients with life-limiting diseases. This study aims to clarify if these patients actually have GOCd more frequently when diagnosed with COVID 19 and to understand whether this frequency varies among cancer and non-cancer patients or in patients with poorer outcomes.

Methods: The national COVID-19 Palliative Registry collected data on patients with life-limiting illnesses and COVID-19 from September 2020 to December 2021 in various settings of care across Canada. Chi-square tests compared the practice of GOCd prior and after diagnosis of COVID 19 infection and between patients with cancer and non-cancer primary diseases. Multivariable analysis was used to explore factors associated with lower rates of discussions.

Results: The mean age among 1041 patients was 83 years, 55% were female, 64.5% were treated as outpatients and 30.6% died. 176 (16.9%) patients had diagnosis of cancer as primary disease or comorbidity. 49.5% patients had GOCd before and 54.3% after the diagnosis of COVID 19 ($p<0.001$). Patients with cancer had access to GOCd prior to COVID-19 more frequently than non-cancer patients in general (OR 6.21, $p<0.001$). Although, there was no significant difference between these two groups regarding first GOC conversations triggered by COVID 19 diagnosis (CI 0.53-3.71). Those who died had a lower frequency of GOCd (OR 0.57, CI 0.42-0.78, $p<0.001$), markedly among non-cancer patients (OR 0.55, CI 0.34-0.87, $p 0.001$).

Conclusions: Approximately half of the patients with life-limiting disease and COVID-19 have a GOCd conversation with the majority of the GOCd occurring prior to COVID-19 diagnoses and with an increase of less than 5% after infection had been confirmed. GOCd were more frequent in patients with cancer, but not necessarily in those that experienced poorer outcomes or died. Continued efforts are needed to increase GOCd and exploration of end-of-life preferences, especially in those without cancer.

FC 3.4 Insights into the Exploration and Monitoring of the Personal Values, Wishes and Needs of Patients with Advanced Cancer by Hospital Professionals: A Generic Qualitative Study

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Background/aims: Exploring and monitoring the patients' personal values, wishes, and needs (VWN) by professionals is essential to guide appropriate palliative care.

Aim: To gain insight into communication concerning the exploration and monitoring of VWN of patients with advanced cancer by hospital professionals

Methods: A generic qualitative study was conducted from February 2022 to July 2022. Oncology nurses, nurse practitioners, residents and medical specialists providing care to adult patients with advanced cancer were recruited at an outpatient clinic in a Dutch academic hospital. Data-collection: in-depth semi-structured interviews using a topic list and participatory observations using an observation framework. The surprise question was used to identify patients with advanced cancer for observations. Data were analyzed using thematic analysis.

Results: Eleven professionals (aged 33-64, female N=8) participated. Seven interviews and 13 observations were conducted. How professionals explored and monitored the patients' VWN emerged from experienced based beliefs originating from the professionals' personal values and work experiences. These were influenced by the local collaboration. Three experienced based beliefs were identified: 1) providing safety, 2) supporting decision making and 3) alignment about care and treatment. The exploration and monitoring of VWN was strongly dependent on the individual professional involved. Active attunement to ensure care and treatment fit the patients' VWN was limited observed.

Conclusions: Although all professionals considered the exploration and monitoring of the patients' VWN to be important, a systematic approach in discussing these topics seemed lacking which may impair the continuity of appropriate care. This study emphasizes the need for the development of a structured approach to explore and monitor the VWN of patients with advanced cancer receiving outpatient care to improve appropriate palliative care.

FC 3.5 A Geriatrician Shared-care Model Improves Outcomes for Older Neurosurgical Inpatients with Life-limiting Diagnoses

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Background/aims: Our hospital provides a quaternary neurosurgery service for one Australian state. Over a third of neurosurgical inpatients are aged 65 years or older, most with life-limiting conditions such as brain cancer or intracranial haemorrhage in the setting of frailty. They are at higher risk of hospital-acquired complications such as delirium and require complex decision-making regarding goals of care (GOC) and discharge planning. International evidence supports benefits for older surgical inpatients of Comprehensive Geriatric Assessment, a geriatrician-led, multidisciplinary intervention.

Methods: From February to September 2021, the Departments of Geriatric Medicine and Neurosurgery piloted a shared care service. Outcomes (eg hospital length of stay [LOS], goals of care discussion) for older neurosurgical patients during this period were compared to a retrospective cohort of older neurosurgical patients during the same months of 2019. Anonymous surveys of medical, nursing and allied health staff were performed before and after introduction of the service.

Results: Compared to 2019, the Neurosurgery-Geriatrics service reduced LOS by 2.6 days in neurosurgical wards (15.3 days in 2019, 12.7 in 2021) and by 1.7 days in rehabilitation wards (from 13.4 to 11.7 days). GOC documentation improved from 2.7% in 2019 to 56.5% in 2021. The shared care service was well received by staff on Neurosurgical wards, with respondents agreeing there was improved management of frail older patients; improved understanding of patient goals of care; streamlining the process for rehabilitation and palliative care referrals; and improved junior doctor confidence and safety in managing older patients on the ward.

Conclusions: Shared care of older neurosurgical patients by geriatricians improves outcomes for frail older patients with life limiting diagnoses, including improved communication and documentation about goals of patient care. Further analysis of the service will include patient and family reported outcomes.

FC 3.6 How Do Renal Clinicians Present Treatment Options to Older Patients with Advanced Kidney Disease? A Conversation Analytic Study

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Background/aims: For older people with kidney failure, especially those with comorbidities or poor performance status, the survival benefits of dialysis are uncertain and its quality of life impact greatest. There is significant variation in the uptake of the alternative treatment option - conservative (non-dialytic) care (CC). How clinicians communicate about treatment options strongly influences patients' decision-making, but this has been under-researched.

Aim: To identify and describe how treatment options are discussed in talk between older people (age 65+) with advanced chronic kidney disease (eGFR <20) and renal clinicians.

Methods: Outpatient consultations between kidney doctors/education nurses and eligible patients were video-recorded at 4 UK renal units, transcribed and subject to conversation analysis. 78 consultations have been recorded so far (target n=100); analysis of the complete dataset will be presented at the Congress.

Results: Preliminary analysis has focused on 24 consultations (involving 9 renal consultants and 2 specialist education nurses) in which decisions about future care in the event of renal failure were discussed. In 15/24

cases, CC was implicitly rather than explicitly referenced; in 3/24 the option of not having dialysis was not mentioned at all. Several interactional features conveying dialysis as normative and CC as less favourable were identified: sequential delay (CC presented last); differing ways of presenting dialysis and CC, e.g. framing of CC as minimal or negative; clinician resistance to non-dialysis as a future course of action.

Conclusions: Despite evidence that dialysis does not reliably extend older patients' lives at acceptable costs to their quality of life, clinicians' conversations with patients about treatment options often push towards dialysis, with patients having to work hard within consultations to promote their preference for CC. Findings will form the basis of a new communication training intervention for clinicians.

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FC 4 - F Health Services Organisation

FC 4.1 How Effective Is Specialist Palliative Care? A Meta-analysis with Meta-regression to Identify Active Ingredients of Service Composition, Service Structure and Delivery Model

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Background/aims: Specialist palliative care (SPC) addresses holistic needs in life-limiting disease. Service delivery models are diverse but the optimum configuration is unknown. Aim: To systematically review evidence regarding models of specialist palliative care and assess which intervention components are most effective.

Methods: Systematic review of pre-print and peer-reviewed randomised controlled trials (RCTs) on MEDLINE, CINAHL, and the Cochrane library (1st Jan 2000 to 1st Oct 2022). RCTs with a sample size calculation testing SPC intervention versus usual care in adults with life-limiting disease and including patient or proxy-reported outcomes as primary or secondary endpoints were included. We used random-effects meta-analysis and meta-regression after converting all outcomes into minimally important difference (MID) units.

Results: 43,425 titles were screened; 39 RCTs were included (14 in non-cancer conditions, risk of bias: 6 low/19 some/14 high). Quality of life (QoL) improvement of 1 MID unit at 2 weeks to 3 months was found in at least 20% in the SPC group vs usual care (MID effect size 0.66, 95% CI: 0.35 to 0.98; RR 1.20). The number needed to treat (NNT) to achieve a benefit of at least 1 MID change through SPC was 18. QoL was also significantly improved at 3 to 6 months follow-up. Emotional outcomes showed a statistically significant improvement of at least 1 MID in 22% of SPC patients. The NNT was 14. Attrition rates, risk of bias, and service composition explained differences in RCT effect sizes. Best MID effect sizes were achieved with teams including more professions than doctors/nurses, providing more services than symptom assessment or advance care planning, and more flexible availability.

Conclusions: Small to moderate benefits for QoL and emotional outcomes are seen, with larger effect sizes achieved with broader multidisciplinary teams and models with a greater range of services and availability.

FC 4.2 Specialist Palliative Care in Germany: Comparing Patient Characteristics and Symptom Burden

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Background/aims: In Germany, specialist palliative care (SPC) is provided by palliative care units (PCU), palliative care advisory teams in

hospitals and specialist palliative home care (SPHC) teams. Palliative care needs are considered a major factor in determining in which SPC setting patients are treated. Systematic comparisons are lacking, so we aimed to comparatively describe patient characteristics and PC needs in SPC on admission.

Methods: Cross-sectional study of patient episodes in SPC services in Germany, data collection from 04/2021 to 09/2022. Descriptive and comparative statistics on patient demographics and symptom burden measured by the Integrated Palliative Outcome Scale.

Results: 3115 care episodes (PCU: 753, advisory teams: 1568, SPHC: 794) from 28 teams. Average age between 71 (advisory teams) and 75 years (SPHC) with an oncological diagnosis in 1115/1559 (71%) of advisory team, 566/785 (71%) of SPHC, and 595/753 (79%) of PCU episodes. Overall symptom burden with at least one severely or overwhelming symptom varied from 1383/1568 (88%) in advisory teams to 683/753 (91%) on PCU and 719/794 (91%) in SPHC. Of these, patients were suffering from ≥ 5 severely or overwhelming symptoms in 288/794 (36%) SPHC, 585/1568 (37%) advisory team, and 285/753 (38%) PCU episodes. In SPHC, no burden due to pain was reported in 116/794 (15%) episodes, compared to 203/753 (27%) PCU and 481/1566 (31%) advisory team episodes. High psychosocial needs and practical matters (≥ 1 severely or all the time) were reported most frequently on PCU with 535/753 (71%), followed by 1095/1568 (70%) in advisory teams and 490/794 (62%) SPHC episodes.

Conclusions: The frequently perceived divergences within SPC have not been reflected by the data: Overall symptom burden was similar across settings. Little difference was seen regarding symptom burden of pain with slightly higher values in SPHC. Psychosocial needs were relevant in all SPC settings, with highest values in inpatient settings. Funding: G-BA Innovation Fund, no. 01VSF18018.

FC 4.3 Implementation of Integrated Palliative Care into Cancer Services - A Systematic Review

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Background/aims: Despite evidence documenting the benefits of early integration of palliative care (PC) in cancer care, there is less clarity around the effective approaches to PC in cancer care services.

Aims: This systematic review identifies the approach to the implementation of integrated PC services, focusing on formal reporting according to implementation frameworks. Enablers and barriers are discussed for the implementation of hospital-based PC programs in high-income countries for people with advanced cancer.

Methods: A systematic review, Prospero* registered, including mixed-methods studies was conducted in 2021 and reported as per PRISMA statement. The databases searched included Ovid MEDLINE, EMBASE, EMCARE, PsycINFO, CINAHL (EBSCO), Cochrane Library, Informit Health and Clinicaltrials.gov. We used the Critical Appraisal Skills Program and the Mixed Method Assessment Tool to assess quality, rigor and risk of bias. A narrative approach was used for data synthesis.

Results: 41 full-text articles were screened and 15 were included. In six studies the PC implementation explicitly cited the use of frameworks including those based on RE-AIM (Reach, Effectiveness, Adoption,

Implementation, Maintenance), Medical Research Council evaluation of complex interventions, and World Health Organisation constructs of health service evaluation. Enablers to implementation included an existing supportive culture, adequate funding, and human resources, embedding the program into existing workflows and electronic database systems. Meanwhile, challenges included inadequate communication with patients and health professionals and administrative barriers.

Conclusions: The use of rigorous implementation science to underpin the development of PC services is currently limited. This appears to represent the next step required to take the field forward and achieve appropriate translation of evidence around the integration of early palliative care into practice.

FC 4.4 Everybody Needs a Buddy - Developing an Additional Support System for the Last Year of Life. Qualitative Insights from Triangulated Interviews and Focus Groups Discussions

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Background/aims: Unmet needs are prevalent for those wishing to be cared for and die at home and their relatives. Although structures and services exist to support patients and their families, these offer do not reach those affected in real time resp. at the time where they are needed the most. We aim to define elements of an additional support system necessary for patients in their last year of life and their families to enable dying at home.

Methods: This work reports data from a larger mixed-methods study ("Dying at home – what support do families need?"), which was conducted to explore support needs for patients who wish to die at home, their caregivers (interviews) and health and social care professionals (HSCP, focus groups). Interviews were transcribed verbatim and analyzed thematically (content analysis), and triangulated by applying the theory of social support.

Results: Individual interviews were conducted with bereaved family caregivers ($n=30$), patients and caregivers ($n=15$) and four focus group discussions with HSCP ($n=22$) in Germany (total $n = 67$). Our results show the broad range of elements to address unmet emotional, informational, appraisal and instrumental needs in end-of-life home care for those dying, their families, and HSCP. Informants stated a contact person providing real-time information on professional support services and support the initiation of adequate end-of-life-home care was lacking, a so-called 'buddy'. Differences between groups in support needs were found (e.g. cancer/non-cancer patients).

Conclusions: Additional support is required to consolidate the existing health and social care structures when they fall short of directing care in accordance with the needs of patients and families. To meet their needs, proactive support is relevant. One approach to support and guide patients and their families and enabling home death could be the concept of a 'buddy' for the last year of life who acts as a low-threshold volunteering contact person with a real-time knowledge.

FC 4.5 Towards a Model of Person-centred Care for People Living with Cancer, Heart Failure and Chronic Obstructive Pulmonary Disease in Uganda

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Background/aims: WHO recommends person-centred care in palliative care, but this has not been defined in most African health systems. We aimed to develop a patient/family and health worker driven model of person-centred care for people living with cancer, heart failure and Chronic Obstructive Pulmonary Disease.

Methods: We conducted qualitative interviews with patients, informal caregivers, and health professionals from three tertiary care institutions in Uganda. Adult patients and their caregivers were purposively recruited from both outpatient and inpatient settings. Data were analysed using inductive thematic analysis and the themes were mapped onto the Santana and Donabedian frameworks for health services quality improvement i.e., structure, process, and outcomes.

Results: We recruited 25 patients (15 female, 10 male), (11 heart failure, 10 cancer) with median age of 48 years (range 22- 67 years) from outpatient ($n=9$) and patient ($n=16$) settings; 15 caregivers (9 female, 6 male) and 15 health professionals (8 female, 7 male). We present themes by domain of quality improvement. i) structure- promote-palliative care values at organisational level, integration of palliative care into medical and nursing curriculums, support for the health workforce, care facilities should prioritise patient /caregiver friendly infrastructures. ii) Process - two-way communication between patients/families and health professionals, information sharing, compassionate care, communication, shared decision making, integrated care, and access to care. iii) Outcome -patient reported outcomes (e.g. physical symptoms, spiritual distress, disability, and rehabilitation) and patient reported experiences of care.

Conclusions: A model of person-centred care for patients living with cancer, heart failure, and chronic respiratory diseases can be improved by pulling moveable levers such as training of the health workforce, better communication and information sharing, compassionate care, and prioritising patient reported outcomes and experiences.

FC 4.6 Management of Out-of-Hours Crises, Medicines and Care in the Last Days of Life for Adults Living at Home with Palliative and End-of-Life Care Needs

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Background/aims: Palliative and end-of-life care needs to be accessible at home at all hours to all who need it. The availability of out-of-hours care is unclear.

Aim: To understand what UK palliative and end-of-life services are available out-of-hours for adults living at home.

Methods: Structured interviews with UK professionals with commissioning/leadership responsibilities or knowledge of palliative care provision, purposively sampled by geographical area. The topic guide was informed by stakeholder priorities, including crisis management, palliative medicines access, and care at the end-of-life. Descriptive statistics for closed questions and thematic analysis for open discussion were undertaken.

Results: 71 interviews across 60 UK areas were conducted. Most areas provided out-of-hours nursing services to address practical problems

(e.g. catheter) but were often overstretched. Prescription/administration of palliative medicines was theoretically possible in all areas but was limited by workforce capacity, rurality, and models of care. In 40 (67%) areas, pharmacies were available on weekends, while in 20 (33%) areas there were limitations, including less availability overnight or for home delivery. Anticipatory prescribing was seen as essential. 54 (90%) areas had a service that could support personal and complex care needs in the last days of life. Diverse models mostly reported general practitioners and community nursing teams as the first port of call. Access to specialist palliative care was available by phone/video call in >80% (n=50) of areas, constrained by early recognition/referral. Home visits from specialist palliative care teams were rarely available overnight, though more were available at weekends.

Conclusions: Challenges out-of-hours are present across all aspects of accessing medicines, managing crises, and providing end-of-life care at home. Care may be available in theory but is limited in practice by workforce capacity, time constraints, and geography.

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FC 5 - E Education and Advocacy

FC 5.2 Towards Consensus on Specialist Expertise in Palliative Care in the Netherlands

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Background/aims: In the Netherlands, palliative care is provided by generalist care professionals if possible, and provided by palliative care specialists if necessary. However, it is not yet clear or agreed upon what specialist expertise entails, how it relates to generalist care, and which educational requirements need to be met for a professional to call themselves a 'specialist'. Furthermore, it remains to be determined whether, in addition to generalists and specialists, 'experts' in palliative care should be recognized, and on which grounds.

Methods/Aims: To reach national consensus on what is understood by the generalist-specialist-expert distinction in palliative care in The Netherlands, and which education or training this requires.

Methods: This three-year study includes a survey among care providers and a scoping review in order to prepare a modified Delphi study to establish consensus on specialist expertise in palliative care.

Results: We focus on presenting our findings from the survey (N=861). Results show major differences in how professionals describe themselves based on continuing education. Out of 226 nurses who received a post-graduate palliative care course, 9 call themselves generalist, 78 specialist and 137 expert. Out of 120 physicians who have received palliative care executive training, 8 call themselves generalist, 50 specialist, and 62 expert. Furthermore, it is found that most professionals value more clarity and agreement with regard to the distinction generalist-specialist-expert. We also present how other countries organized this distinction based on the results of the scoping review.

Conclusions: We discuss what may explain the diverging ways in which professionals self-identify based on continuing education in palliative care, and which steps to be taken in order to establish broad consensus and clarity on the generalist-specialist-expert distinction. Establishing an educational framework on specialized palliative care on different professional levels is part of this.

FC 5.3 Palliative Care Goes to School – An Innovative Project for Upper School Classes in Vorarlberg

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Background/aims: What do young people know about Palliative Care? How do they deal with bereavement, illness and end of life issues? The legalization of assisted suicide in Austria brought up the idea, to inform pupils about the practical work of a Palliative Care Unit

Pupils should know about the possibilities of palliative care support and symptom control as an alternative to assisted suicide. Another aspect is, to display the diversity of medical and nursing profession.

Methods: A model for the 2 hours school visits with a well defined structure, combining different teaching methods, was implemented: interactive introduction, a short input about Palliative Care, presentation of nursing interventions, discussion of a patient's history, a question round (including the topic assisted suicide), design of a mourning poster and a final quiz game.

The project was founded by the Association for Supporting Palliative Care in Vorarlberg.

The attitude of pupils towards Palliative Care and assisted suicide was evaluated through a questionnaire, which the children had to complete a week before (T0) and a week after (T1) school visit.

Results: From 01.03. – 30.05.2022 a multiprofessional team (5 nurses, 3 physicians) visited 26 upper class schools in Vorarlberg. A total number of 550 teenagers between 15 and 19 years could be informed by this pilot project. The number of pupils on site varied from 12 (single class) up to 84 (several classes from one year). Even with the „big groups“ an interactive exchange was possible (f.e. creation of a mourning poster, Kahoot Quiz).

Conclusions: The teachers and the pupils highly welcomed the possibility of getting an insight into practical palliative care work. The multiprofessional team was impressed by the interest most of the children showed for palliative topics. In arrangement with the Education Directorate the project should be expanded for all upper class schools in Vorarlberg.

FC 5.4 Teaching Skills in Multiprofessional and -disciplinary Collaboration in Medical Curricula Might Facilitate Detecting Patients Benefiting from Palliative Care – Presentation of a New Elective

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Background/aims: Learning about the importance of multiprofessional and -disciplinary cooperation is crucial in modern medicine when aiming adequate and personalized treatment to patients. However, developing required collaborative skills is often underrepresented in medical curricula. In implementing a new elective titled “The multimodal treatment of oncological patients” designed for a small group of undergraduate medical students, we aim to fill this gap by following the path of a prostate cancer patient's disease from curative to best supportive care intended treatment.

Methods: The elective was conducted multiprofessionally and -disciplinary in repeated joint meetings. Involved disciplines are urology, radiotherapy, psycho-oncology, and palliative care. We conducted seminars, e-learning sessions and communicative training sessions involving simulation patients, featuring the same actors throughout the course in order to build a consistent doctor-patient relationship. After completion of the elective, each participating student is supposed to take part in an online

evaluation. The outcome is calculated using the Comparative Self-Assessment (CSA) Gain.

Results: Best practice videos shown in both seminars and e-learning, including breaking bad news, informed consent, first contact to palliative care, and family discussion were developed. The focus lies on interdisciplinary collaboration, e.g. in simulated tumor boards, family discussion and early referral to palliative medicine through primary physicians.

Conclusions: Delivering the importance of multiprofessional and -disciplinary collaboration is crucial and underrepresented in medical curricula. Using prostate cancer as an example disease, we can integrate multiple disciplines into the disease treatment and teach students about the benefit of such cooperation. Early integration of palliative care is often missed. We hope to raise awareness to this delicate topic in medical training in order to achieve a more open interaction.

FC 5.5 “What Does the Public Know about Palliative Care?”: A Population-based Survey in Two Urban and Two Semi-urban Cities

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Background/aims: The need for public education on palliative care (PC) has been widely argued for. Assessing the public knowledge of PC in the local context being targeted, is an essential part of developing effective educational interventions. The aim of this study is to examine the knowledge of PC among citizens in Flanders, Belgium.

Methods: Cross-sectional population-based survey among a random sample of 4400 citizens in two urban and two semi-urban Flemish cities. Knowledge of PC was measured using the Palliative Care Knowledge Scale (PaCKS) and a Hurdle model was applied to test associations with sociodemographics, personal experience with PC, informal caregiving and professional experience in health care. An assessment was also made of the congruence between self-estimated and actual knowledge and the information sources through which knowledge on PC was obtained.

Results: Response was obtained for 2008 (45,6%) citizens. The mean PaCKS score was 7,87 (SD 3,41; range 0-13) and gaps in knowledge as well as well-known facts were identified. For instance: 82% of the respondents answered correctly that PC is not specifically for people with cancer, only 32,2% knew that improving the ability to participate in daily life is a goal of PC and more than half of the respondents did not know that PC is not exclusively for people who are in the last six months of life. Further, 52.4% of respondents underestimated their knowledge on PC. Older age, non-religious beliefs, higher educational levels, having professional experience in health care and knowing PC through personal experience were significantly associated with higher knowledge scores while gender and informal caregiving experience were not.

Conclusions: Our findings suggest that misconceptions and knowledge gaps exist in the general public. Effective strategies to improve the public knowledge of PC are warranted and should be developed with sociodemographic characteristics and exposure to PC kept in mind.

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FC 5.6 How Much Does the United Kingdom Public Know about Dementia and the Role of Palliative and End-of-Life Care? A Representative Public Opinion Poll

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Background/aims: The number of people dying with dementia is increasing. Although dementia is the leading cause of death in the United Kingdom (UK), public knowledge and perceptions around dementia, including care towards the end of life, are unknown. Our aim was to gain an insight into public knowledge and perceptions around dementia, and the role of palliative and end-of-life care.

Methods: An online public opinion poll, sampling UK adults aged 18+, was conducted in collaboration with “YouGov” in April 2022. The poll included 11 sociodemographic (e.g., age, gender, region) questions and 11 questions about current and future levels of need, research and care funding, charity awareness, palliative care for dementia, and priorities for dementia care. Questions were developed with input from an opinion poll expert and informed by previous polls. Results were weighted to be representative of all UK adults.

Results: 2133 adults received and completed the opinion poll. Only 6% of the public correctly identified dementia as the leading cause of death (38% heart disease), and only 7% correctly identified that dementia deaths will more than double by 2040. Fewer than half (42%) were aware that dementia is a terminal illness and 51% believed that people with dementia can benefit from palliative care. 17% of the public were aware that most dementia care in the UK is paid for by people with dementia and their families. The top two public priorities for dementia care were ‘involving the person with dementia and their families in care and treatment decisions’, and ‘good management and treatment of symptoms and providing comfort’.

Conclusions: We identified major gaps in public knowledge and understanding of dementia, and the role of palliative and end-of-life care. There is an urgent need to educate the public about dementia, demystify the care experience, equip audiences with knowledge of services that could support them, and create advocates demanding high quality care.

FC 6 - H Grief and Bereavement

FC 6.1 LGBT+ Partner Bereavement: An in Depth Qualitative Interview Study and Appraisal of the Acceptance-disclosure Model of LGBT+ Bereavement

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Background/aims: Support from social networks is vital after the death of a partner. Lesbian, gay, bisexual and/or transgender (LGBT+) people can face disenfranchisement and isolation in bereavement. The Acceptance-Disclosure Model (of LGBT+ bereavement) posits that LGBT+ bereavement experiences are shaped by whether they feel able to disclose their bereavement to others, and how that disclosure is responded to. This study aimed to explore LGBT+ specific experiences of partner bereavement and decision making processes regarding disclosure of relationships/identities; and appraise the Acceptance-Disclosure Model using primary qualitative data.

Methods: In-depth qualitative interview study positioned within a social constructivist paradigm. Data were analysed using reflexive thematic analysis.

Results: 21 LGBT+ bereaved partners from across England were interviewed. Participants described LGBT+ specific stressors in bereavement: lack of recognition of their loss; inappropriate questioning; unwanted disclosure of LGBT+ identities; and fears of discrimination when accessing support. Direct questions about LGBT+ identities can feel confrontational due to the legacy of discrimination. LGBT+ people show agency in their disclosure of identities, which varies across social networks. Challenging intersections between LGBT+ identities and other aspects of culture or self were described, with some choosing to hide their LGBT+ identities to retain relationships and avoid disenfranchisement. These findings provide evidence to support the Acceptance-Disclosure Model.

Conclusions: Not all LGBT+ people want to talk directly about their identities. Sensitive communication is needed to build trust, and explore support needs, in line with preferences around disclosure of identities. Five recommendations for inclusive practice are presented. The Acceptance-Disclosure Model may have utility to explore bereavement for other disenfranchised groups. This study was supported by the Marie Curie Research Grants Scheme: HR-17/18-5668.

FC 6.3 Is Pre-bereavement Collaboration between Family Caregivers and Healthcare Professionals Associated with Post-bereavement Emotional Wellbeing? A Population-based Survey

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Background/aims: Family carers are considered to be an essential part of the healthcare team in the care for people with a serious illness. Consequently, it is crucial that family carers and healthcare professionals collaborate efficiently. In this study, we aim to investigate emotional wellbeing of family carers of people with serious illness post-bereavement and its association with pre-bereavement collaboration with healthcare professionals.

Methods: Population-based cross-sectional survey of bereaved family carers of people with serious illness (N=3000) who died two to six months before the sample was drawn (November 2019), identified through three sickness funds in Belgium. The questionnaire consisted of both validated and self-developed items. Emotional wellbeing of family caregivers after bereavement, measured by the PANAS instrument, was our primary outcome. The exposure variable of interest was family caregivers' evaluation of the collaboration with healthcare professionals. Various socio-demographic and clinical characteristics were considered as possible confounders.

Results: Response rate was 55% (N=1,539). As measured by the PANAS, family caregivers scored lower on positive affect (PA) and higher on negative affect (NA) compared to a normative sample. Most family caregivers evaluated the pre-bereavement collaboration with healthcare professionals positively. Family caregivers' evaluation of collaboration with healthcare professionals pre-bereavement was positively associated with PA and negatively with NA, also when controlling for confounding effects of socio-demographic and clinical characteristics of the bereaved family carers and the deceased person.

Conclusions: There is a positive association between perceived quality of collaboration at the end of life between healthcare professionals and family caregivers and post-bereavement emotional wellbeing of family caregivers. Our findings suggest the pertinence of attention

from healthcare professionals to effective collaboration with family caregivers.

FC 6.4 Relatives' Grief at Three Moments after Death of a Loved One during COVID-19 Pandemic (the CO-LIVE Study)

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Background/aims: The COVID-19 crisis has had a devastating impact on people who have lost a loved one and has complicated their grieving experiences. Rich qualitative description of these experiences is lacking. The aim of this study was to get in-depth insight in the nature of bereavement of relatives who lost a loved one during the COVID-19 pandemic.

Methods: We followed 10 bereaved relatives (mainly daughters) and interviewed them 2-3 times after their relative died in the first wave of COVID-19 pandemic (shortly after death and after 12 and 18 months; 29 interviews in total). Analyses took place according to a phenomenological inspired approach.

Results: We found that losses were threefold, i.e.: the loss of the loved one; the loss of the (desired) way to say farewell and the loss of social support due to COVID-19 measures. We identified five forms of how grief processes of the several losses interacted and developed overtime: overshadowed grief, cumulative grief, triggered grief, derailed grief and conciliatory grief. For example: in overshadowed grief the mourning for the loss of the deceased loved one is overshadowed with pain about the circumstances in which this death took place and the latter remains in the foreground. Relatives still struggled with the lack of acceptable farewells, and this affects the emotional and existential pain of the loss. This prevents dealing with the new situation of picking up life again.

Conclusions: Grief after COVID-19 bereavement of a loved one appears to exist of multiple losses that manifest to different forms of complex grief experiences. These grief' experiences might ask specific attention of health care professionals exploring (online) possibilities to comfort the pain coming forth of these COVID-19 related losses.

FC 6.5 Should We Be Concerned about Those Who Abandon or Refuse Support in Grief? A Comparative Risk Analysis

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Background/aims: The rate of abandonment or refusal of support in grief is relatively high, but little is known about the risk associated with it. The present study intends to verify to what extent people who abandon or refuse follow-up are at risk in grief, compared to those who adhere to professional support.

Methods: An analysis of the risk in grief of family members in palliative care was performed, comparing the group of people who abandoned or refused support with those who accepted follow-up in grief. The risk assessment was previously performed using hetero-assessment instruments.

Results: The sample is composed of 169 subjects, mostly female (74.6%), spouses (42%) or children (37.9%), with a mean age of 57.37 (SD= 15.72). The rate of refusal or abandonment of the consultation was 25.4%. This group does not differ in terms of age and gender, however, spouses are more likely to abandon/refuse. Compared to people

who accepted follow-up, the group withdrew/refused support showed more manifestations of anger ($x^2=13.46$; $p=.019$), accusation and guilt ($x^2=22.85$; $p=.000$) and worse adaptation to grief ($x^2=37.14$; $p=.000$). In addition, this group has more psychiatric history ($x^2=6.37$; $p=.041$), more previous suicide attempts or suicidal ideation ($x^2=7.93$; $p=.019$) and more difficulty in assigning meaning to the loss ($x^2=16.00$; $p=.000$). **Conclusions:** Considering the high risk detected in this group, it is important to develop preventive measures against abandonment/refusal. Actively and early identification of these individuals, intervening directly in the process of suffering associated with loss, along with family intervention in the disease process, will enhance gains in adherence to the grieving process, which is desired with less suffering, more adjustment and less suffering indices during the bereavement period. Funding: none; No conflicts registered.

FC 6.6 The Need to Commemorate – A New Way of Having Funerals during COVID-19

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Background/aims: Funerals are an important part of the grieving process, facilitating support, comfort, and helping to process the reality of the death. In Australia during the COVID-19 pandemic, the capacity to hold funerals was limited and the implications for mental health and adjustment are unknown.

To examine the experience of restricted funerals for a death from any cause, during the COVID-19 pandemic.

Methods: In this national mixed-methods study, 2,200 bereaved Australians completed an online survey, and a subset participated in semi-structured interviews ($n=100$). Data were analysed using descriptive statistics and thematic analysis.

Results: Most participants experienced restrictions on funerals (67%), however 65% did attend the funeral in-person and 12% attended via video link. For some, no funeral was held (15%). Three themes emerged from the interviews: 1) A new way of having funerals; 2) Family togetherness unfulfilled due to disrupted rituals and; 3) Differing views to restricted funerals. Interviewees described COVID-19 funerals involving social distancing, streaming and careful planning with funeral directors and clergy to manage changing restrictions. Being unable to attend in-person and/or congregate left participants feeling 'empty' and without closure. Some felt proceedings were unsatisfactory and that the deceased had not been honoured properly, whereas others felt restrictions enabled funerals to be more intimate and concerns for being 'on-show' vanished. Participants described the inability to integrate the death(s) into their reality when attending online, particularly when overseas.

Conclusions: During COVID-19, bereaved people experienced a mixture of frustration, relief, and lack of reality in response to restricted funerals. The need for family togetherness was unanimous, yet unfulfilled for many. Strategies to facilitate family togetherness need to be prioritised in current and future pandemics.

Funding: Medical Research Future Fund (MRFF)

FC 7 - B Challenges in Symptom Management

FC 7.1 Comparative Study on the Effect of Aerobic Exercise and Tai Chi on Emotional Symptom Cluster for Patients with Late-stage Lung Cancer: A Three-arm Randomized Clinical Trial

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Background/aims: An emotional symptom cluster comprising sleep disturbance, depression, anxiety, and fatigue is prevalent in late-stage lung cancer patients, negatively affecting their quality of life. Yet, no effective treatment is available for this symptom cluster. This study aimed to investigate and compare the effects of aerobic exercise (AE) and tai chi (TC) on the emotional symptom cluster, and its individual symptoms in late-stage lung cancer patients.

Methods: This study was a three-arm randomized controlled trial. Participants were randomized into

- 1) AE group,
- 2) TC group, or
- 3) self-management control group.

For 16 weeks, the AE group received two 60-minute supervised exercise sessions and home-based exercises per month; TC group received 60-minute classes twice a week; whereas the control group received information on the physical activity guideline. Assessments were done at baseline, post-intervention (T1), and eight-month post-intervention (T2). A linear mixed-effects model was used to study the between-group differences in outcomes.

Results: A total of 226 patients with late-stage lung cancer were recruited and randomized into AE group ($n=75$), TC group ($n=76$), and self-management control group ($n=75$). The analysis indicated significant group x time interaction effects in AE and TC compared to control for the emotional symptom cluster at T1 (AE: $d, -1.347$, $P<0.001$; TC: $d, -1.803$, $P<0.001$) and T2 (AE: $d, -0.827$, $P=0.033$; TC: $d, -1.060$, $P=0.004$), as well as sleep disturbance, anxiety, and depression.

Conclusions: This is the first study examining the comparative effect of AE and TC on the emotional symptom cluster, and its individual symptoms in patients with late-stage lung cancer. The results indicated that AE and TC were superior to control for alleviating the emotional symptom cluster, with statistically significant results, while the effects of AE and TC were comparable.

FC 7.2 Determining Sedating Doses for Sedative Drugs – A Group Delphi Process

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Background/aims: Sedation in palliative care (PC) is a controversial topic. Empirical data indicate prevailing uncertainty when purpose of use of sedative drugs is "sedation".

Aim: The aim of this sub-project of the consortium project iSedPall was to determine cut-off values for dose intervals/doses, which are expected to result in a continuous effect/defined depth of sedation (RASS-PAL -1/-3), for sedative drugs.

Methods: Group Delphi Study with a prior online survey. Participants were nurses, pharmacists, and physicians with experience in PC. Based on a literature review, statements regarding cut-off values were developed for 11 potentially sedating drugs used in PC. Consensus was defined as > 75% agreement. Statements with lower agreement in the survey/Group Delphi rounds entered the next Group Delphi round. Between the Group Delphi rounds (5 small groups, 3 - 4 participants

each), the results of the preceding round were presented and discussed with the whole group and, if necessary, statements were adapted for the following round.

Results: 25/30 invited professionals participated in the online survey, 17 in the Group Delphi. 12 statements were consented in the survey. The initial Group Delphi questionnaire comprised 22 statements on 10 drugs. After 3 rounds, consensus was reached for all statements, determining cut-off doses/dose intervals for lorazepam, midazolam, diazepam, levomepromazine, haloperidol, melperon, pipamperone, propofol, dexmedetomidin, and trazodone.

Conclusions: The literature-based and expert-consented doses at which mild or deep sedation can be expected can inform dose recommendations for intentional sedation to relieve suffering. Equally important, they can serve as “red flags” to raise awareness when sedation has to be expected with drugs used in other indications, e.g. anxiety. The doses cannot replace an individual assessment but can support a more conscious use of sedatives in PC.

Funding: German Ministry for Education and Research

FC 7.3 Palliation of Dyspnea with Mouthpiece Ventilation in Patients with COPD Exacerbation – A Pilot Feasibility Study

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Background/aims: In patients with advanced chronic obstructive pulmonary disease (COPD) the response to conventional treatments of dyspnea is diminished at the time of acute exacerbation (AECOPD). Noninvasive ventilation (NIV) through mouthpiece (MPV) is known to relieve hypoventilation and gas exchange, but its efficacy in relieving dyspnea in non-hypercapnic exacerbation is unclear. The aim of the study was to assess the feasibility of MPV in relieving dyspnea among patients with non-hypercapnic AECOPD.

Methods: In this prospective single arm pilot study, the change in dyspnea by MPV was measured with numeric rating scale (NRS) (0-10). Overall benefit and adverse events of the intervention were assessed. Eighteen patients with advanced COPD and non-hypercapnic AECOPD and at least moderate dyspnea (NRS \geq 4) were treated with MPV in University Hospital. The patients used MPV for a minimum of 15 minutes.

Results: The median decrease in dyspnea was -1.5 (95 % confidence interval (CI) = 0.0 - 2.5, $p = 0.006$) on NRS after the treatment period lasting a median of 16.9 minutes. Of the patients, 61 % found MPV beneficial and almost half of the patients were willing to use MPV again. The most common adverse event was dry mouth, but no serious adverse events occurred. The use of MPV did not increase the sense of anxiety or pain.

Table 1. Proportion of patients agreeing completely or partly with statements concerning mouthpiece ventilation after the intervention period.

Statements on mouthpiece ventilation	n	%
Mouthpiece ventilation relieved my dyspnea	8	44.4
Mouthpiece ventilation was beneficial for me	11	61.1
I complied well with mouthpiece ventilation	14	77.8
Mouthpiece ventilation was unpleasant	6	33.3
I would like to use mouthpiece ventilation again for my dyspnea	8	44.4

Conclusions: Mouthpiece ventilation is feasible and may relieve dyspnea in patients with advanced COPD suffering from non-hypercapnic AECOPD. Further studies are needed to verify the effectiveness of MPV in relieving dyspnea.

FC 7.4 Morphine Gap in Cameroon: More Administrative Facilitation Required to Reduce Suffering

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Background/aims: Many patients in Low- and middle-income countries lack access to the opioid medicines that the World Health Organization designates as essential for pain control. Disparities in opioid consumption are partly related to policies affecting opioid access. Pain associated with cancer can significantly influence an individual's morbidity and quality of life. Therefore, Pain relief is fundamental to quality of life and palliative care.

AIM: To evaluate the availability of oral Morphine in relation to pain control need in Cameroon and national opioids regulation policies.

Methods: Analysis of opioid consumption data for Cameroon as published by the international narcotic control board (INCB), followed by a descriptive literature review of publicly available documents on pain control needs and opioid regulations for Cameroon using PubMed, Medline, Google Scholar, Google, Ministry of Public Health Website and National Institute of Statistics Cameroon.

Results: The annual consumption of morphine in Cameroon has steadily increased from 0.07 mg/capita in 1985 to 0.35 mg/capita (7.6 kg) in 2012. About 55.3 % of cancer and HIV related deaths are associated with moderate/severe pain. Almost all (98%) of patients dying of HIV or Cancer have untreated moderate /severe pain. An average annual import of 3.4kg of Morphine was recorded between 2001 and 2013, while a minimum of about 183Kg is required for HIV and cancer patients only. Importation of morphine is subject to signed authorization signed by the minister of public health.

Conclusions: There is a huge unmet need for pain relief with oral morphine in Cameroon. Limited access is at least in part from unduly strict national narcotic drug policies and regulations. Continuous advocacy with the ministry of health is essential to reduce the suffering of many Cameroonians.

FC 7.5 Subcutaneous Ketamine Infusion in Palliative Care Patients for Major Depressive Disorder May Be Feasible – Findings from Phase II Feasibility Study (SKIPMDD)

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Background/aims: Background: Major depressive disorder (MDD) affects 10-20% of people with advanced life-limiting illnesses, but effective treatments are limited, particularly when the prognosis is short. Ketamine is emerging as a rapidly effective antidepressant against MDD in people who are otherwise well. A feasibility study is needed before conducting a definitive study to explore its use in the palliative setting.

Aim: To determine the feasibility, safety, tolerability, and potential antidepressant activity of subcutaneous ketamine infusions for MDD in the palliative setting.

Methods: An open-labelled, single-arm, phase II feasibility study was undertaken between Jul 2019 and Oct 2021 (Australian New Zealand Clinical Trial Registry Number: ACTRN12618001586202). Adults (≥ 18 years old) with advanced life-limiting illnesses and MDD from any care setting were recruited from four palliative care services in Sydney, Australia. Weekly subcutaneous ketamine infusions (0.1-0.4mg/kg) over two hours were given using an individual dose-titration design. Outcomes assessed were feasibility, safety, tolerability and antidepressant activity with descriptive statistics and qualitative content analysis performed.

Results: Out of 99 referrals, 11 met eligibility criteria. Ten participants received ketamine and were analysed for responses. The feasibility criteria set *a priori* were achieved, with a mean recruitment rate across sites of 0.54 participants per month and a positive response rate of 50% among treated participants ($\geq 50\%$ reduction in baseline Montgomery-Åsberg Depression Rating Scale). No clinically relevant harms were found.

Conclusions: A future definitive trial of subcutaneous infusion of ketamine for MDD in the palliative setting may be feasible. Individual dose-titration of subcutaneous ketamine infusion appears to be well-tolerated, producing sufficient and rapid antidepressant signals to justify further rigorous evaluation.

FC 7.6 Randomised, Placebo Controlled, Dose-escalating, Double-blind Studies of Medicinal Cannabis for Symptom Management in Patients with Advanced Cancer

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Background/aims: Following robust public pressure, medicinal cannabis was legalised in Australia for palliative care. This was not underpinned by research evidence.

Methods: Participants were adults with advanced cancer and symptom distress (Edmonton Symptom Assessment Scale (ESAS) score of $\geq 10/90$) who received self-titrated MC oil or matched placebo for 28 days. The primary outcome was ESAS total symptom distress score (TSDS) at day 14. Secondary outcomes were: individual symptom scores, symptom burden over time, patient determined dose, opioid use, depression, anxiety, quality of life and adverse events. In a series of RCTs, placebo has been tested against CBD (MedCan-1), CBD:THC 10:10mg/ml (MedCan-2) and CBD:THC 20:1mg/ml (MedCan-3).

Results: In MedCan-1, a planned 58 participants on CBD and 63 on placebo reached day 14. The change in TSDS from baseline was -6.2 (SD 14.5) for placebo and -3.0 (SD 15.2) for CBD with no significant difference between arms ($p=0.24$). Similarly, there was no difference in proportion of "responders" (reduction in TSDS by ≥ 6) (placebo 58.7%, CBD 44.8%, $p=0.13$). All individual symptom scores improved over time in both arms and most participants reported feeling "better" or "much better" at days 14 and 28. There was no effect of CBD on any secondary outcome measure. Adverse events did not differ between arms. In MedCan-2, any contribution of THC to symptom relief is being assessed. MedCan-3 assesses a different cannabinoid combination and secondary outcomes highlighted as being of potential benefit in the previous studies (sleep, anxiety, happiness).

Conclusions: Controlled trials of medicinal cannabis are feasible and popular with patients. As CBD alone does not improve symptom management above that provided by palliative care alone, we continue to investigate the role of THC in various cannabinoid preparations.

FC 8 - B End-of-Life Care and Decisions

FC 8.1 Nursing Home Staff's Experiences with End-of-Life Communication: An Interpretive Phenomenological Study

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Background/aims: High-quality end-of-life care relies on effective and regular communication. Unfortunately, healthcare professionals who work in the nursing home (NH) setting often experience emotional discomfort and lack of confidence when sustaining end-of-life communication, and are prone to omit or postpone such communication with negative impact on care quality. In-depth exploration of their experience may help identify needs and underpin the development of educational interventions to help NH staff engage in these conversations. Therefore, this study explores the lived experiences of end-of-life communication among NH staff.

Methods: An interpretive phenomenological study based on van Manen's hermeneutic approach, that is comprised of 4 lifeworld existentials (spatiality, corporeality, temporality, relationality) and offers a heuristic guide for reflecting on the human experience, was employed. Semi-structured in-depth interviews involved 21 healthcare professionals (4 NH managers, 4 chief nurses, 3 chief medical officers, 3 nurses, 3 psychologists, 2 occupational therapists, one chief nurse aide, and one nurse aide) across 6 North-west Italian NHs.

Results: End-of-life communication was an all-encompassing experience and teamwork assumed a central role in communicating at the end of life. Discussion during team meetings promoted reflexivity about the best way to tailor communication to individuals and situations (spatiality), helped manage challenging emotions and situations (corporeality), helped plan time for communication (temporality), and promoted family caregivers' awareness about disease progression based on a shared plan (relationality).

Conclusions: Teamwork was key in delivering high-quality communication to residents. Educational interventions targeted at NH staff including communication skills training should arrange interdisciplinary learning environments in which healthcare professionals can benefit from group feedback.

FC 8.2 Changes in Health-related Quality of Life and Symptom Burden towards the End of Life in Patients with Advanced Cancer: Longitudinal Results from the eQuiPe Study

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Background/aims: Cross-sectional studies have found a lower health-related quality of life (HRQoL) and higher symptom burden in the last 3 months of life, however longitudinal results are lacking. Therefore, this

study aimed to, longitudinally, assess the change in HRQoL and symptom burden towards the end of life in patients with advanced cancer.

Methods: A prospective, multicenter, observational study on the quality of life and care in patients with advanced cancer (eQuiPe). HRQoL was measured every three months using the EORTC QLQ-C30 (range 0-100), including all subscales and symptoms scores. Multivariable mixed effect analysis was used to assess the association between HRQoL and symptom burden over time until death.

Results: In total, 760 deceased patients were included for analysis with a mean age of 66 (SD 10) years and 52% were male. The most common primary tumor type was lung (29%), colorectal (20%) and breast cancer (13%). The mean HRQoL decreased from 79 (14) in > 12 months before death to 66 (18) in the last 3 months of life. Multivariable analysis showed a significant decrease in HRQoL in ≤ 9 months before death compared to >12 months before death, with the steepest decline in the last 3 months of life (β -16.2, $p < 0.001$). The symptoms fatigue, pain, appetite loss, dyspnea, constipation and nausea significantly increased in the last year of life, whereas diarrhea, insomnia and perceived financial burden did not significantly change over time. The presence of multiple comorbidities (β -7.4, $p < 0.001$) and a higher continuity of care (β 0.7, $p < 0.001$) was associated with HRQoL.

Conclusions: The HRQoL decreases significantly towards the end of life with the steepest decline in the last 3 months. This trend is associated with the presence of multiple comorbidities and perceived continuity of care. The observed downwards trend in HRQoL may guide the decision-making process for initiation of treatment and the early initiation of end-of-life care in patients with advanced cancer. Funded by Foundation Roparun.

FC 8.3 Effect of Anticholinergics for the Treatment of Death Rattle of Cancer Patients in the Last Days: A Multicenter Prospective Cohort Study

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Background/aims: Death rattle occurs in the dying phase and can be distressing for patients' families and healthcare providers. Although anticholinergics are often prescribed for death rattle management in daily practice, evidence of their effectiveness is limited. This study aimed to investigate the effectiveness of anticholinergics for death rattle in dying cancer patients.

Methods: This is a prospective cohort study enrolled Terminally ill adult (20 years or older) cancer patients who developed substantial death rattle (Back score ≥ 2) from 23 palliative care units in Japan. Anticholinergic treatment for death rattle was prescribed according to primary physician's decision. The primary outcome was the proportion of patients whose death rattle improved, which was defined as a Back score of ≤ 1 . We compared the proportion of improved cases in patients treated with (AC group) and without (non-AC group) anticholinergics, controlling potential confounders by employing propensity score weighting.

Results: Of the 1896 patients enrolled, we included 196 who developed a substantial death rattle. Of these, 81 received anticholinergics. 56.8% in the AC group and 35.4% in the non-AC group had an improved death rattle at 8 h after baseline. In the weighted analysis, AC group showed significant improvements in death rattle, with an adjusted odds ratio of 4.47 (95% CI, 2.04–9.78; $P = .0024$). All sensitivity analyses achieved essentially the same results. In the subgroup analysis, anticholinergics were strongly associated with death rattle improvement in men, patients

with lung cancer, and type 1 death rattle (adjusted odds ratio 5.81, 8.38, and 9.32, respectively).

Conclusions: In this propensity score-weighted analysis, anticholinergics were associated with death rattle improvement in terminally ill patients with cancer who developed substantial death rattle.

FC 8.4 Deciding between Dialysis and Conservative Care in Older People with Advanced Kidney Disease: A Mixed Methods, In-depth Study at One Renal Unit

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Background/aims: Annually, >46,400 Europeans age 65+ develop kidney failure and start dialysis. Yet the survival and quality of life benefits of dialysis are uncertain among older people, particularly those with comorbidities/poor performance status. Conservative care (CC) is an alternative to dialysis for these patients, but variation in usage rates is high and the causes of this unclear.

Aim: To explore the context of treatment decision-making for patients age 65+ with eGFR < 20 at one UK renal unit.

Methods: Mixed methods study involving: ethnographic observation; clinician interviews; video-recording of outpatient consultations; patient and caregiver interviews with a sub-sample of video participants. Observation fieldnotes and interview and consultation transcripts were analysed thematically, with segments of consultations subject to Conversation Analysis. Findings were triangulated.

Results: 18 hours of observation and 6 clinician and 7 patient and caregiver interviews were conducted; 30 consultations were videoed, involving 13 clinicians, 22 patients, 11 caregivers. Disease complexity, uncertain progression, the hypothetical nature of the treatment decision and time pressure meant that in routine consultations, care planning discussions were often postponed – even when patients attempted to initiate them. Tensions were evident between clinician, patient and caregiver priorities. In discussing treatment decisions, clinicians tended to omit exploration of patients' goals/values and orient decision-making towards dialysis, focusing on its practicalities. Clinicians reported avoiding talking to patients about the implications of treatment choice for quality of death; this was confirmed in the video data.

Conclusions: Managing advanced kidney disease and negotiating treatment decision-making is complex for clinicians, patients and caregivers. Clinician imperatives dominate consultations. Findings from this renal unit and 3 others will inform an intervention to improve decision-making support.

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FC 8.5 Discrepancy of Clinical Appraisal between Hemodialysis Nurses' and Physicians' Responses to the Surprise Question

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Background/aims: Serious illness conversations are prerequisite for quality of care in patients approaching the end of life. Despite this, patients on hemodialysis are rarely offered these conversations. A reason for this is uncertainty about when the patient is approaching the end of life. The Surprise Question "would I be surprised if this patient died within the next six or twelve months" can be used as a support to identify patients who are approaching the end of life. However, the need for exploration on how clinicians justify and motivate decisions in different identification methods such as the Surprise Question has been stressed. The aim was to explore responses to the Surprise Question from nurses and physicians regarding patients on hemodialysis, and how these answers were associated with patient clinical characteristics.

Methods: In this cross-sectional study we included 361 patients treated with hemodialysis for whom 112 nurses and 15 physicians responded to the Surprise Question regarding six and twelve months. Patient characteristics were obtained from the National Renal Registry and performance status and comorbidities were assessed. Interrater agreement between nurses' and physicians' responses, and the association to patient characteristics were analyzed using Cohen's kappa and logistic regression.

Results: There was a similarity in the proportions of patients for whom nurses and physicians answered "no, not surprised" to the Surprise Question. However, there was little agreement between which patients it concerned. Performance status and albumin were associated with the responses in both groups. Comorbidity were associated with the responses from physicians but not from nurses.

Conclusions: The findings indicate that nurses and physicians have different perspectives in their clinical assessment, which highlights the importance of an open communication between physicians and nurses to support the initiation of serious illness conversations.

FC 8.6 Changing Places, Spaces and Faces: A Mixed Methods Study Showing the Changing Preferences about Place of Care at the End-of-Life Since the COVID-19 Pandemic

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Background/aims: During the covid-19 pandemic, the number of home deaths increased as people avoided institutionalised settings. The research investigates the changing profile of place of death and the impact it has on the future of hospice services.

Methods: Mixed methods:

- (1) systematic review to understand the evidence base around place of care preferences;
- (2) analysis of mortality data to show the percentage increase in home deaths and highlight peaks;
- (3) interviews with 37 participants (15 carers and 22 hospice staff) to explore reasons behind the decision-making and identify impact on quality of life using the ICECAP-CPM.

Results were discussed at two stakeholder roundtable events to draw out policy and practice implications for hospice care.

Results: There was a significant change in place of death towards home deaths for those dying from non-covid related conditions. Increased hospital deaths were more closely linked to the presence of covid on the death certificate. Risk factors associated with hospital deaths included black and minority ethnic groups, lower socio-demographic factors and the presence of an underlying health conditions such as cardiovascular disease and diabetes. Qualitative data analysis reveals that preferences around decision-making to be cared for at home were due to a fear of contracting the virus in institutionalised settings (hospices and hospitals) and visiting restrictions. Quality of life remained high for hospice inpatient and community patients showing good symptom control and communication but concerns were raised about dignity, coping, being with people who care and feeling supported during the main lockdown period. Policy roundtables identified the need for better workforce support and systems of community support for carers.

Conclusions: It is timely to address the future of 'hospice' and explore how services can better support people in communities who are the main providers of end-of-life care and support the changing hospice workforce.

FC 9 - G Diversity and Disparities

FC 9.1 Sawubona! Supporting Health Care Professionals to Make End of Life Care Accessible for All

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Background/aims: Little is known about how current UK policy for end-of-life care planning fits with the social, cultural and religious values and beliefs of ethnic minority communities. However, evidence suggests that healthcare professionals lack awareness, confidence, knowledge and skills in providing culturally sensitive end-of-life care for ethnic minority patients. The 'Thinking Ahead' (NIHR HS&DR 17/05/30) research study explored how terminally ill patients from ethnically diverse backgrounds, and their family care givers, think ahead about deterioration, dying and engaging with healthcare professionals to optimise care. Here we describe key findings from the study and the evidence-based resources developed to support healthcare professionals in talking about end-of-life and goals of care for patients and their families.

Methods: A qualitative study including comparative thematic and cross case analysis from 18 longitudinal patient case studies (93 interviews), 19 interviews with bereaved family and workshops with 50 public and professional stakeholders.

Results: The key message arising from this research resonates with the Zulu greeting "Sawubona" which literally translates to "I/we see you". Where people feel known, especially in respect of any ethnically-or culturally-driven values or stances, greater trust can be engendered resulting in care that is more relevant, timely and personalised. Outputs from this work include e-learning resources, a number of audio stories and a learning guide.

Conclusions: The resources hosted on the Health Education England End of Life Care for All (e-ELCA) e-learning programme and LOROS Hospice websites (<https://loros.co.uk/research-at-loros/thinking-ahead/thinking-ahead-stories>) are a step towards building professional confidence and expertise in supporting people from ethnically diverse backgrounds to engage in thinking ahead about deterioration and dying at a time and at a level with which they feel comfortable.

FC 9.2 Improving Care for Aboriginal and Torres Strait Islander People with Advanced Cancer in Australia

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Background/aims: Indigenous Australians experience inequities at every point of the cancer continuum from cancer aetiology through to end of life (EOL). These inequities are cumulative in effect and partially due to reduced access and engagement with cancer services, often resulting in sub-optimal care. This includes low access and utilisation of palliative care services.

Aim: To explore and understand the needs of Indigenous people with advanced cancer and palliative EOL care needs.

Methods: A co-design approach was used with an iterative process of collaborative yarning to privilege the voices of Indigenous people. An Indigenous Community Advisory Group conceptualised, designed and guided the research. Focus groups & interviews were undertaken with Indigenous people with a lived experience of cancer & palliative care, Indigenous health professionals, & palliative care clinicians. An inductive thematic analysis approach was used.

Results: 22 Indigenous people with a lived experience of cancer & Indigenous health professionals, & 59 palliative care clinicians participated. Key themes emerged describing: complexities of identification; appropriate supports for patients & family when navigating news that cancer is getting worse; guarded time for Indigenous health professionals to integrate Indigenous ways of 'knowing, being & doing'; care provision in both relationship & treatment; early involvement of Indigenous health professionals in care; early, active & collaborative involvement between palliative care services & community-led Indigenous health services; need for deeper, contextualized, face-to-face cultural training; & Indigenous community desire to learn more of palliative care & services available.

Conclusions: This study provides key Indigenous informed culturally appropriate & safe responses for guiding urgent improvements for access to & delivery of cancer & palliative care for Indigenous people with advanced disease.

FC 9.3 Community Engagement to Overcome End of Life Disparity in an Urban American Chinatown Community

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Background/aims: Compared to others, ethnic Chinese are more likely to: receive aggressive end-of-life (EOL) care, die in the intensive care unit and be less familiar with advanced directives/hospice. This pilot aimed to provide interactive, linguistically sensitive, curriculum-based education to elder Chinese Americans engaged in their community around taboo topics (serious illness, advanced care planning, EOL care, bereavement) to improve goals of care and decrease disparities.

Methods: During the COVID-19 pandemic, 5 (topics and a wrap up) 1.5 hour Zoom-based community engagement sessions were led by a palliative care physician partnering with a community service agency trusted by elders in the local Chinatown community. They recruited participants, provided translation services for educational materials and discussions to minimize the influence of language barriers, and facilitated Zoom platform use. As appropriate, multidisciplinary guests included chief medical

officers of hospice and Medicaid, oncology fellow, researchers, chaplain, and medical students.

Results: Each session had 30-40 attendees who were eager to participate, engaged virtually and open to difficult discussions. Conversation was lively and fun. An informal post-session participant survey showed 100% of participants found sessions helpful and desired future discussions, 6/13 had identified a health care proxy, 8/13 found discussion on grief helpful and 6/13 planned for conversations with family. The community partner continues to rave about the program, its benefits and desire to repeat it.

Conclusions: Lessons learned: be flexible based on attendees' interests, "let go of the agenda"; authentic expert panelists speaking to the continuum of each topic greatly enhanced attendees' experience; humility and humanizing the health care system is essential; and pre- and post-test and survey are needed to assess the program's impact. Funded by Tisch Fellow Award Grant awarded to Dr. Vesel from Jonathan M. Tisch College of Civic Life at Tufts University.

FC 9.4 Patients with Migrant Background in Specialist Palliative and Hospice Care in Germany

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Background/aims: Patients with migrant background (PMB) seem to be underrepresented in hospice and palliative care (HPC) in Germany. Evidence about their representation, challenges in care and strategies used to counter them is scarce.

Aim: To provide a nationwide assessment of HPC for PMB, their representation, challenges in care and strategies against them.

Methods: In 2019, an online questionnaire with questions on number of PMB, care specifics of the last PMB in the institution, and strategies to counter challenges (e.g. use of interpreters) was sent to all HPC institutions in a national database. Quantitative data was analysed descriptively, qualitative data was analysed using qualitative content analysis.

Results: 332 institutions participated (40.7% volunteer hospice services; 23.2% palliative home care teams, 15.3% palliative care units, 12.7% inpatient hospices). On average, they had cared for 11.2% PMB in the last year (0-100%), depending on federal state, urban or rural area and type of service (palliative home care teams: 16.7%, volunteer hospice services: 6.1%). The last PMB was mostly from Turkey (21.1%), Russia (12%) or Syria (9%). Challenges were experienced regarding, among others, organization of care and relationship between HPC professionals, patient and family. 56.2% cases had language barriers, but in only 24.4%, profession interpreters were used (staff: 42.3%; friends and relatives: 78.6%). 17.1% were not satisfied with professional interpreters. In general, only 7.8% regularly use professional interpreters, most (68.7%) mostly rely on friends and relatives of the patient.

Conclusions: PMB are regularly cared for in palliative and hospice care in Germany, with a wide variety of degree of experience. Language barriers are evident, and use of friends and relatives for interpretation is widespread, but can be burdensome for them and may lead to wrong interpretations. Both HPC professionals and interpreters should train professional interpretation for these vulnerable patients.

FC 9.5 Global Ideas, Local Models: Cultural Sensitivity in Community-based Palliative Care in Brazil and Indonesia

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Background/aims: Palliative care services are increasingly implemented in diverse socio-cultural settings around the world.

Our ethnographic project aimed to explore how palliative care services are adapted to local socio-cultural contexts in Brazil and Indonesia.

Methods: We used qualitative research methods to study local models of palliative care provision in Brazil and Indonesia. These countries were chosen because of similarities in stages of palliative care service development, and yet difference in health care organization and dominant religion. After scoping initiatives, in each country one thriving community-based initiative was selected for an in-depth case study through semi-structured interviews and participant observation. Three months of research were conducted in each site. Thematic analysis was first done for the individual cases, then compared across cases to establish differences, similarities and patterns.

Results: The case studies of community-based initiatives reveal how local values are included in the development and practice of palliative care. They further reveal how these programs build on existing local health care structures, while also incorporating practices derived from global trainings, thereby increasing awareness of palliative care. They finally show how use of the concept of 'palliative care' may be sensitive in particular socio-cultural contexts, and how health care workers adapt their language and practice to this sensitivity.

Conclusions: As palliative care services are implemented in various socio-cultural settings, a better understanding of successful community-based models for palliative care provision is needed to adapt services to local contexts.

This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No 851437).

FC 9.6 "Too Many Pages of Easy-read Is Boring and Stressful": Exploring and Testing the Information Preferences of People with Intellectual Disabilities

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Background/aims: Health information, including information about death and dying, must be tailored towards the communication needs of the recipient. For people with intellectual disabilities (ID) this means making complex information easier to understand. There is a lack of empirical evidence supporting the effectiveness of the different methods and components of communicating such information in accessible formats, including easy-read (= documents with simple sentences alongside pictures) and other formats.

AIMS: To explore how people with ID access health information, and what types of accessible information they prefer.

Methods: The project team members included 7 people with ID. (1) They explored the issues in several group sessions, discussing their own experiences and assessing a range of accessible information materials, including easy-read leaflets, videos and picture stories. (2) They held 4 online focus groups with PwID (n=10) (3) The findings were analysed thematically through discussions with the project team and (4) applied to producing an accessible version of the annual report *Learning From Lives & Deaths of People with Learning Disabilities (LeDeR)* (a review of 3,304 deaths of PwID in England in 2021).

Results: There was strong agreement among the 17 people with ID. Their preferred way of accessing health information was by asking a doctor or nurse, followed by searching the internet and talking to family or friends. Preference for type of information materials was

- (1) videos;
- (2) picture stories;

- (3) easy-read information materials, although these should be short.

Following these results, the project team produced and narrated an accessible video of the *LeDeR* report. Feedback from PwID has been positive.

Conclusions: Health professionals should know about, and have access to, accessible information materials. Whilst easy-read materials are the most readily available format of accessible information, they are not necessarily the most effective. Further research into this is needed.

FC 10 - A Innovation and E-Health Solutions

FC 10.2 Leveraging the Personal Health Train and FAIR-data to Improve Palliative Care

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Background/aims: Having up-to-date insight into delivered palliative care (PC) is essential to improve it. However, centralized data collection is difficult due to privacy concerns and legal restrictions. We developed a system that calculates PC indicators using the Personal Health Train (PHT). Through the PHT, analyses are executed on-site and only aggregated results are shared either locally or beyond. This can be used nationwide without compromising patient privacy and was piloted in our hospital.

Methods: Patient data was obtained from the hospital's electronic health record. Inclusion criteria were: deceased ≤ 5 years ago, ≥ 18 years old, and contact with the hospital in year of death. Data was further standardized following the FAIR-principles (Findable, Accessible, Interoperable, Reusable) and uploaded to a FHIR-server (Fast Healthcare Interoperability Resources). Indicators for advance care planning (ACP) were based on the presence of treatment limitations recorded. We operationalized potentially inappropriate end-of-life care as: place of death, ≥ 2 ED-visits, ≥ 2 hospital admissions, ≥ 1 ICU admission, and combined length-of-stay ≥ 14 d in the n days before death.

Results: A PHT-node was installed on-site and connected to the FHIR-server. An algorithm calculating indicators was run on the node. An interactive dashboard was created visualizing the indicators, which can be split by PC team involvement, specialty, diagnoses, presence of treatment limitations, and age. In the first 7 months of 2022, 1072 deceased, of which 34% had ≥ 1 positive indicator. The PC consultation team was involved in 19%.

Conclusions: We successfully used the PHT with FAIR data to calculate aggregated statistics describing the status of palliative care at our hospital. Deploying this solution in hospitals and other institutions (e.g., hospices) throughout the Netherlands offers a scalable alternative for a centralized palliative care registry, and new possibilities for (inter) nationally analyzing data without risking patient privacy.

FC 10.3 PROTECH - Proactive Delivery of Palliative Care by Using Machine Learning Technology to Identify the Last Year in Life

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Background/aims: Cancer patients in their last year of life are a priority group with worsening symptom burden, decreasing quality of life, and rising healthcare costs. A palliative support system could be delivered proactively to improve outcomes. We lack a solution to systematically predict for patients approaching their last year in life. Current prognostication solutions are subjective, disrupt operational workflows, and are not responsive to the cancer treatment landscape. We aim to build an explainable machine-learning model to predict death within the next 12 months using Electronic Health Record (EHR) data.

Methods: Cohort includes newly diagnosed Stage 3 or 4 solid organ cancer adult outpatients visiting NCCS between 1st July 2017 to 30th June 2020. EHR data spanned 1st July 2016 to 31st December 2021. We incorporated cancer characteristics, comorbidities, laboratory results and cancer treatment data. Feature engineering was guided by data science and clinical experts. We trained a random forest model on 75% of the cohort before testing on the unseen 25%. Each unique patient had a randomly derived prediction point (T0) based on actualized outpatient cancer visits. We framed this as a binary classification problem: "Given a patient and T0, predict the mortality of that patient within 12 months from T0, using EHR data prior to T0".

Results: A total of 2254 Stage 3 and 3802 Stage 4 cancer patients were included in this dataset. Thirty-one percent of patients died within the 12-months after T0. Albumin and neutrophil-lymphocyte-ratio features ranked highest in variable importance. Our model predicted death within the next 12-months on the held-out test set with an accuracy of 83.14%, AUC of 0.89, and F1 score of 0.70. As a sensitivity analysis, model performance remained stable over 20 iterations of randomly generated T0s.

Conclusions: We found promising performance for a machine-learning model to identify the last 12-months in life using EHR data. More feature engineering and model building work is ongoing.

FC 10.4 Telemedicine and Advance Care Planning Conversations in an Ambulatory Palliative Care Clinic during the COVID-19 Pandemic

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Background/aims: The delivery of palliative care for cancer patients has been impacted by the COVID-19 pandemic. Telemedicine has been adopted as a method to provide palliative care in ambulatory settings. Few studies have shown the potential impact of telemedicine on conducting advance care planning (ACP) for these patients. Our aim was to determine the association between in-person vs virtual consultations along with the year of consultation (pre-pandemic: 2019; peri-pandemic: 2020-21) and the frequency of documented components of ACP (illness understanding, values, trade-offs, substitute decision maker (SDM), code status, preferred location of death).

Methods: This was a retrospective cohort study of patients with breast, gastrointestinal, gynecological and lung cancer referred to the outpatient palliative care clinic at an academic hospital in Toronto, Canada in 3 distinct time periods: Apr-Jun from 2019-21. Descriptive statistics were used to characterize clinical information: age, sex, disease site, PPS and proportion of virtual visits. Multivariable logistic regression analyses were used to determine the association between year of consultation and each component of ACP, controlling for clinical information.

Results: The odds of documenting SDM (OR 5.3, p=0.002) were significantly higher in 2021 vs 2019, while the odds of documenting illness understanding (OR 14.8, p<0.001), trade-offs (OR 6.4, p=0.004) and preferred location of death (OR 6.5, p<0.001) were significantly higher in

2020 vs 2019. There were no differences in discussion of code status or values.

Conclusions: Most components of ACP discussions were shown to be conducive to telemedicine encounters. Use of telemedicine possibly highlights the importance of conversational aspects of palliative care in the absence of physical exams. Telemedicine also allows for the inclusion of family members in distant locations which may facilitate ACP conversations. Future work will enable us to enhance models of palliative care delivery in outpatient settings.

FC 10.5 Capturing Inpatients' with Palliative Care Needs and their Carers' Real-time Experiences: A Feasibility and Acceptability Study

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Background/aims: Background: Most expected deaths in high income countries occur in hospital, and a significant proportion of inpatients at any one time have palliative care needs. Inpatient palliative care quality needs monitoring to inform improvement. Patient Reported Experience Measure (PREM) use is one way of understanding care quality.

Aim: To test the feasibility and acceptability of a brief PREM for inpatients with palliative care needs, their families/carers ('carers') and the acute care team.

Methods: *Design:* A two phase sequential mixed methods study. Phase 1: appraisal of the PREMs' face and content validity ('acceptability') from patient / carer and clinician perspectives via semi-structured interviews and focus groups. Two PREMs were included: ConsiderATE and the Australian Hospital Patient Experience Question Set. Phase 2: feasibility of administering the selected PREM using PREM completion and a focus group as measures.

Analysis: Thematic analysis of qualitative data occurred through data immersion, coding, categorising and generation of themes. Mid-point data integration and meta-inference informed the preferred PREM for Phase 2. PREM and implementation data were presented using descriptive statistics. End-point data integration via joint display tables informed feasibility and acceptability within the Australian hospital context.

Results: 27 interviews with: patients (n=19), carers (n=8); and 3 focus groups with: clinicians (n=5), hospital executives (n=5) and consumers (n=5). Data integration informed the selection of ConsiderATE due to alignment with what matters most for patients with palliative care needs and ability to inform change. ConsiderATE was administered to 80 participants (71% response rate). Mean completion time was 6.12 minutes and 34% (n=27) participants required assistance.

Conclusions: ConsiderATE is an acceptable and feasible PREM for the inpatient setting. Research exploring the use of PREM data to drive meaningful improvements in care is required.

FC 10.6 CARer-ADministration of As-needed Subcutaneous Medication for Breakthrough Symptoms in People Dying at Home (CARiAD): Rapid Implementation, Quality Improvement and Accelerating Impact of New Practice

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Background/aims: In the UK, most people wish to die at home. Timely symptom control is crucial. When people become unable to swallow,

as-needed subcutaneous injections for breakthrough symptoms require a healthcare professional (HCP) to travel to the home to administer. The wait can be distressing.

The UK NIHR-funded CARIAD feasibility trial explored the practice of lay carer administration of these injections. This practice is new to most of the UK. We led urgent all-Wales policy development in the pandemic context (March 2020). Rapid implementation followed, starting in the North Wales region.

Methods: We analysed the first robust, real-world UK data set emerging from 3 teams in the large North Wales geography, on clinical effectiveness and safety of the practice. Parallel quality improvement initiatives focused on outcome collection/analysis, information governance and lay carer training processes. We co-founded the UK national Community of Practice (CoP) for HCPs and set up an Impact Acceleration project.

Results: Until October 2022, 89 patients had a total of 979 carer-administered injections (median = 8 per patient, range 1 to 57). HCP support was sought in only 12.33% of instances. Data show timely symptom control for patients (median waits down from 105 to 10 minutes) and increased likelihood of dying at home. Carers reported feeling empowered and well-supported by HCPs. The practice is safe.

Learning between HCP teams is shared via regular regional meetings and the national CoP; this continues to inform all-Wales policy refinements and practice across the UK. A regional 'CARIAD carers group' was established with 'Impact Acceleration' funding to guide future improvements.

Conclusions: North Wales implementation is UK-leading and is supporting activities to extend the reach of the practice across the UK, ensuring more people can benefit. The practice is transformative, reframing carer roles for those dying at home, supporting a sustainable shift away from the medicalisation of end of life.

FC 11 - B Experiencing the COVID-19 Pandemic

FC 11.1 Dying during the COVID-19 Pandemic in Sweden: Relatives' Experiences of End-of-Life Care (the CO-LIVE Study)

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Background/aims: The COVID-19 pandemic has seen many deaths, but the majority were for causes other than COVID-19. However, end-of-life care in all settings has been affected by measures limiting the spread of the virus, both for patients with and without COVID-19. The Swedish coronavirus strategy was different compared to many other countries, which might have affected end-of-life care.

The aim was to describe the experiences of end-of-life care for bereaved relatives in Sweden during the first 6 months of the pandemic ("first wave") and to compare the experiences for deaths due to COVID-19 with the experiences for deaths for other reasons.

Methods: A random sample of addresses for 2400 people who died during March-August 2020 was retrieved from the Swedish Person Address Registry. Relatives were contacted with a questionnaire regarding the cause of death and their experience of end-of-life care, with a focus on communication, participation, and trust.

Results: In total, 587 relatives (25% response rate) answered the questionnaire (14% COVID-19-deaths, 65% non-COVID-19-deaths, 21% uncertain). In the COVID-19 group 28% of the relatives were allowed visits without restrictions compared to 60% in the non-COVID-19 group ($p < 0.01$). Only 28% of the relatives in the COVID-19 group reported that

the person received "enough care from physicians," significantly fewer than the non-COVID group (65%, $p < 0.01$).

Conclusions: Relatives' experience of end-of-life care for persons with COVID-19 was significantly worse than relatives of persons without COVID-19, but also relatives for persons without COVID-19 were negatively affected.

FC 11.2 Collaborations during COVID-19: Visiting Geriatric Service and Community Palliative Care

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Background/aims: There is a growing demand for Community Palliative Care (CPC) services looking after residential aged-care facility (RACF) residents, due to ageing population and increasing medical complexities. The demand is even higher during the COVID-19, putting additional burden on an already strained healthcare system. This study looks at the role of a visiting geriatric service to RACF to help supplement and complement the CPC in looking after this cohort, especially during COVID-19.

Methods: We reviewed the electronic medical records of a tertiary teaching hospital for RACF residents referred to the visiting geriatric service between 2019-2021. Information collected include baseline demographics, proportion deemed palliative (and the indication), number referred to CPC and time until CPC contact.

Results: There were 983, 1644 and 1751 referrals to the visiting geriatric service in 2019, 2020 and 2021. An increase in RACF residents being palliated by the visiting geriatric service was noted, accounting for 64 (6.5%), 107 (6.5%) and 123 (7.0%), although this did not reach statistical significance. Additional 26, 74 and 87 residents were deemed at risk of deterioration and hence recommended for CPC involvement. A further 23 residents were transferred to hospital for palliation.

25.6% of palliative cases in 2020 and 2021 were related to COVID-19, either directly or indirectly. In those years, there was a significant increase in the time from when CPC is referred until the time of CPC contact (2.6 days vs 6.8 days, $p < 0.01$).

Conclusions: There was a significant increase in demand for both visiting geriatric service and CPC during COVID-19. Visiting geriatric service was able to assist CPC by early assessment and management of RACF residents followed by CPC referral. This is especially valuable to ensure adequate symptom relief for palliative patients (and those at risk) while simultaneously avoiding unnecessary hospital transfer, at a time when there is an unprecedented demand on the healthcare system.

FC 11.3 Treatment of Patients with de Novo Metastatic Cancer in Times of the COVID-19 Pandemic: An Observational Study

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Background/aims: During the COVID-19 pandemic recommendations were made to adapt cancer care to prevent infections in vulnerable patients and decrease the burden on healthcare. This study aimed to investigate treatment of patients with de novo metastatic cancer during the COVID-19 pandemic.

Methods: Treatment of patients diagnosed with de novo metastatic cancer during five periods between January 2020 and May 2021 was compared with reference data from 2017/2019. Patient-, tumor- and treatment characteristics were obtained from the Netherlands Cancer Registry. The proportion of patients receiving different treatment modalities after diagnosis was compared by period. Treatments were analyzed by primary tumor type using logistic regression and were adjusted for age, sex and comorbidities. Time between diagnosis and first treatment was compared using a Mann Whitney test.

Results: Surgery of the primary tumor declined slightly in the period after the first COVID-19 peak in 2020 (7.1% to 5.9%, $p < 0.01$). Patients with metastatic cancer of the urinary or gastrointestinal tract were less likely to receive surgery during this period, OR 0.73 (95%CI:0.56-0.95) and OR 0.81(95%CI: 0.68-0.96) respectively. Use of hormonal therapy and chemotherapy increased mainly in the first months of 2021 (12.1% to 14.0%; 28.4% to 31.6%, $p < 0.01$). In this period, patients with metastatic cancer of the gastrointestinal or respiratory tract were more likely to receive chemotherapy (OR 1.20, 95%CI:1.08-1.34), while patients with metastatic cancer of the male genitalia were more likely to receive hormonal therapy (OR 1.30, 95%CI:1.06-1.58). Time between diagnosis and first treatment decreased in all periods, most pronounced during the first COVID-19 peak, namely 4.8 days.

Conclusions: Some shift in treatment modalities was seen during the COVID-19 pandemic. Surprisingly, time between diagnosis and first treatment was shorter. Overall, efforts to maintain the best care for patients with metastatic cancer seem to have limited the impact of COVID-19.

FC 11.4 The Real Cost of COVID-19 Lockdown: Indigenous Reflections on Dying and Bereavement during Lockdown

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Background/aims: International research confirms the negative impacts of COVID-19 'Lockdowns' on end-of-life experiences and bereavement. However, we know little about how the social restrictions impacted Indigenous peoples. In Aotearoa New Zealand, family caregivers were confronted with an enormous challenge, to care for, and bury their dead, without help from close and extended family, spiritual leaders and healers with crucial cultural knowledge. The aim of the study was to investigate the impact COVID-19 Lockdowns had on Indigenous New Zealanders end-of-life caregiving and bereavement.

Methods: Kaupapa Māori Research methods, and an inductive thematic analysis, informed the research design. Face-to-face interviews explored 29 families' caregiving and bereavement experiences during lockdown. Creative arts methods were used to produce an online photographic exhibition of 23 family stories and portraits. Seventeen Funeral Directors,

21 Indigenous health professionals and 2 community elders were interviewed for their perspectives.

Results: Māori end-of-life care customs and processes changed during COVID-19 Lockdown reflecting the capacity of families to learn, adapt and change. Initial policies restricted families from being together. One person at the bedside made it difficult to carry out cultural and spiritual rituals. Social media technology helped some families adapt funeral customs and perform cultural rituals. Being separated from each other, and having cultural and spiritual customs disrupted, caused individuals to experience complex and disenfranchised grief.

Conclusions: If they are to centre on equity, pandemic health policies must take into consideration larger family configurations and end-of-life caregiving customs and rituals that Indigenous people want and need. Indigenous families find cultural strength and resourcefulness in each other. The communal needs of Indigenous families must be considered to ensure optimal bereavement care outcomes.

FC 11.5 Especially Psychosocial and Spiritual Care Were Limited due to the Protective Measures during Four Time Periods in the COVID-19 Pandemic: Longitudinal Survey Study among Healthcare Professionals

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Background/aims: During the COVID-19 pandemic, the virus and protective measures hindered caregivers from providing multidimensional end-of-life care. The aim of this study is to examine the extent to which different dimensions of end-of-life care were limited at different time periods during the COVID-19 pandemic and how COVID-19 measures were associated with this.

Methods: Health care providers (HCPs) from different settings who provided end-of-life care were asked to complete a questionnaire four times: in spring 2020 (T1), fall 2020 (T2), Dec 2020 - Apr 2021 (T3) and May 2021 - Sept 2021 (T4). They were asked to what extent they felt that medical, nursing, psychosocial and spiritual care were limited during the COVID-19 pandemic. We used a X²-test to analyze differences between dimensions and Generalized Equation Estimations to analyze differences between periods and associations with COVID-19 measures (corrected for HCP characteristics including setting).

Results: Questionnaires were completed by 321 (T1), 308 (T2), 179 (T3), and 142 (T4) respondents. Compared with T4, HCPs experienced care in all dimensions significantly more often as limited by COVID-19 at T1-3, especially T1 for psychosocial (OR=12.63) and for spiritual care (OR=10.84). Also, in all periods, spiritual and psychosocial care were more often perceived as limited than medical and nursing care ($p < 0.01$).

Limitations in all dimensions of care (during all time periods) were associated with a lack of personal protective equipment (from OR=2.57 for nursing to OR=2.93 for psychosocial care) and not being allowed to provide post-death personal care (from OR=1.67 for nursing to OR=2.24 for medical care). HCPs experienced psychosocial and spiritual care more often as limited when there were visiting restrictions (OR=2.10 and OR=1.70, respectively).

Conclusions: This study highlights the need for explicit attention to psychosocial and spiritual care and closeness in the last phase when taking visiting and safety measures.

Funding: ZonMw

FC 11.6 Prognostic Factors for Outcomes from COVID Infection in Patients with Life-limiting Diseases – A Retrospective Cohort Study from the Canadian Palliative COVID-19 Registry

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Background/aims: Understanding the trajectory of patients with life-limiting diseases infected with COVID-19 is essential to support better planning for their care. This study aims to analyze demographics, settings of care and medical background of patients with life-limiting diseases who were treated for COVID-19 in Canada and to explore possible predictors of disease severity and death due to COVID-19.

Methods: The COVID-19 Palliative Registry was a national clinician-completed registry that collected data from September 2020 to December 2021 of the baseline characteristics and outcomes of patients with life-limiting illnesses and infected with COVID-19 in various settings of care across Canada. Multivariable regression analysis was used to identify variables associated with severity and death.

Results: In total, 1041 patients were included from 5 provinces in Canada. 80.9% were white, 55.1% female and the median age was 83 years. Dementia was the most prevalent primary life-limiting disease (513, 49.3%). 64.5% were treated as outpatients, 301 (28.9%) were hospitalized and 91 (8.7%) admitted to ICU. 295 (28.3%) had highly symptomatic COVID-19 (with 4 or more symptoms) and 333 (32%) had at least one complication from COVID-19. Overall mortality in the studied population was 30.8% (while mortality from COVID-19 in general population in Canada was 1.02% in the same period) and 15.8% of asymptomatic patients died. Male gender and morbid obesity were independent risk factors for complications from COVID-19 ($p < 0.002$). Mortality was surprisingly higher among patients who were less than 73 years-old (40.6%) and in male gender (39.2%) and lower (24.8%) in patients whose primary disease was in a stable phase or in remission ($p < 0.001$).

Conclusions: Patients with life-limiting disease presented with high symptom burden, severity, hospitalization and mortality due to COVID 19. Male gender was associated with a higher risk for complications and death. Mortality was also unexpectedly high in younger and asymptomatic patients.

FC 12 - C Family Caregivers

FC 12.1 The Safari Concept: Culture, Metaphors and Suffering in the Journey to Communicate with Families in Rwanda

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Background/aims: Effective communication is essential for the optimal delivery of healthcare services. In developing countries, family members typically shoulder a great deal of the burden of caring for patients.

Families serve as caregivers, provide food and transport, and pay bills. The contributions of family members at end-of-life are thus crucial to the plan of care in low- and middle-income countries. In an effort to create a formal model of end-of-life care that is suitable to the Rwandan context, we must begin by understanding the suffering of families and the community at the end of life.

Objectives: To understand the language of suffering expressed by patients' families to optimize communication at end-of-life care.

Methods: We observed and described the behavior of more than eight hundred meetings of healthcare staff with family members and patient caregivers in hospitals, hospice, and at home.

Results: We developed a framework called "Safari," which means "Journey" in Swahili, based on a Rwandan social-cultural approach to decode the language of suffering from families and caregivers during family meetings. Twelve animal archetypes were used to describe families' suffering behaviors, language, and expectations. The framework has helped healthcare providers improve their understanding of and communication with families.

Conclusions: The Safari concept is a Rwandan homegrown solution to increase effective communication between healthcare providers, families, and caregivers. In the context of communities where traditional practices are still relevant, the modern approach to palliative care should embrace sociocultural values to optimize communication.

FC 12.2 Strategies to Reinforce a Sense of Security in Patients and Family Caregivers in Palliative Home Care – An Ethnographical Study

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Background/aims: Patients and their family caregivers (fc) experience a wide range of challenges in palliative care at the patients' home. Both feel unprepared and insecure according to symptom interpretation and management. The emotional adaption in mostly rapid changing situations also lead to insecurity of patients and fc. The aim of this study was to understand the interventions of the palliative home care teams (PCT): Which strategies use PCT to strengthen a sense of security in patients and fc?

Methods: The data collection was conducted according a participatory ethnographical design. The researcher observed home visits of 6 PCT (nurses (n=24)/physicians (n=9) and documented 60 consultations in the private home of 44 patients and fc. Using the Grounded Theory Methodology these fieldnotes were coded and central concepts identified.

Results: To evolve a sense of security of the patients and their fc the PCT used 4 different strategies:

Two strategies were coded as "encouraging": "Reassurance" and "Empowerment". Reassuring strategies were positive feedback and passing compliments about useful coping and self-management strategies. They also replied compassionate and empathetic to emotional expressions. Reassuring interventions fostered the awareness of existing resources and competences. Empowerment: the PCT educated and enabled patients and fc to cope with their symptoms and feelings and thereby enlarged their (self)caring capacity.

Two other strategies were rather "relieving" and "unburdening": The PCT either used "conciliating" strategies to avoid the reduction of a sense of security or they gave "directive instructions" to reinforce secure symptom management.

Conclusions: Four strategies to strengthen the sense of security of patients and fc could be identified. Further research is necessary to explore in which situations they are reasonable and useful for

patients and how PCT can use these strategies rather consciously than unwittingly.

FC 12.3 Optimum Hospice at Home Services for End of Life Care: Findings from a Mixed Methods Realist Evaluation of Family Carers' Experiences and Implications for Service Delivery and Development

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Background/aims: Hospice at home (HAH) services aim to support patients to receive care and die at home. A wide range of service models exist in England with little evidence of what works best, for whom and in what circumstances. We aimed to find out what is the best service configuration that would allow more patients to die where they prefer and to have a good quality of death. This paper addresses the following sub-components: what were family carers' experiences of HAH care; what did good support look like; and what were the barriers/enablers.

Methods: Realist evaluation: literature review; survey to inform case study site framework; mixed methods case studies including interviews with commissioners, managers, hospice staff and carers; and two national consensus events with stakeholders to test/refine the findings. Carers were recruited on entry to the hospice service and interviewed 6-months post-bereavement. Staff were recruited via hospice service leads. Interviews were analysed in monthly meetings, with two lay co-applicants, using normalisation process theory to underpin realist methodology.

Results: 143 interviews were conducted with 9 commissioners, 76 hospice staff and 58 carers across twelve case study sites. HAH staff were key in co-ordinating/integrating care in the home. Carers consistently highlighted the knowledge, skills and ethos of HAH staff and that they had time to care, in a way other services did not. Staff assessed the needs of patient and carer, enabling them to support both in a flexible and compassionate manner. Gaps existed in post-bereavement support, especially for younger adults caring for children/adolescents at home.

Conclusions: Carers valued the time, expertise and compassion of HAH staff. Services need to be clear about their remit from the start, so that families know exactly what can, or cannot, be provided. This helped establish confidence in the service and build strong relationships with patient and carer. HAH needs to regularly review the needs of the carer/patient dyad.

FC 12.4 Bereaved Family Experiences with COVID-19 Visitation Restrictions in Palliative Care Units: A Web-based Cross-sectional Survey

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Background/aims: Through a web-based post-bereavement survey, clarify the experiences of bereaved families (BFs) of patients who died in palliative care units with COVID-19 visitation restrictions (VR) in Japan.

Methods: Data responses from BFs of patient who died in palliative care units February 2020-December 2021 were analyzed using a Japanese Hospice and Palliative Care Association web-based survey system. Participants were asked about perceived VR and experience caring for dying patients under VR.

Results: Participants included 998 BFs from 48 units. Mean patient age was 76±12 years; 53% of BFs were 64 years or younger; 53% were children; 30% were spouses. VR experiences were reported by 79% of participants. For BFs with VR, visit frequency in the week before the patient's death was 38% daily, 18% 6-4 days, 25% 3-1 days, and 19% 0 days, less often than for BFs without VR (56% daily, 16% 6-4 days, 18% 3-1 days, 10% 0 days, P=0.0001). BFs with VR reported that VR were unavoidable (86%), staff made efforts to communicate (82%), staff were in contact frequently about the patient's condition, making them feel secure (67%). They also responded that family was lonely (80%), patient would have been lonely (76%), not knowing the patient's condition created worry (56%), and patients with serious conditions should not have VR (45%). BFs without VR reported more often that patients achieved good death (P=0.0002) and satisfaction with care (P=0.001). VR were not associated with depression or complicated grief in BFs (P=0.48, P=0.18, respectively).

Conclusions: Despite VR, 56% of BFs were able to attend to loved ones for 4 or more days during the patient's last week. Most BFs accepted VR as unavoidable; although they felt lonely and anxious, they evaluated care provided by staff positively. VR did not affect BFs' post-bereavement depression and complicated grief.

FC 12.5 Roles and Experiences of Informal Carers Providing Care for People with Advanced Cancer in Africa: A Systematic Review and Critical Interpretive Analysis

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Background/aims: There is a high prevalence of cancer in Africa. Approximately 80% of cancers are diagnosed at an advanced stage, and most care relies heavily on families. We aim to understand roles and experiences of informal carers in Africa, impact of care on individuals and communities, and support available.

Methods: A systematic review following PRISMA reporting guidelines. Critical interpretive synthesis was used to identify themes and develop a framework of the constituents of an informal carers' experience.

Results: We searched nine databases, identifying 8,123 studies. We included 31 studies from Sub-Saharan Africa (29/31, 94%), with Uganda accounting for 29% (9/31) of included studies. Carers were mostly women, aged 30-40 years. Caring roles included nursing, fundraising, emotional support, and care coordination. Caring was time consuming with some carers reporting 121hrs/week of caring, associated with an inability to pursue paid work and depression. Four themes demonstrated experiences and impact:

- 1) intrapersonal factors: carers having a strong sense of familial obligation, and grappling with gender roles and altered sense of identity,
- 2) interpersonal factors: the ripple effects of a cancer diagnosis on the household, and changing social and sexual relationships,
- 3) community factors: carers navigating cultural norms on nature and location of caring, and
- 4) health system influences: significant negative financial impact, benefits of professional help and tensions between traditional and modern medicine.

Conclusions: Our review highlights the multifaceted roles and experiences of informal carers in Africa, amidst extensive cultural and community impact. Carers experience a strong sense of obligation and willingly undertake care, but at the expense of relationships, financial security, and psychological well-being. Support for carers, including flexible working hours/ carers' allowance, should be incorporated as part of universal health coverage.

FC 12.6 Unmet Needs of Relatives of Patients with Advanced Cancer in the Last Year of Life: Longitudinal Results of the eQuiPe Study

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Background/aims: Unmet needs of relatives of patients in the palliative phase will not only impact their own quality of life, but may also negatively affect the patients' health outcomes. The aim of this study was to assess the changes of unmet needs of relatives of patients with advanced cancer in the patient's last year of life and identify specific unmet needs in subgroups.

Methods: A prospective, longitudinal, multicenter, observational study on quality of care and quality of life of patients with advanced cancer and their relatives was conducted (eQuiPe). Unmet needs of relatives were measured every three months using the PNPC-sv caregiver questionnaire (44 items). Change of reported unmet needs in the last year, and the differences in unmet needs between different subgroups of relatives were analyzed.

Results: In total, 409 relatives were included with an average of seven unmet needs in the last year before death of the patient (ranging from 1 to 44). Unmet needs were most prevalent in the domain "caring for the patient" (12% - 35%), especially "knowing what physical signs I should notice", and in the domain "psychological problems" (9% - 40%), especially "fear for physical suffering of the patient". During the last three months of life, relatives needed more support about how to handle and recognize symptoms of the patient. Other relatives reported "missing a conversation with a professional caregiver about the situation without the patient" more often as unmet need compared to partners.

Conclusions: The domains "caring for the patient" and "psychological problems" are most unmet for relatives. Support from professional caregivers should focus on these domains. It seems especially important that during the last phase of life more support is given focused on dealing with the symptoms of the patients instead of on dealing with the disease.

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FC 13 - D Palliative Care for Older People

FC 13.1 Improving Comfort Levels of Staff to Discuss End-of-Life in Long Term Care Homes

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Background/aims: As the population ages, more people will die in long-term care (LTC) homes. Yet most LTC homes do not offer structured palliative education for their staff. The purpose of this study was to evaluate two multidisciplinary educational initiatives (i.e., workshop, e-learning modules) on improving staff capacity and comfort with end-of-life communication in LTC.

Methods: We used a mixed methods design in three LTC homes in Ontario, Canada. First, 40 LTC staff completed surveys before and after attending a 4-hour interactive workshop about communication within a palliative approach to care. After the workshop, we debriefed with staff to explore their perceptions of the workshop and suggestions for improvement. Based on these findings, we developed and piloted eight e-learning modules with 76 LTC staff. We collected qualitative data to explore the acceptability of using these modules online.

Results: Using a paired t-test we found that staff knowledge and comfort to engage in discussion with residents about death and dying improved after attending the workshop ($p < 0.027$). Staff reported that the workshop was helpful but stated that it was difficult to take the time to attend the workshop in person and suggested that using more reflection and case examples would be helpful. Also, staff found the e-learning modules to be acceptable and appreciated the holistic nature of them. However, they suggested some improvements to the user-interface and workflow components to improve the usability of them.

Conclusions: Both in-person workshop and e-learning modules are acceptable and can assist in improving staff comfort to engage in discussions about death and dying to better support residents living in LTC and their family/friends.

FC 13.2 Perceptions of Deprescription in Primary Care – A Qualitative Interview Study with Health Care Professionals, Patients and Caregivers

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Background/aims: At the end of life some medication may no longer be beneficial to patients, yet may cause harm. These include side effects, pill burden, medication interactions and economic costs. Discontinuation of Potentially Inappropriate Medication (PIM) in response to changed life circumstances is referred to as deprescription.

Despite widespread intent to minimise PIM use, real-life practice of deprescribing medication is poorly enacted in primary care. Literature details that 45% of patients in the last months of life received prescriptions that were potentially inappropriate, and 25% used this medication on the day of death. This study explores the factors influencing deprescribing in primary care for patients with life limiting conditions and their health professionals.

Methods: Qualitative study with semi-structured interviews conducted between June and October 2022, with purposely selected patients and

health practitioners (HCPs; GPs, pharmacists, nurses) in Utrecht, The Netherlands. Inductive thematic analysis was employed for data analysis.

Results: 17 Interviews were performed, with three main themes emerging from the data:

Uncertainty; influenced by the poor reliability of predictions of life expectancy and lack of clear guidance regarding deprescription.

Lack of awareness; relative underexposure of risk of PIMs and overlooking of patients that could benefit from deprescription, especially within the chronically ill and elderly population.

Discontinuity of care; deprescribing is an ongoing and sensitive process facilitated by a trusted treatment relationship, personalised care and multidisciplinary collaboration.

Conclusions: This study identifies options to further facilitate deprescription in the last phase of life in primary care, like embedding deprescription in multidisciplinary routine care, supported by training on medication risks and guidelines customised for primary care that promote shared decision making. This study was funded by ZonMW.

FC 13.3 Promoting Advance Care Planning in Chinese Older Population Using a Gamification Approach: A Feasibility Trial

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Background/aims: Conversations on death and dying issues have generally been regarded as difficult across cultures. Gamification has emerged for introducing emotionally sensitive health topics to laypersons. Hence, we developed a board game about end-of-life care through systematic review and co-design with stakeholders and end-users. This study aims to examine the feasibility and acceptability of an advance care planning (ACP) board game among Chinese older adults.

Methods: A mixed method study, including a one group pre-test post-test study and focus group interviews, was conducted. Mentally competent adults aged 60 years or over were recruited through three community centres. They were invited to a one-hour game session in the centre. Wilcoxon signed test and qualitative content analysis were performed.

Results: Thirty community-dwelling older adults, with a mean age of 72.7 years (range 63 – 85), participated. At baseline, half of the participants have never planned for end-of-life care. They reported a significantly higher level of self-efficacy for sharing end-of-life care preference with surrogates at post-intervention ($p = 0.008$) but changes in the level of readiness for ACP was not significant. The participants generally appreciated that the game content triggered them to have life reflection and enabled them to learn more about end-of-life care. Besides, they found the game valuable for them to learn from peers. Many participants emphasized that the game facilitators influenced the overall game experience. They also suggested extending the session time to facilitate in-depth discussion and providing more follow-up support to facilitate family communication and documentation of care decisions.

Conclusions: This study is the first undertaking a gamification approach for promoting ACP in the Chinese communities. The findings showed that the game can be an educational tool to raise public awareness about end-of-life care and provided opportunities for sharing and peer learning in a relaxing atmosphere.

FC 13.4 Co-producing a Decision Aid Tool to Support Future Planning and End of Life Care Planning Discussions with Older Family Carers of People with Intellectual Disabilities

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Background/aims: The majority of people with intellectual disabilities (PwID) live at home with parents. There is limited research about supporting families as parents get older and worry about what will happen to their sons/daughters after they die.

Aims: (1) Understand the experiences and concerns of older PwID and their families about future planning; (2) Co-design and evaluate resources to support future planning and discussions about parents' end of life care

Methods: 1. Interviews with PwID (using inclusive methods such as storytelling), parents and siblings (N=36) analysed using Framework Analysis; 2. Experience-based co-design workshops with PwID and families; 3. Mixed methods evaluation exploring families' views and experiences of using the resources and their impact on planning for and anxiety about the future.

Interviews and co-design workshops were co-facilitated by researchers with and without ID.

Results: For parents, end-of-life planning meant ensuring their son/daughter would be happy and safe after they die. Some felt that there were no options outside of the family home where they would be adequately supported and valued. Those who wanted to make plans felt social services would only engage when there was a crisis, despite hoping to avoid such crises through future planning.

The co-design group developed Planning Ahead Cards to help families think and talk about the future. This included sections to aid plans for transitions in care and discussions about illness and dying. Preliminary results suggest the cards help families to think in detail about what is important, but some found the level of detail reduced accessibility.

Conclusions: Families need support to make plans and avoid crises following parental death. Involving PwID and families in designing resources to address these issues is vital to ensure they are useful and accessible. Planning Ahead Cards are a promising resource and will be adapted based on feedback from families before being made freely available.

FC 13.5 Memory Processes Are Needed to Promote Meaning in Life for Older Adults with Dementia: A Systematic Review and Narrative Synthesis

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Background/aims: Background: Meaning in life (MiL) can be understood as a need for value, purpose and self-worth that is shown to help people better tolerate pain, fatigue, and perceive higher quality of life, which may be particularly relevant in aging and advanced illness. Several interventions have showed to improve MiL as an outcome in older adults, yet little is known about how these interventions work. As part of a narrative synthesis of the literature on MiL interventions on older adults, we found memory processes were often leveraged to promote aspects of MiL. This encouraged a sub-analysis of the mechanisms underlying MiL for those with dementia.

Aim: To review and describe how psychotherapy interventions can promote MiL in older adults with dementia.

Methods: A search of keywords related to interventions to facilitate MiL in older adults was carried out in 4 databases: PubMed, CINAHL, PsycInfo, and Embase. Inclusion criteria were: original studies using interventions aimed at improving MiL for older adults, defined as age ≥ 60 years old. Narrative synthesis was used.

Results: After duplicates were removed, a total of 2,095 articles were reviewed for title and abstract. A final 49 full text articles met inclusion criteria of which 4 were carried out in people with dementia representing 208 patients. The interventions used different methods to promote reminiscence based on life review and mnemonic processing with an emphasis on recall of memories related to life satisfaction. All studies were longitudinal and applied group interventions among people with

mild dementia. Consistent improvements were seen for MiL when facilitating memories of positive events.

Conclusions: Episodic memory related to past experiences and social support from a group seem to be key elements to improve MiL in older adults with dementia, showing a key role of memory that restricts their applications to the early stages of dementia.

FC 13.6 Intranasal Dexmedetomidine for Pain Management in Older Patients: A Cross-over, Randomized, Double Blind, Active-controlled Trial

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Background/aims: Daily care procedures provoke breakthrough pain and anxiety in palliative situations. Dexmedetomidine may be an alternative to opioids during nursing procedures for older patients.

Our aim was to compare the efficacy of intranasal dexmedetomidine with subcutaneous opioids on the intensity of pain and anxiety during comfort management procedures.

Methods: Design: Randomized, active controlled, double blind, crossover trial (NCT03151863).

Setting/participants: Patients aged ≥ 65 years were randomized to receive, 45 minutes before nursing care, either intranasal dexmedetomidine together with subcutaneous placebo, or intranasal placebo together with subcutaneous opioid. Each of these two interventions were administered in a cross-over design and spaced out over a 24- or 48-hour time period. The primary outcome was the number of patients with an Elderly Caring Pain Assessment score >5 . Secondary outcomes included pain, sedation score, and vital signs.

Results: Due to difficult recruitment, the trial was interrupted after inclusion of 24 patients. Three patients withdrew after randomization, leaving 21 patients undergoing 42 complete sessions for descriptive analyses. Of the 21 patients, 12 (57.1%) were women, and their median age was 84, Inter Quartile Range (75 to 87). Nine (42.9%) patients presented an Elderly Caring Pain Assessment score >5 when receiving subcutaneous opioids, and 7 (33.3%) with intranasal dexmedetomidine. Hypoxemia occurred in a single patient receiving subcutaneous opioids. No episode of bradycardia was observed.

Conclusions: Intranasal dexmedetomidine is feasible in elderly patients and may be an alternative to opioids to ensure comfort during nursing care. Future studies are needed to confirm the efficacy and safety of this procedure.

FC 14 -B Palliative Care in non-CA Conditions

FC 14.1 Early Palliative Care among Older People with Non-malignant Chronic Conditions: A Randomized Controlled Trial

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Background/aims: Patients with non-malignant chronic conditions are used to being referred to palliative care services when their health status

is deteriorated and closer to their end-of-life than other patients, such as those with cancer.

The study aims to determine the effect of an early palliative care intervention (based on the implementation of a needs assessment tool, NATPD) on the health-related quality of life (HRQOL), functional status, symptomatology and psychological health of older patients with complex chronic conditions.

Methods: For that purpose, a multi-centre randomized controlled trial (RCT) is being performed in Valencia (Spain), Thessaloniki (Greece), Amadora (Portugal) and Inverness (UK). In total, 358 patients over 65 years old with complex chronic conditions (i.e., chronic obstructive pulmonary disease, frailty, or cardiovascular diseases) have been recruited. Participants have been randomly allocated to the intervention or to care as usual which are being evaluated throughout several time points: baseline, after 6 weeks, 6, 12 and 18 months of enrolment in the study. The main end-point is HRQOL measured through the EQ-5D-5L questionnaire, as well as other outcomes including symptomatology, functional status or emotional distress.

Results: The total sample mean age is 77.2 years and controlled are females (58.2%), married (43.2%) and have a primary school education (44.2%). Patients have been living with a chronic condition or multimorbidity for a mean of 8.9 years.

Compared with usual care, we expect NATPD intervention significantly improves HRQOL at an effect size of 0.20 assuming a 95% confidence interval. These results are in line with previous studies where early palliative care interventions have been implemented.

Conclusions: Despite the expected small effect size, this impact over HRQOL may be relevant for the patients with high symptomatology and limited prognosis.

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FC 14.2 Development of Criteria for Identifying Potentially Inappropriate Prescribing in Patients with Organ Failure Receiving Palliative Care (PIP-OF-PAL): A Delphi Consensus Exercise

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Background/aims: The presence of organ failure in patients referred to palliative care services contributes to unique therapeutic challenges. These include polypharmacy, altered physiological responses and pharmacokinetic states and the need for prescription of medicines for symptom control which are tailored to such altered pharmacokinetic states. Healthcare professionals who work with these patients may benefit from tools to optimise prescribing in these circumstances.

Aim: To develop and validate by Delphi consensus criteria for identifying potentially inappropriate prescribing in patients with organ failure receiving palliative care.

Methods: A Delphi consensus exercise was undertaken. The criteria were developed initially from a scoping review and refined by the Project Steering Group. 30 individuals with recognised expertise were invited to participate and asked to rate their level of agreement with each criterion using a 5-point Likert scale. For each statement, consensus was based on the median response and the interquartile range. Consensus (agreement) was achieved when $\geq 75\%$ of panel members agreed that a criterion should be included or excluded from the final list.

Results: 24 consultant physicians in palliative medicine participated in two Delphi rounds. 20 criteria reached consensus in Round 1. No criteria were outright rejected. 12 criteria were adapted following feedback from the consensus panel and review by the project steering group. In Round 2, nine further criteria which had been modified reached consensus. Three criteria failed to reach consensus. In total, consensus was reached for 29 prescribing criteria across four organ failure groups (respiratory; cardiac; renal and hepatic).

Conclusions: The PIP-OF-PAL criteria are the first validated criteria that focus on potentially inappropriate medications and potential prescribing omissions in patients with four organ failure types that may be receiving palliative care. Future work will assess the inter-rater reliability of the criteria's application.

FC 14.3 Associations between Social Deprivation and Palliative Care Needs Among Individuals with Cystic Fibrosis

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Background/aims: Cystic fibrosis (CF) is a genetic illness that affects >105,000 individuals and is characterized by high symptom burden and disruptions in social and functional roles. While prior research suggests that indicators of socioeconomic deprivation (e.g., education level, income) are associated with pulmonary function among people living with CF (PLwCF), little is known about how social determinants of health may influence palliative care (PC) needs. This study aimed to evaluate associations between social deprivation and PC needs among PLwCF.

Methods: We analyzed data from a multisite CF PC trial in North America using multivariable logistic regression. Social deprivation was evaluated at the individual level using patient-reported monthly finances, education level, and social support. PC needs were assessed using the integrated palliative outcome scale (IPOS). High PC needs were defined and dichotomized as the presence of at least 9 moderate or severe IPOS concerns. As a sensitivity analysis, we modeled PC needs as a continuous variable using negative binomial regression.

Results: Among 218 PLwCF, we found that the odds of reporting high PC needs were associated with not having enough monthly finances compared to just enough (AOR: 5.55, 95% CI: 1.45-21.09) and increased perception of treatment burden (AOR: 1.83, 95% CI: 1.31-2.56). Further, odds of endorsing high PC needs were associated with female sex (AOR: 2.25, 95% CI: 1.01-5.01) and not using modulator therapy (AOR: 2.81, 95% CI: 1.19-6.62). Forced expiratory volume was not associated with high PC needs (AOR: 1.01, 95% CI: .99-1.02). Results from our sensitivity analyses were consistent.

Conclusions: Further investigation is needed to understand potential mechanisms mediating the relationship between indicators of socioeconomic deprivation and palliative care needs. Qualitative interviews with PLwCF could help elucidate such connections and serve as an important step towards developing PC interventions in this and other genetic illness populations.

FC 14.4 Strengthening the Integration of Palliative Care in Care Homes through Implementation of a Person-centred Outcome Measure: A Multi-method Qualitative Study

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Background/aims: Covid-19 highlighted gross inequalities in experience and outcomes for older people in care homes and variable access to palliative care. Person-Centred Outcome Measures (PCOMs) may facilitate integrated palliative care but their use in care homes is limited.

To co-develop principles of integrated palliative care for care homes and evaluate implementation of a PCOM, the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) to support provision of palliative care in care homes.

Methods: Phase 1 informed by co-design methodology: online workshops with Patient and Public Involvement representatives and health and care professionals working in and with care homes.

Phase 2 qualitative study: focus groups with care home staff following implementation of IPOS-Dem in 2 care homes. Data were analysed thematically and integrated across phases.

Results: Phase 1: 4 online workshops comprising 20 participants identified 4 key principles for integrated palliative care:

- 1) Person-centred care and the resident's voice;
- 2) Relationships and communication;
- 3) Standardised, structured care processes;
- 4) Resources and training.

Phase 2: 14 care home staff participated in 2 focus groups. Use of IPOS-Dem by staff facilitated each principle through

- 1) early identification of holistic needs facilitating person-centred care;
- 2) structured information-sharing of complex needs to improve communication between family, junior and senior care staff, and health professionals;
- 3) Systematic assessment, monitoring and referral processes;
- 4) Ease of use to facilitate routine care processes (e.g handover).

Opportunities to strengthen implementation included integration of IPOS-Dem in digital records and a process to inform care plans.

Conclusions: IPOS-Dem implemented into routine care processes of care homes is a scalable and sustainable intervention to strengthen integration of person-centred palliative care involving residents, care staff and health professionals.

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FC 14.5 Exploring Intensive Care Unit (ICU) Consultations with a Focus on Treatment Limitations: A Critical Incident Analysis

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Background/aims: Frequently, the ICU is consulted when a (frail) patient critically deteriorates in a general ward. However, considering patient-tailored care, this potentially leads to the escalation of care disproportionately with the preferences of the patient, quality of life, and pre-existent functioning. Alternatively, other medical specialists, such as the palliative team, can be consulted to discuss less-invasive treatment options based on comfort.

Aim: To gain better insight into the underlying motives behind ICU consultations for patients with a focus on (prior) documented treatment limitations (such as do-not-resuscitate, do-not-intubate, comfort-only preferences) or for whom intensivists deem ICU treatment too invasive. Concomitantly, explore the potential role of an earlier involvement of the palliative team in these consultations.

Methods: A qualitative study using a critical incident technique and thematic analysis. In total 36 individual interviews were conducted, in the period between April-July 2022, with 18 ICU nurses and intensivists (in-training) consulted by general wards of a tertiary academic centre.

Results: The palliative team was involved in 6% at the time of consultation, 84% of the patients were estimated to have a life expectancy of fewer than 12 months, and 58% died within 2 months. The themes frequently discussed were awareness of the burdens of ICU treatment, establishing conformity about supervision, and timely communication about treatment limitations. Participants acknowledged the

underutilization of the palliative care team due to invisibility (outside office hours) but saw a potential role in the earlier consultation of this team.

Conclusions: Although intensivists are watchful for inordinate invasive care and share responsibility for counselling or discussing treatment limitations, earlier involvement of the palliative care team before ICU consultation can help in discussing alternative more patient-tailored treatment options instead.

FC 14.6 Palliative Care Needs of People Living with Dementia Following an Unplanned Hospital Admission in the UK: A Longitudinal Cohort Study

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Background/aims: People living with dementia (PLWD) experience unplanned hospital admissions in the last year of life. This may indicate unmet symptoms and concerns that could benefit from a palliative care approach. To describe the palliative care symptoms and concerns of PLWD following an unplanned hospital admission.

Methods: Longitudinal cohort study using validated measures (ie, Clinical Dementia Rating Scale (CDRS), Symptom Management at the End of Life in Dementia (SMEOLD)) of physical, psychological and behavioural symptoms and concerns of PLWD. Preferences at the end of life were recorded. PLWD and their family carers (as proxy respondents) were recruited during admission from four acute hospitals and assessed every two months for 12 months once PLWD was discharged.

Results: Preliminary analysis of baseline data on 74 PLWD is reported (5 PLWD and 69 proxy respondents completed assessments); recruitment is ongoing. PLWD were on average 85 years old, female (66%), White British (78%) and resided in their own home (49%) or in a care home (49%). CDRS scores indicated 75% of PLWD have moderate to severe memory impairment. Commonly reported symptoms affecting the PLWD were agitation (44%), pain (45%), lack energy (79%) and poor mobility (81%). Average SMEOLD scores were 22.8 (SD=8.2) indicating poor symptom control. While 79% of PLWD had a do not resuscitate order (DNAR), only 11% had a record of their preferred place of care/death and 6% had an advance decision to refuse treatment.

Conclusions: The findings indicate this is an older patient group living with marked cognitive impairment from dementia and symptoms and concerns causing distress. Although indications of nearness of end of life with unplanned hospitalisation, advanced age and dementia, advance care planning was limited to DNARs with minimal recording of preferences for the person at the end of life. These findings validate the urgent need to implement a palliative care approach, particularly after an acute event such as an unplanned hospitalisation.

FC 15 - H Psychosocial and Cultural Challenges

FC 15.1 The Desire to Die in Patients with Life-limiting Conditions.

Overview of Systematic Reviews

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Background/aims: Suffering can arise from a multitude of sources when living with life-limiting illnesses and is often expressed as a desire to die. An extensive systematic review of the desire to die with people with end-stage disease was published by our team in 2011. More than ten

years later, other systematic reviews (SR) have been carried out that have expanded our knowledge on the conceptual definition, etiology, and assessment of the desire to die. The aim of this review was to synthesize, appraise and update the systematic review evidence of the desire to die in people with life-limiting conditions.

Methods: We performed an overview of systematic reviews (SR) and updated SR of primary studies. Literature searches were carried out in four databases (PubMed, CINAHL, Scopus, Web of Science) restricted to systematic reviews since 2011 followed by a search for original articles from the date of the most recent systematic review. SR and original articles from using quantitative and qualitative methods were included and integrated using methodology outlined by Whittemore and Knafelz (2005). We defined a priori a synthesis of definitions, the lived experience, assessments, and frequency of the desire to die.

Results: A total of 12 systematic reviews since 2011 and 33 primary studies dated from 2017 were included. Definitions and the lived experience converged on multifactorial reasons, meanings, and functions for people that can vary in intensity at distinct moments. Frequency remains variable depending on the wording used by assessments that have been developed.

Conclusions: The desire to die is a complex phenomenon, fluctuating over time that requires a holistic approach and deeper exploration. This overview and update underscores the need to identify clinical strategies to address this phenomenon.

FC 15.2 An Initial Programme Theory for Social Support Interventions in Palliative Care

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Background/aims: Social isolation and loneliness in palliative care can contribute to low mood, pain, and suffering towards the end of life. Hospices in the UK provide a range of day and outpatient services that facilitate social support for patients and caregivers. These interventions aim to reduce unmet social need and improve wellbeing and quality of life; but there is limited understanding of the contexts and mechanisms that lead to outcomes.

We aimed to develop evidence-based explanations of how social support interventions can improve outcomes in palliative care, for whom, and in what circumstances.

Methods: Informed by realist evaluation, qualitative data collection took place in nine independent hospices in England. These were interviews with hospice service-providers (n=19) and researcher observations of day services (n=12). Sampling of research locations was informed by an online survey¹. Analysis via context-mechanism-outcome configurations led to the development of an initial programme theory.

Results: Palliative care patients and their caregivers experience loneliness and social isolation due to the losses associated with illness, changing support needs, and contextual constraints on emotional communication. Coming together with others 'in the same boat' encourages honesty, reciprocity, and gains in confidence. The holistic safety of the hospice environment thus enables acceptance and adaptation to change.

Conclusions: In some contexts, social support can improve ability to cope with illness and prepare for dying. This could improve quality of life for patients and alleviate burden on caregivers. Ongoing research explores increasing complexity in patient need, and variation in practice since the Covid-19 pandemic.

- Bradley, N. et. al. (2022). A survey of hospice day services in the United Kingdom & Republic of Ireland: how did hospices offer social support to palliative care patients, pre-pandemic? *BMC Palliat Care* 21, 170. doi: 10.1186/s12904-022-01061-9

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FC 15.3 Vigil Volunteers in Palliative Care - Opportunities and Challenges

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Background/aims: In Denmark professional caregivers cooperate with formal organized vigil volunteers in palliative care to citizens who are imminent dying. The volunteer sit with the dying when no one else is there and offer relief to the next of kin. It is imperative to be aware of experiences drawn from existing cooperation practice if sustainable volunteer-professional caregiver-cooperation is to be maintained and developed in future palliative care. This study aims to investigate challenges and/or opportunities associated with vigil volunteers in homecare and nursing homes.

Methods: Data was collected through participant observations and interviews. The study is a part of a Ph.D. completed in August 2022. Two formal organized vigil volunteer groups provided access to observations of vigil watching and access to their formal group meetings. Three nursing homes in two municipalities gave consent to participation. A phenomenological sociological everyday life approach was used, and thematic analysis structured the analytical process. Concepts rooted in Symbolic Interactionism interpreted the empirical data.

Results: The study was based on 65 hours of participant observations and 13 interviews (8 individual and 5 group-interviews) with a total of 27 informants (13 volunteers and 14 professional caregivers). Analysis revealed five overall themes: 1) Time to stay 2) Relief that matters 3) Boundaries yes- but not without exceptions 4) Institutional traditions -barriers for dialogue 5) Knowledge and competencies.

Conclusions: The study concludes that time Vigil volunteers have to sit at the dying's bedside and offer relief to the next-of-kin relief contrasts the time professionals can offer these care-tasks. Boundaries are marked and maintained by both parties but also overstepped and stretched based on situation-specific care. The study points to the importance of challenging existing institutional cooperation-traditions to strengthen dialogue and mutual knowledge between volunteers and professional caregivers.

FC 15.4 Changes in Social Connection over the Last Years of Life and their Relationship with End-of-Life Outcomes. A Longitudinal Survey Study in 14 European Countries

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Background/aims: Social connection is among the strongest determinants of health, but its role in well-being at the end of life is poorly understood. Using an established conceptual model, we examined changes in the *structure* (e.g. size, marital status), *function* (receiving care/help), and *quality* components (e.g. emotional closeness, loneliness) of social connection in people's last years of life, and to which extent they predict end-of-life outcomes (symptoms, healthcare use, place of death).

Methods: Longitudinal survey data of SHARE, the largest pan-European cohort study of people aged ≥ 50 . We included participants of waves 4 and 6 (approx. 4 years apart; when 'social networks' were assessed), who have since died and for whom a proxy provided an interview on the last year of life (1-2 years after wave 6). We conducted generalized linear mixed model analyses.

Results: We studied 1451 individuals (2902 assessments) in 14 European countries (47% female, mean age at death 80, standard deviation 9.6). Towards death, social network size ($p=0.023$) and geographic proximity

($p=0.013$), likelihood of receiving care from others ($p<0.001$), emotional closeness to social network members ($p<0.001$), loneliness ($p<0.001$), and likelihood of not being partnered increased ($p<0.001$). We found no significant changes in contact frequency ($p=0.272$) and satisfaction with social network ($p=0.054$). Structure components of social networks (i.e. size, proximity, contact, marital status) predicted healthcare use and place of death; while function (i.e. social support) and quality components (i.e. loneliness) predicted symptoms.

Conclusions: While some aspects of social connection deteriorate towards the end of life, several stagnate or improve, countering prevalent ideas of generally declining social trajectories. We demonstrate a need for conceptual clarity regarding the social domain, distinguishing the components constituting social connection and their distinct roles for end-of-life outcomes.

Funding: Research Foundation-Flanders

FC 15.5 Dignity in Palliative Care from the Patients' and Family Caregivers' Perspective in Lebanon

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Background/aims: Preserving patient dignity is an overarching tenet in palliative care. Though patient dignity and its multiple facets have been studied in Western societies, as evidenced by dignity assessment tools and dignity conserving interventions, it is minimally assessed in the Middle Eastern context. This study aims to explore the interpretations of the concept of dignity in palliative care from the patients' and family caregivers' perspectives within the Lebanese setting.

Methods: A qualitative interview study with fourteen patients with palliative needs and fifteen family caregivers to understand how dignity is interpreted and preserved in illness. The data were analysed inductively using reflexive thematic analysis. The findings from the two groups of participants were compared against each other and with the Chochinov Model of Dignity.

Results: Patients' and family caregivers' interviews revealed four common themes about maintaining dignity: a) The importance of faith b) Preserving physical, social, and mental wellbeing c) The central role of family d) Compassionate and equitable health care. When comparing the findings to the Chochinov Model of Dignity, *preserving self-image, equitable and affordable health care* were two new subthemes that surfaced as necessary for safeguarding dignity during illness. Faith and family support emerged as key themes anchoring patient dignity. On the other hand, *Autonomy*, a subtheme mentioned in the Chochinov Model, appeared to be of less importance in this participant group.

Conclusions: In contrast to Western countries, faith and family ties in Lebanon are central in understanding and preserving dignity for patients with palliative needs. This study demonstrates the nuanced meaning of dignity and how cultural values, and the overall context shape patients' and family caregivers' needs and interpretations of dignity. The findings may have useful implications for policy, clinical practice, community initiatives, and education.

FC 15.6 How Compassionate Is your Neighbourhood? A Cross-sectional Survey Study Measuring Neighbourhood Participation Regarding Serious Illness, Death and Loss

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Background/aims: Civic engagement around serious illness, death and loss is an indispensable part of Compassionate Communities. Previous studies have measured the degree of community participation around illness, death and loss in palliative care services, but not yet in neighbourhoods. We aim to gain insight in the degree of neighbourhood participation around serious illness, death and loss (e.g. volunteering, community groups and caring for neighbours), and to measure the association between this neighbourhood participation and perceived neighbourhood social cohesion.

Methods: We conducted a cross-sectional survey in two neighbourhoods in Flanders, Belgium. We distributed the survey to a random sample of 2324 adult inhabitants. Results were analysed via a hierarchical, ordinal regression.

Results: A total of 714 respondents in the two neighbourhoods completed the survey (31% response rate). The majority reported experiences with serious illness, death or loss in the last year (e.g. 60% lost someone they knew very well). Neighbourhood participation around serious illness, death or loss was performed by 46% of the respondents, primarily via volunteering (10%) and by helping close neighbours (33%). Social cohesion was measured via attraction to living in the neighbourhood, psychological sense of community and interactions with neighbours. We found a significant association between this perceived social cohesion ($\beta=0,039$; $OR=1,040$; $CI=1,025-1,054$) and neighbourhood participation in illness, death and loss, which only slightly decreased when adding generic neighbourhood participation to the analysis.

Conclusions: Our results suggest that when developing neighbourhood participation around serious illness, death and loss, we should focus on activities that strengthen neighbourhood social cohesion, rather than stimulating generic neighbourhood participation. Future research should measure which aspects of social cohesion are particularly correlated with neighbourhood participation around illness, death and loss.

1.2.7 Pediatric Palliative Care Day

PPC 1 - Witness to Suffering: the Clinician Experience

PPC 1 - 2 Learning to Respond to Suffering

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Background/aims: Suffering is embedded in all our lives and manifests in different ways as we continually find ourselves getting what we don't want, not getting what we do want, and facing the impermanence of everything including our bodies and minds that will fade and die no matter what we do. Caring for children who will likely die before reaching adulthood means that in addition to having to cope with the suffering embedded in everyone's lives, the pediatric palliative care clinician must also cope with the many work-related losses that are part of daily work. Additional challenges are adapting to the understandable human limitations of parents as they face their worst fear. Learning how to respond to such suffering, in ways that can bring rich meaning and value to our own lives as caregivers, is possible in different ways. A common thread in approaches to healthfully adapting to multiple losses in a pediatric palliative care career is the capacity to bring a specific type of "mindful" awareness, that is non-judgemental and curious, together with a self-awareness that is de-identified from the concept of self. The learnable ability to bring a specific type of self-awareness to the work of pediatric palliative care clinician will be outlined.

Methods: -

Results: -

Conclusions: -

PPC 1 - 3 "Look Long and Hard:" The Impact of a Child's Death on the Clinician

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Background/aims: The death of a child is the endpoint of an illness continuum that extends from the child who is seriously ill, to a child who is living under the threat of death, to a child who is dying. Thus, consideration of the impact of a child's death on the individual clinician, as well as on the team, encompasses this spectrum in all its complexity. A core challenge, both personal and professional, is to learn how to preserve oneself while at the same time sustaining the ability to be effective and empathic. A framework within which clinicians can make sense of their experience of a child's illness and death, with the goal of enhancing their coping, will be offered. The underlying theme is that the impact of a child's death on an individual is affected by many intertwined factors: situational (e.g., nature of death), deeply personal (e.g., loss history), relational (quality of the relationship with the child and family) and systemic / sociocultural.

Methods: AS ABOVE

Results: AS ABOVE

Conclusions: AS ABOVE

PPC 2 - The challenges of Living with and Dying from a life-limiting illness - The children's, Parents' and Professionals' experiences

PPC 2.1 'My Life Is a Mess but I Cope': An Analysis of the Language Children with Life-limiting and Life Threatening Illnesses Use to Describe their Own Condition

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Background/aims: Children with life-limiting and life-threatening conditions are rarely involved in research. Engaging them directly enables them to express the meaning of their condition in their own words. This study aimed to explore the language children use to describe their condition and its impact on their life, to inform strategies for engaging children about their priorities.

Methods: Semi-structured, qualitative interviews with purposively sampled children with life-limiting and life-threatening conditions. Data were analysed using thematic analysis, discourse analysis and the discourse dynamics approach to identify figurative language.

Results: *Participants:* 26 children (6 cancer; 20 non-cancer) aged 5-17. *Findings:* Children as young as five provided rich descriptions of their condition, including: diverse negative emotions often contextualised by what they 'can't do' ('can't do anything', 'can't go anywhere'), and comparisons to healthy ('normal', 'usual') peers, with their condition singling them out ('the one that has something', 'the sick one'). Others expressed ambivalence ('doesn't bother me', 'not really fussed') or acceptance using idiomatic phrases ('I can live with that', 'you're still you, you haven't gone anywhere'). Metaphor were common, including familiar journey and battle metaphors, and novel usages related to zombies, gaming, superheroes, toys and animals. Children used medical jargon related to their condition, combined with preferred words for their body ('tummy', 'belly', 'butt') and had capacity to create comparatives and superlatives to describe symptom severity (no hurt, hurt a bit, a whole lot, like crazy, really hurt, worse, better).

Conclusions: Children make deliberate language choices when describing their condition, and can express holistic needs, and changes in health status. Clinicians should observe and mirror children's language to enhance discussions about priorities. This study was funded by European Research Council's Horizon 2020 programme [Grant ID:772635].

PPC 2.2 Spiritual Concerns of Children with Life-limiting and Life-threatening Conditions and their Families

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Background/aims: Background: Despite being a core domain of palliative care, primary data on spiritual and existential concerns has rarely been collected among children with life-limiting and life-threatening conditions (LLTTC) and their families. Existing evidence has tended to focus on the religious aspects among children with cancer.

Aim: To identify the spiritual needs of children with LLTTC.

Methods: Cross-sectional semi-structured, qualitative interview study with purposively sampled children (aged 5-17) with LLTTC, their families, and clinicians recruited from six hospitals and three children's hospices in the UK. Commissioners of paediatric palliative care services were also recruited through networks. Verbatim transcripts were analysed using Framework analysis.

Results: 106 participants: 26 children (5-17 years), 53 family members (40 parents/carers of children 0-17 years and 13 siblings (5-17 years)), 15 health and social care professionals and 12 commissioners of paediatric palliative care. Themes included: living life to the fullest, meaning of life and leaving a legacy, uncertainty about the future, determination to survive, accepting or fighting the future, and role of religion. Children as young as five years old identified needs or concerns in the spiritual domain of care beyond religious needs to existential and value-based spiritual concerns.

Conclusions: Addressing spiritual concerns is essential to providing child- and family-centred palliative care. Eliciting spiritual concerns may enable health and social care professionals to identify the things that can support and enhance a meaningful life and legacy for children and their families. Developing and utilising simple tools which include all aspects of the spiritual domain- from religious needs to existential and value based concerns may make a difference in delivering on this area of paediatric palliative care.

Funding: European Research Council's Horizon 2020 programme [Grant ID772635]

PPC 2.3 Living with Childhood Cancer and Upholding a Healthy Couple Relationship – Findings from the Family Talk Intervention

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Background/aims: Supporting the maintenance of a healthy couple relationship while living with childhood cancer has the potential to result in significant physical and psychological health benefits for the child but also for the parents. However, very few studies have focused on the relationship between parents during the child's illness period. Hence, the aim of this study was to explore the couple relationship among parents living with a dependent child with cancer and whether a family intervention could provide support to the couple relationship.

Methods: The study was based on interviews with 26 dyads of parents who had taken part in the Family Talk Intervention (FTI). It is a manual-based family intervention with the goal to facilitate family communication

about illness-related topics (e.g. prognosis), support parenting, and make the children's voice visible. Interviews were analyzed with focus on the couple relationship using conventional content analysis.

Results: The parents expressed that their couple relationship was subjected to trials while also having a child with severe cancer illness. Parents found it difficult to make their relationship a priority during the demanding situation and expressed disagreements on how they should stay connected and communicate with each other. Gendered differences were observed, where men and women had different ways to manage the couple relationship. Participating in the FTI was regarded positive and supportive as the parents had been given time to talk to each other and reflect on their couple relationship during the intervention process. In some cases, FTI had also guided the couple to seek further support regarding their relationship.

Conclusions: There were disagreements between parents regarding how to manage the couple relationship while having a severely ill child. Even if FTI was supportive, a future couple intervention should be developed with a special focus on the parents' relationship.

PPC 2.4 In-depth Investigation into the Lived Experiences of Palestinian Mothers Caring for More than One Child with Palliative Care Needs: A Qualitative Study in the Occupied Palestinian Territory

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Background/aims: Qualitative research into the experiences of mothers who have one or more children with palliative care needs is highly needed on a global level. In the occupied Palestinian territory (OPT), which has political complexity and limited resources, there is a critical need to comprehend the circumstances regarding the care of children with life-limiting and life-threatening illnesses.

The purpose of this study is to understand the experiences of mothers caring for more than one child with palliative care needs.

Methods: This study adopted a qualitative descriptive method to gather data from several paediatric units in two OPT cities, Tulkarm and Ramallah. Individual, semi-structured, face-to-face and telephone interviews were conducted with 21 mothers caring for more than one child with palliative care needs. The data collected were analysed using a thematic analysis strategy.

Results: The data obtained from the interviews were organised and contextualised into seven major themes that reflected the prevailing experiences of mothers:

- (1) the significant life changes following children illness,
- (2) show the experience of caring for a second child with palliative care needs differed from the first,
- (3) how mothers attempted to appear strong and conceal their pain and weaknesses so they could face their suffering,
- (4) lack of support,
- (5) economic difficulties,
- (6) stigma and
- (7) social isolation.

Despite the lack of support, the mothers reported seeking support through interactions with other mothers in similar situations, communications with healthcare personnel, religion and familial support.

Conclusions: There is a significant need for emotional and physical support for mothers and the implementation of cultural-based social services to alleviate the extensive health consequences on mothers caring for more than one child with palliative care needs.

PPC 2.5 Navigating the 'Two-truths': A Qualitative Study of How Paediatricians Approach End-of-Life Decision-making for Children with Life-limiting Conditions

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Background/aims: Shared decision-making is routinely recommended as the ideal decision-making approach for children with life-limiting conditions. For decisions with grave consequences, such as end-of-life decisions, paediatricians often direct decision-making. However, how paediatricians undertake decision-making and their expectations of parents in this process remains unclear. This study aims to describe how paediatricians undertake the process of end-of-life decision-making for a child with a life-limiting condition.

Methods: This qualitative phenomenological study involved 25 purposively sampled paediatricians. Verbatim transcripts from individual semi-structured interviews, conducted between May 2019 and June 2020, underwent thematic analysis. Interviews were based around a case vignette matched to clinical experience of each paediatrician.

Results: A process of physician-led end-of-life decision-making was described. Paediatricians first contemplate that the child's death is approaching, then prepare themselves by ensuring there are no reversible factors at play. They then inform parents of this view and, if needed, hold discordant views between parents and themselves about the child's death in a 'fruitful tension'. Ultimately, they seek to bring parents' view of child in line with theirs to facilitate goal alignment.

Conclusions: Paediatricians feel responsible for facilitating alignment of parental understanding of the child's health status with their own. This is achieved either through direction or by holding differences between parental and paediatricians' truths about the child's health in tension to provide time, space, and clarity. This alignment was seen as key to enabling end-of-life treatment decisions, without which conflict in end-of-life decision-making can arise or persist.

PPC 2.6 Parent to Parent – Bereaved Parents' Experience in the Development of Parent Focused Paediatric Palliative Care (PPC) Podcasts

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Background/aims: Families caring for a child with a life limiting condition face complex challenges. Parents live with unimaginable and often unspeakable distress and devastation, while preparing for loss and grief. Parents known to specialist PPC services report a strong need for compassionate support and guidance. Parents often seek support and guidance from other parents.

Development of parent focused podcasts aimed to share insights, experiences and advice to support others caring for a child with palliative care needs, who is likely to die from a life limiting diagnosis.

The perspectives and impact on bereaved parents' who participated in developing a series of parent to parent podcasts, as a resource to support others, was investigated and analysed.

Methods: Parents known to a specialist PPC service were invited to participate in recording a podcast series.

Parent feedback informed topics to explore. Each episode was parent focused and parent driven.

In total eleven PPC podcast episodes were produced.

Evaluation progressed via semi structured, in depth interviews with parent participants at key stages of the podcast development.

Responses were analysed using descriptive content analysis.

Formal evaluation identified benefits and challenges.

Results: Bereaved parents' reported a strong desire to assist other parents in opportunities to improve services and supports for children who are likely to have a short life.

Twenty-one bereaved parents and one adult sibling participated. Bereaved parents' felt empowered to speak of their experiences openly, identified a strong bond, a sense of community and spoke of sharing a 'sacred space' with other parent participants.

Key challenges and areas for improvement were identified and changes implemented throughout.

Conclusions: Parent focused podcasts are authentic, raw stories. Bereaved parents' participation in development of parent to parent podcasts was viewed as a positive, valued experience. A 'gift' to future families that will ensure ongoing learning in PPC.

PPC 3 - Supporting Displaced Children with Palliative Care Needs and Their Families

PPC 3 - 1 An Exploration of the Experiences of Children's Palliative Care for Forced Migrant Families and Those who Care for Them

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Background/aims: Children with palliative care needs have multifaceted conditions. Often such conditions result in complexity and unpredictable journeys for families laced with long-term grief, stress, relentless care giving and unmet needs. There is frequently a mismatch between the services offered to parents and standards of care.

This study focuses specifically on families who have been forced to leave family, belongings, and all sources of support which often leaves them feeling displaced and powerless. For health care professionals (HCPs) the diversity and differences in cultural, and spiritual need encountered may be bewildering and confusing. This study aims to highlight forced migrant families plight, raise awareness of their unique needs and offer recommendations for future research and clinical guidelines.

Methods: The study design for this research utilises Interpretative Phenomenological Analysis (IPA) to both privilege participant perspectives and use an active in-depth cyclical process of reflection and reflexivity within data analysis to reveal rich personal accounts. This approach enabled multiple perspectives of children's palliative care to be considered, whilst keeping families at the core of the study and preserving the individual contexts of the families involved. Alongside IPA creative research methodology using 'draw and talk' and poetic interpretations were utilised to enhance participant expression and gain further invaluable insights from the many advisory groups involved in this study.

Results: Within this study, 14 participants contributed to 12 interviews including two family interviews with one family. Many aspects raised by families related to the need for compassionate, holistic, family centred care which considers individual belief systems alongside experiences of trauma. Families expressed the need for HCPs to be emphatic and understand the implications of judgements, labelling, discrimination and hostility they faced. HCPs discussed lack of access to services, protocol led care, limited time to build relationships with families, communication barriers and HCP burnout which were hindering to the care provided.

Conclusions: Further education is needed to support HCPs. The use of a cultural humility model may be helpful in improving self-awareness and offering a more open-minded lens to care. Creative approaches used in this study were helpful in understanding complex issues such as truth-telling and hope, as well as a mechanism for meaningful advisory group input.

PPC 3 - 3 Exploring the Palliative Care Needs of Children in Refugee Settlements in Uganda

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Background/aims: Palliative care for children should be provided wherever the child is who needs care, whether that be at home, at school, in a clinic, in a hospital, in a hospice, as well as including in humanitarian settings. It should be provided by all health providers and not just by palliative care specialists. Since 2016 the importance of palliative care within humanitarian crises settings has been recognised, with palliative care being included in the SPHERE handbook in 2018 and the ongoing development of guidelines for paediatric palliative care in organisations such as Medicines San Frontieres (MSF) and the publication of a handbook by the World Health Organization. However, there has been minimal data with regards to the need for palliative care provision in humanitarian settings. Work in several countries is ongoing to understand the needs of people - both adults and children, living with chronic diseases amongst refugee communities. In Uganda there are approximately 1.45 million refugees, 59% of whom are children. This paper will report on some of the work being undertaken in Uganda to explore the palliative care needs of children in refugee settlements.

Methods: Mixed methods study in refugee populations including rapid participatory appraisal, training and mentorship and needs assessment undertaken between 2018 and 2022, in host and refugee populations in Obongi and Adjumani Districts, Northern Uganda. Tools used include the children's palliative outcome scale, the distress thermometer and ECOG. Ethical approval was gained from UNCST and children with unmet clinical needs were signposted for support.

Results: The results of several studies undertaken in Northern Uganda will be reported on. Initial data suggests high levels of need for children's palliative care, with significant unmet PC need and high levels of distress amongst children and their families. Data analysis is ongoing and initial results will be shared in this presentation.

Conclusions: It is essential that we address the palliative care needs of children living in humanitarian settings. Yet little is known of the magnitude of the need for children's palliative care in such settings, nor the burden of unmet need. Studies such as this one will contribute to the evidence base for providing palliative care for children in humanitarian settings beyond that of anecdotal accounts and contribute towards recommendations for the provision of children's palliative care in humanitarian settings.

PPC 4 - Programs, Tools and Frameworks of Care in Pediatric Palliative Care

PPC 4.1 Feasibility, Acceptability and Potential Effects on Parents of a Modular Pediatric ACP Program (MAPPS)

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Background/aims: Previous research indicated that ACP is perceived as helpful by families and professionals in pediatric palliative care. Validated models for pediatric ACP were lacking. After developing a Modular Pediatric Advance Care Planning Program (MAPPS) in a participatory approach, we piloted the MAPPS intervention during a 24 months

period. We aimed at testing the feasibility, acceptability and potential effects of MAPPS on parents.

Methods: We evaluated the program using a qualitative and quantitative approach. Qualitative methods included participant observation of discussions and interviews with families. Quantitative evaluation comprised the use of questionnaires including the Decisional Conflict Scale (DCS) and the Hopkins-Symptom-Checklist-25 (HSCL-25) before the first session (baseline) and directly after the last session for each case. Qualitative data were analyzed by means of conversation analysis (observation) and content analysis (interview). Quantitative data were analyzed using Mixed Models and Wilcoxon Test.

Results: 42 families were included in the study. All respondents participated in the quantitative evaluation. Observation of discussions and interviews were carried out in 20 cases. The DCS data showed a significant increase of decisional confidence of parents after participating in MAPPS. Results of HSCL-25 showed that MAPPS did not increase the levels of depression and anxiety of parents. Qualitative analysis revealed high acceptance and satisfaction with MAPPS. Parents appreciated the modular approach and the possibility of including values and wishes in advance directives. Focusing on the child's resources and quality of life and reviewing possible future emergency scenarios were perceived as helpful.

Conclusions: The pilot phase confirms a good feasibility and high acceptance of the MAPPS program by families, as well as a positive influence on the decision-making confidence of affected parents.

PPC 4.2 Development of a Screening Tool to Assess and Quantitate the Interdisciplinary Care Needs of Pediatric, Adolescent & Young Adult Cancer Patients in an Academic Cancer Center

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Background/aims: Early integration of collaborative interdisciplinary palliative care (IPC) has been shown to improve quality of life, symptom-related distress and psychosocial stress for pediatric, adolescent and young adult (PAYA) cancer patients and their families. Each member of the interdisciplinary pediatric team (IPT) equally contributes to the total care of the PAYA. Resources are limited and no standardized method has been made available to trigger 1) timely palliative care (PC) consultation or 2) intensification of already-involved IPT interventions. As a Quality Improvement (QI) project, a novel screening assessment, the COMPAASS (COMprehensive care program for Pediatric, Adolescent, and young Adult Supportive care Screening tool), was created by our IPT to quantitate PC needs for PAYA.

Methods: COMPAASS has 10-equally weighted, interdisciplinary (pediatrics, palliative care, psychology, social work, child life, nursing, rehabilitation, case management, spiritual care, cultural) domains (0-3 points/domain with max score 30) to quantitate the severity of the global needs of PAYA inpatients in an academic pediatric oncology unit. Criteria were based on IPT expertise and literature review. Inpatient scores were assessed over a 30 day period. Daily scores were used to evaluate the trajectory of clinical status throughout the hospitalization.

Results: 24 PAYA oncology/hematopoietic transplant patients were evaluated (M:F 1:1); ages 0-30 years; Black 1, Asian 3, Caucasian 3, Hispanic 15, Mixed 2. Patient scores (mean 11.6 +/- 6.26, mode 7, median 10.5)). Daily means ranged 9 - 13 with intrateam scoring concordance.

Conclusions: Serial assessment throughout hospitalization was useful to quantitate global IPC needs for stable, progressively ill, and moribund patients. Scores may identify those PAVA patients needing both earlier PC consultation and also intensified IPT care. In future, we will continue to integrate COMPAASS scoring for inpatient oncology care and will expand use into the outpatient setting.

PPC 4.3 Facing Healthcare Threats: The Digitalization Process to Transform a Chronic Complex and Pediatric Palliative Care Service into a Hybrid Service

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Background/aims: The number of children cared by paediatric palliative care (PC) teams has grown due to the technification of care and the consequent increase in survival. Recent years demonstrated that healthcare management is undergoing a paradigm change, facing challenges in costs, workforce, and care delivery like never seen before. Information and communication technologies will play an important role to deal with this problem. In this setting, the chronic complex and paediatric palliative service (CCPPS) of a paediatric hospital has started a digitalization process to become a hybrid service (face-to-face + digital assistance).

Methods: The digitalization process is carried out through 2 research projects:

- AICCELERATE, a European Research project that aims to demonstrate the scalability of Artificial Intelligence (AI) to different healthcare uses. A social robot has been created to help parents to take care of their children with severe neurologic impairment at home. It collects information about child symptoms and provides health literacy to the parents. Using information provided by the robot and extracted from the electronic health record, AI algorithms will predict the risk of health deterioration of each child.

- Integration of remote monitoring devices in a videoconference station that will be placed at child's home. It will allow virtual visits from the CCPPS with the required frequency when the child is exacerbated.

Results: The social robot has been tested in the simulation laboratory and is going to face the pilot phase with families. The recruitment of the first families to test videoconference station has started.

Conclusions: Paediatric PC, despite having a minority target population, can be the promoter of technology development to cover unmet needs of this population. This development will contribute to the necessary change in healthcare system in the next years. Because of the specificities of PC, is important to preserve face-to-face assistance but it can be empowered with digital attention.

PPC 4.4 Treatment of Refractory Symptoms and Forgoing Hydration and Nutrition in Children at the End of Life

K.C. van Teunenbroek¹, R.L. Mulder¹, A.Y.N. Schouten¹, B. Borggreve², H. Rippen³, J.M.A. Verheijden³, L.C.M. Kremer^{1,5,6}, A.A.E. Verhagen⁷, E.M.C. Michiels¹, on behalf of the guideline working group refractory symptoms

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Hospital, Utrecht, Netherlands, ⁷Beatrix Children's Hospital, University Medical Centre Groningen, University of Groningen, Department of Paediatrics, Groningen, Netherlands

Background/aims: Children with life-threatening diseases often experience distressing symptoms. Sometimes, new symptoms arise close to the end of life or symptom progression may be such that symptoms do not respond to interventions. These symptoms have become refractory symptoms. There is an urgent need for guidance on refractory symptom treatment (palliative sedation) and in line with that, forgoing hydration and nutrition. In the Netherlands, no evidence-based guidelines on these topics exist.

As part of the revision of the Dutch guideline for paediatric palliative care, we aimed to develop recommendations to provide guidance on palliative sedation and forgoing hydration and nutrition.

Methods: A multidisciplinary guideline panel reviewed current literature on palliative sedation and forgoing hydration and nutrition in children at the end of life by conducting a systematic literature search. The GRADE methodology was used to grade the evidence. Recommendations were based on evidence (if available), clinical expertise and patient values.

Results: No eligible studies on palliative sedation and forgoing hydration and nutrition were identified. Recommendations were based upon international guidelines, clinical expertise and patient values. We formulated a total of 26 recommendations on the process of providing palliative sedation and forgoing hydration and nutrition. This included recommendations on communication, preparation, execution and evaluation.

Conclusions: We identified large knowledge gaps for palliative sedation and forgoing hydration and nutrition. This opens opportunities to address these topics in future international research. Despite these knowledge gaps, we provide the first recommendations on the process of palliative sedation and forgoing hydration and nutrition in the Netherlands. With these, we hope to support children, parents and health care providers during these difficult processes and improve quality of life for children at the end of life.

PPC 4.5 Palliative Care Framework for Management of Foetuses and Neonates Acrania and Anencephaly

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Background/aims: Acrania is the partial or complete absence of the flat bones of the cranial vault with complete but abnormal development of the cerebral hemispheres. The term is often used interchangeably with anencephaly, although in anencephaly the cerebral hemispheres are absent. Both are life-limiting conditions, with anticipated survival of hours to weeks.

Aim: To develop a framework for the management of foetuses and neonates with acrania and anencephaly.

Methods: A retrospective review of all referrals with acrania or anencephaly to a tertiary palliative care service over a 10 year period (2012-2022). We reviewed the characteristic of referrals; age at death; liaison with the neurosurgical service; and use of symptom management plans.

Results: 7 patients with acrania and 5 with anencephaly were referred to the service, 5 antenatally and 7 postnatally. 8 were discussed with the neurosurgical team.

All patients referred had a symptom management plan, but only 3 required symptom management medications.

Survival varied from a few hours to 14 days.

Conclusions: Based on a review of our clinical experience, we recommend the following for all foetuses/neonates with acrania or anencephaly:

1. Antenatal referral to neurosurgery and palliative care, ideally in a joint consultation with the antenatal/neonatal team

2. Neurosurgical team should advise on the potential for surgical intervention and management of skull lesion, including head dressings
3. There must be a clear birth plan, including resuscitation and symptom management
4. Consideration should be given to the use of prophylactic enteral antibiotics to minimise infection risk and also to the management of any acute infections
5. Place of care, in the first few hours and in the first few weeks, should be planned antenatally
6. All families should have access to bereavement support from diagnosis

PPC 4.6 Developing a Neonatal Referral Pathway to a Specialist Hospice-based Team

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Background/aims: Figures from 2016-2020 reveal that in our hospice's geographical catchment area, there were 1,921 perinatal and 767 neonatal deaths; however, the hospice, where a specialist paediatric palliative care team is based, received only 81 referrals during that time. To better support the needs of families during this difficult time, the hospice considered strengthening their referral pathway and improving their offer of support to neonatal intensive care units (NICU).

Methods: A baseline survey from NICU staff was carried out in 2021. From April 2022, monthly joint meetings between specialist palliative care and neonatology clinical leads were held to address the baseline survey findings, align national guidance and develop clinical care pathways. Ongoing referral data was captured and analysed annually.

Results: The survey identified key areas, including offering hospice support within NICUs via an identified link to health care professionals, education, attending complex multidisciplinary meetings, and developing consistent palliative care policies and pathways across the neonatal networks. So far, the monthly meetings supported the development of a referral pathway (including antenatal and neonatal referrals), clarified the referral criteria and produced a rapid transfer document to support end-of-life-care outside a NICU. Furthermore, close working led to regular attendance at the regional foetal medicine meetings, supporting interdisciplinary learning, aligning professional understanding, and identifying possible referrals at an earlier stage. This has resulted in joint working in antenatal clinics and wards as well as in NICUs, enabling the implementation of advance care planning and symptom management.

Conclusions: An approach addressing the key concerns from a neonatology perspective with regular collaborative interdisciplinary working enables increased palliative care support and in-reach into NICU and antenatal services. The impact on referrals to palliative care will be analysed after 1 year.

PL 1 Advance care planning with children and young people, parents and professionals

PPC Advancing Pediatric Palliative Care: The Value of Research Projects that Aim for Scientific as Well as Practical Outcomes

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Background/aims: Pediatric palliative care aims to improve the quality of life of seriously ill children and their families, it is thus of major importance that patients and family experience added value of pediatric palliative care. In the Netherlands researchers are challenged to not only gain knowledge, but to also develop and implement practices that empower children, parents and healthcare professionals. The aim of this presentation is to share and reflect on research projects aimed at advancing pediatric palliative care practice, through promoting an interdisciplinary approach and child-parent involvement.

Methods: A combination of qualitative and quantitative methods is preferable to come as close as possible to real life answers to sensitive research questions. We built on our experiences in a diversity of research projects, aimed at: developing pediatric advance care planning, bereavement care for parents during end of life, exploring the spiritual dimension of parental caregiving and understanding parental caregiving experiences.

In collaboration with a national network of pediatric palliative care organizations interdisciplinarity and active child-parent involvement was guaranteed during the development, execution, evaluation and implementation of the projects to be able to align practices to actual child/family and healthcare professional needs and expertise.

Results: All projects delivered scientific and practical outcomes. Data collection and -analysis resulted in clear descriptions of the lived experience of the different stakeholders in PPC or in explanatory representations. These were presented as scientific papers and published in Q1 peer reviewed journals. In addition, we used study results to develop educational materials, skills training and practical tools for health care professionals, children and parents.

Active involvement of all stakeholders appeared to be time consuming, but the collaboration between parents, healthcare professionals and researchers was fruitful regarding mutual understanding and development of a 'skilled companionship'. Our approach revealed important facilitators and barriers of intensive collaboration/companionship that can inform future projects.

Conclusions: Clear focused research projects with a mix of scientific and practical outcomes can make the difference in advancing pediatric palliative care. The 'alignment approach' needs and supports interdisciplinary collaboration and child-parent participation.

PL 2 Hearing Children's Voices

BW Food, Toys and Love: The Voices of Seriously Ill Children and Their Siblings

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Background/aims: As pediatric palliative care develops into an interdisciplinary field, it is crucial to further our understanding of children's psychological responses to serious illness. In many ways, patients and siblings live the illness in mirror image: while the patient endures the physicality of the illness in all its relentless presence, the siblings are witness to its ravages. All the children must cope with great uncertainty, confronted with the threat, if not the actuality, of premature separation, loss, and death. This presentation will provide a portrait, through words and images, of the children's experience. Selected psychological themes will include: the impact of the illness itself, the children's awareness of their condition (or their sibling's), decision-making, and the process of anticipatory grief. The children's words and artwork provide touchstones for understanding the essence of pediatric palliative care. Furthermore, what emerges is the recognition that across all life stages, from early childhood through adulthood, the challenges of living with serious illness are universal

1.2.8 Workshops

W1 Skills Workshop : The Compassionate Breath - Breathlessness Anxiety Management

This workshop is targeted at conference attendees interested in learning about embodied skills to support holistic care for people living with breathlessness/anxiety in chronic and advanced illness. The workshop is of relevance to clinicians and researchers wishing to explore person-centred values and practice in both care and research contexts, underpinned by principles of *reflexivity* and *connectivity*.

We will cover:

Theory: Body-oriented practices foreground proprioception (body-in-space) and interoception (“the material me”). For people living with frightening breathlessness, re-establishing a safe relationship with the body is foundational; this occurs via co-regulation with a safe other. I will explain how and why relational, embodied practices interrupt common spirals of cognitive, emotional and behavioural reactivity and support agency, control and bodily ease, and how such practices can be used to help patients with complex needs to the end of life, in the moment, and across cultural divides.

Practice: We’ll enjoy a short “Body Breathing” practice (named by patient stakeholders) which can be done sitting/standing/lying and is accessible to all. The aim is to develop procedural knowledge for immediate take-away use.

Discussion: We’ll finish with a short discussion on the relevance of this work to you as a clinician/researcher/person, and how integrating such an approach can improve self-other awareness, attentiveness and compassionate care.

Chair: Kate Binnie (Hull, United Kingdom)

W2 H Miscommunication with the Media

Palliative care deals with topics on a day-to-day basis that can make for headline media stories, and there is much interest from mainstream audiences. But there is also a risk of being misrepresented and misinterpreted. Conspiracy theorists are fishing for stories that confirm certain world views, which can place a seemingly harmless article, research summary or interview segment out of its intended context. Palliative care professionals and organisations engaging with new and old media aim to convey messages that are important, but if pitched in a wrong way, a media story may emerge that runs contrary to initial intentions. This workshop with Dr. Kathryn Mannix, Prof, Mark Taubert and special guests is designed to discuss how we broach and prepare ‘taboo’ topics or areas of controversy. Workshop attendees can actively contribute anecdotes, research findings and strategies, but should be able to formulate a ‘safer’ media strategy by the end of this session. We will discuss checklists when talking to reporters and writing for media outlets, and look at how to get key messages across with precision, minimising potential misinterpretations. With Dr Nicola White, Dr Ollie Minton, Prof Lukas Radbruch, Dr Paul Keeley and James Norris

Chair: Mark Taubert (Cardiff, United Kingdom)

Chair: Kathryn Mannix (United Kingdom)

W 3 H We Are Also Going to Die

I will ask participants first to consider triggers in their lives and those of others for facing this important fact that “We are also going to die”. For example death of a loved one, death of a colleague at work, media stories.

As examples, of reason to face the fact that “We are also going to die” I will structure the discussion under 3 themes and encourage the participants to discuss,

Philosophical: e.g. “If I take death into my life, acknowledge it, and face it squarely, I will free myself from the anxiety of death and the pettiness of life - and only then will I be free to become myself.” Martin Heidegger. I will expand on this and other Philosophers ideas to warm up the group.

Ethics: I will prompt discussion on issues of 1) need to consider death to think about autonomy for oneself e.g. ACP, Appointing Legal Power of Attorney, making a will

2) relationship issues – not being a burden to others, or at least trying to reduce complications for others by talking and planning for one’s own care, death and funeral etc

Psycho-spiritual: what do we need to do to prepare our self psychologically/spiritually given we know that people who have psychological/spiritual/existential suffering often have much more difficult deaths and even worse pain.

Chair: Julia Verne (London, United Kingdom)

W 4 A Designing and Implementing Virtual Palliative Care Courses

In this workshop, participants will learn to develop a virtual palliative care course using the Gagne’s Nine Instruction of Learning (Gagne et al, 2005). This framework is systematic and useful in identifying any gaps in the design process. Various digital tools will be introduced in each step to enhance learning. The trainer will also be sharing her experience in using these tools together with the result of the feedback received from participants of a virtual palliative care course conducted in her institution.

Time

W 5 D Strategies to Provide and Measure Palliative Care Delivery for People with Dementia in Long-Term Care Settings

In this workshop, we will share innovative practices to deliver palliative care in long-term care settings. Clinicians and researchers working in long-term care settings see unmet needs from residents and families, such as inadequate symptom management and breakdowns in communication about care goals, that palliative care providers are well-qualified to address. Yet, despite recognition of its importance, particularly for people with dementia, palliative care is not consistently available in long-term care settings due to a variety of barriers. In this pragmatic, solutions-focused workshop, we consider models of palliative care in dementia, how to implement these and how to measure effectiveness to improve outcomes for the person and family caregiver. We will also consider the impact of these programs on staff in long-term care settings.

We will first present international specialist and generalist models, with internal or external facilitation of palliative care consultations. We then invite you to join a discussion of fit in community or nursing home settings and experiences with such models in different countries. We will discuss strategies for navigating common challenges in implementing palliative care programs and integrating palliative care into the clinical care for people in long-term care settings. Next, we will discuss findings, experiences and potential pitfalls with measuring outcomes, such as with the End-of-Life in Dementia (EOLD) measures. We consider the state of the art of palliative care in dementia, share experiences with various models in different countries, to inspire innovative solutions to improve quality of care and quality of end of life with dementia.

Chair: Jenny T van der Steen (Leiden, Netherlands)

Chair: Kathleen Unroe (United States)

W 6 H Workshop World Grief Café

A new type of interprofessional learning:

The idea of this session was born out of our observation that in clinical palliative care support of family and patients is mainly provided by professionals who cooperate combining the knowledge of their respective disciplines. In our session we want to go one step further and develop interdisciplinary knowledge, crossing the boundaries of disciplines and thereby creating completely new understandings of loss and grief.

Therefore, in this interactive session, we bring together both chaplains, psychologists, social workers, and other interested delegates to work in a world café method towards a shared understanding of what is needed to integrate both dimensions. For this we will draw upon the scientific work we have done on this subject during the last 20 years separately, and in the last 1,5 years with joint efforts.

Chair: Carlo Leget (Utrecht, Netherlands)

Chair: Mai-Britt Guldin (Egå, Denmark)

1.2.9 Special events

1. Public Understanding and Discussion of Dying

The session will start with the TEDx video

<https://www.youtube.com/watch?v=CZDDByTOVr0>

and continue as a session about public understanding and discussion of dying, such as

- what we can learn from public feedback about 'With the End in Mind'? I've had hundreds of messages about it. People want to know more, and many bereavements are unnecessarily painful because deathbed companions misinterpreted the strange noises and patterns of end-of-life breathing.
- how can we as palliative and EoL care practitioners do better at 'narrating' death beds as the person is dying, in order that their beloveds understand what they are witnessing? and more. . .

Chair: Kathryn Mannix (United Kingdom)

2. Palliatief meeting

3. About Books and Communication

A session about listening and communication skills, reflecting both on our own practice and also how we teach our trainees and new staff to be good listeners and avoid the impulse to 'fix' things.

Chair: Kathryn Mannix, (United Kingdom)

4. Digital Legacy Conference

Why this conference is important: Modern day, communication technologies are changing the world. The way in which we live, the ways in which we plan for death and remember our loved one's is increasingly moving into the digital realm. Health, social care and palliative care professionals need to adapt practice, policies and procedures to better support society with this ever-increasingly important area.

What to expect: The Digital Legacy Conference examines society's attitudes and behaviours in relation to technology, end of life planning, death and bereavement. The conference's goal is to empower palliative and end of life professionals to better understand this emerging space and adapt ways of working to embrace it.

Who is the Digital Legacy Conference for?: The Digital Legacy Conference is for those involved in care planning, social care, healthcare, palliative, hospice and bereavement professionals. It is also relevant for policy makers, technologists and academics working within this sector.

<http://digitallegacyconference.com/>

Speakers:

Dr Ros Taylor MBE (Medical Director at Michael Sobell Hospice)

Amarachukwu Callistus Nwosu (Senior Clinical Lecturer in Palliative Care at Lancaster Medical School & Research Lead (Marie Curie Hospice Liverpool))

Sarah Stanley (Research nurse at Marie Curie Hospice Liverpool)

Professor Mark Taubert (Clinical Director at Velindre University NHS Trust in Wales & Founder of TalkCPR)

James Norris (Founder of the Digital Legacy Association & MyWishes)

Chair: James Norris (London, United Kingdom)

1.2.10 Open meetings

OM 1 - APHN - Collaborative Opportunities in Research and Education in the Asia Pacific region

OM - 2 G EAPC Reference Group Palliative Care and Intellectual Disability

Chair: Irene Tuffrey-Wijne (London, United Kingdom)

P 7.001

Exploring the Views and Preferences of People with Intellectual Disabilities, Families and Professionals on End of Life Care Planning with People with Intellectual Disabilities: A Focus Group Study

Abstract Poster Presenter: Andrea Bruun (Kingston, United Kingdom)

P 7.003 "We MUST Be Involved!" Developing and Testing Inclusive Data Collection Methods for End of Life Care Research with People with Intellectual Disabilities

Abstract Poster Presenter: Amanda Cresswell (Kingston, United Kingdom)

P 7.004 Co-producing a Toolkit of Approaches and Resources for End-of-Life Care Planning with People with Intellectual Disabilities, Using Experience-based Co-design

Abstract Poster Presenter: Irene Tuffrey-Wijne (London, United Kingdom)

P 7.018 Exploring the Factors Associated with Avoidable Deaths of People with an Intellectual Disability in England in 2021

Abstract Poster Presenter: Irene Tuffrey-Wijne (London, United Kingdom)

P 5.048 Our Name on the Door: The Importance of Employing People with an Intellectual Disability as Researchers in End of Life Care

Abstract Poster Presenter: Richard Keagan-Bull (Kingston, United Kingdom)

OM - 3 D EAPC Task Force Advance Care Planning in Dementia

OM - 4 G EAPC Task Force Improving Care for LGBT+ People

OM 5 - C EAPC Task Force Social Work

OM - 6 E EAPC Task Force Innovation in Nurse Education

OM - 7 F EAPC Reference Group Public Health and Palliative Care

OM - 8 B EAPC Reference Group Primary Care "Towards Primary Care Providing Universal Access to Palliative Care Worldwide"

The meeting will be co-chaired by Emeritus Professor, Scott A. Murray and Dr Tania Pastrana and will be focused on supporting collective learning about how primary palliative care is developing in different regions around the world. The aim of the meeting is that attendees will learn from and with each other in a truly worldwide forum. Speakers with extensive experience from four large regional palliative care associations will be speaking at the open meeting for 15 minutes.

After the presentations have concluded, Dr Daniel Munday and Dr Sébastien Moine will lead a discussion exploring what primary palliative care means and what the key features are internationally for primary care to be enabled for the effective delivery of palliative care early in illness trajectory of everyone in need within the community.

Chair: Scott Murray (Edinburgh, Scotland, United Kingdom)

Chair: Tania Pastrana (Aachen, Germany)

Chair: Sébastien Moine (Edinburgh, United Kingdom)

OM - 9 YOGA in the Morning

OM 10 - A - Update on EU Funded Research Projects'

OM - 11 A EAPC Research Network Junior Forum

Sharing Palliative Care Interests

Speaker: Karolína Vlčková (Prague, Czech Republic)

Building a Research Career: Challenges and Strategies to Improve Research Skills in Palliative Care

Speaker: David Hui (Houston, United States)

Trajectory of a Young Researcher

OM 12 - I EAPC Reference Group Palliative Care for Children and Young People

Presentation of The Dutch Multidisciplinary Clinical Practice Guideline for Paediatric Palliative Care

OM 13 - H EAPC Task Force Bereavement

OM 14 - G EAPC Task Force Palliative Care for People in Prison

OM - 15 B EAPC Reference Group Neurology and Palliative Care/ European Academy of Neurology (EAN)

OM - 16 E EAPC Reference Group Education and Training in Palliative Care

OM - 17 A EAPC Task Force Leadership in Palliative Care
 OM - 18 H EAPC Reference Group Spiritual Care
 OM - 19 YOGA in the morning

Poster

P 1 - Innovation and E-Health Solutions

P 1.002 A Quasi-experimental Mixed-methods Interventional Study of an Electronic System for Measuring Patient-reported Outcomes in German Specialist Palliative Home Care –Feasibility and Qualitative Findings

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Background/aims: Patient-reported outcome measures (PROMs) benefit care in many ways. eIPOS is an electronic version of the Integrated Palliative Outcome Scale to measure symptom burden and palliative concerns.

Aim: To test and explore the feasibility of implementing the eIPOS in German specialist palliative home care (SPHC).

Methods: Convergent mixed methods design: quasi-experimental study with retrospective/prospective control groups alongside focus groups with professionals. The study nurse screened all patients. Those who were eligible were contacted by phone and if interested, a face-to-face meeting was arranged. In this meeting, eIPOS was introduced and a written consent form was obtained. Data were collected from electronic medical records for all three groups. Descriptive and framework analyses were used.

Results: 1744 patients were screened, n=361 patients met the inclusion criteria and 82 were included (overall recruitment rate 4.7%; meeting inclusion criteria 22.7%). Non-eligibility was due to poor and/or fluctuating health, lack of an internet-enabled device or not being confident to operate such a device. 82 patients (40 women) participated in the eIPOS-arm (avg. 68.5 years; range 23-99). Compared to the control groups (prospective avg. 77.5 years; retrospective avg. 76.4 years), the eIPOS patients were younger (Wilcoxon $p < 0.0001$) and in better general condition (higher Karnofsky scale, greater chance of surviving). In 3 focus groups, professionals (total n=11) indicated that for a successful implementation of an ePROM system, the intervention needed to be integrated into the existing clinical care routine. Professionals welcomed eIPOS for identifying and monitoring symptom burden. They explained that autonomous eIPOS use is challenging due to fluctuating symptom burden and short duration of care. Involving informal caregivers in eIPOS was suggested.

Conclusions: Recruitment was challenging due to poor health and technical issues. But implementation can be helped via a version for informal caregivers.

P 1.003 Learning from the Patient Experience, the SYMPAL+ Project

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Background/aims: Patient information can be used to optimize care either for the individual patient and a specific hospice, and to perform research. A datahub and dashboard were built to collect and share patient record data.

This feasibility study aimed to evaluate the completeness of data.

Methods: A feasibility study was performed using a mixed methods approach.

Patients admitted to participating hospices enrolled, using anonymized patient record data. Data collected were patient characteristics, admission information, illness characteristics, multidimensional assessment and symptom and concerns (S&C). The Utrecht Symptom Diary four dimensional, a validated multidimensional PROM was used to assess physical and psychological symptoms and social and spiritual concerns. The primary outcome was completeness of data analyzed descriptively.

Results: 476 patients, 272 women (57%) were enrolled (1/21/2021 – 05/31/2022). Most patients had cancer (63%) and were admitted for last resort (89%). Patients were admitted for median 16 days, 61 < 3 days and 22 > 90 days.

Completeness: Patient gender and date of birth were complete in all records, marital status in 96%, and philosophy of life in 77%. Diagnosis information was complete in 98% of records, estimated life expectancy in 91%. End of life information was missing in 88 – 95%.

A multidimensional assessment was complete for the physical, psychological, social dimension. The existential status was missing in 20%. The values, wishes and needs were less complete in all dimensions, the existential dimension not described 40% of first care plans.

2133 USD were completed by 317 (67%) patients, 7USD/patient on average.

Symptom burden: Patients suffered from 7.7 s&c concurrently, 4.3 scored > 3. The three most intense s&c: letting loved ones go (6.1), fatigue (5.7), loss of appetite (5.4). Depressed mood (3.4), anxiety (3.3) and nausea (3) were the least intense s&c.

Conclusions: Data from patient records provide information to optimize clinical care, pinpoint the existential dimension as a starting point.

P 1.005 Digital Technology to Optimise Care Access and Quality for Patients with Multimorbidity: A Mixed-methods Systematic Review

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Background/aims: Prevalence of multimorbidity is increasing in ageing populations. It increases the risk of poor quality of life and mortality, and places additional strain on healthcare. Digital technology can potentially improve the access and quality of health services for this population. This study aimed to appraise the evidence for the effectiveness of digital technology among patients with multimorbidity, and user experience.

Methods: A mixed-methods systematic review was conducted on four databases for studies published in English (2000- 2022). Studies were included if they were original research focusing on patient outcomes and/or economic evaluation of digital technology for multimorbid patients. Data were synthesised narratively.

Results: 15 (8 quantitative, 7 qualitative) studies were retained. Six were RCTs, five of which integrated digital interventions into usual care. Digital technology significantly improved exercise capacity (6-min walk test 60m vs -15m, $P=0.004$), dyspnoea (-0.17 vs 0.07, $P=0.05$), physical activity profile (18.1 vs -21.3, $P=0.0015$), disability (5.4 vs 1.3, $P=0.0006$), quality of life (-10.5 vs -0.44, $P=0.0007$), and reduced rehospitalisation

(HR, 0.42; 95%CI, 0.27-0.64; $P < 0.001$). It also improved medication adherence ($p < .001$) and reduced missed doses of medication ($p = .02$) and medication errors ($p < .001$). One study showed that digital technology improved the quality of life of type 2 diabetes and coronary artery disease patients with moderate costs in the short-term follow-up. For most participants, e-Health services were acceptable to improve self-management and enhance care experience. Ensuring effective engagement and its usability required training and support from healthcare providers.

Conclusions: Digital technology has the potential to provide self-management support for people with multimorbidity. This review provides important insights to use eHealth solutions for self-managing symptoms and medication.

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P 1.006 Non-invasive Technology (Bioelectrical Impedance Analysis) to Assess Hydration Status in Advanced Cancer to Explore Relationships between Fluid-status and Symptoms at the End-of-Life

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Background/aims: The role of hydration in causing or alleviating suffering in advanced cancer is poorly understood. Bioelectrical impedance analysis (BIA) is an accurate validated method of assessing hydration status. Previous BIA research demonstrates significant relationships with hydration status, symptoms, and survival in advanced cancer. Further work is needed to study these associations in the dying. This study aimed to evaluate hydration and its relationship with clinical symptoms in dying cancer people with cancer.

Methods: We conducted an observational study of people with advanced cancer in three centres (2 hospices and 1 hospital palliative care inpatient unit). We used an advance consent methodology to conduct hydration assessments in dying people with advanced cancer who were dying. We recorded hydration status (via BIA Impedance index: Height – H²/Resistance - R), symptoms, physical signs, and quality-of-life assessments.

Results: 125 people participated (males n=74 (59.2%), females, n=51 (40.8%). We repeated assessments in 18 (14.4%) participants when they were dying. Hydration status (H²/R) of the dying was not significantly different compared to baseline (n= 18, M= 49.55, SD= 16.00 vs. M= 50.96, SD= 12.13; t(17)= 0.636, p = 0.53). Backward linear regression showed that 'more hydration' (increased H²/R) was associated with oedema (Beta= 0.514, $p < 0.001$) and more pain (Beta = 0.156, $p = 0.039$). 'Less hydration' (lower H²/R) was associated with females (Beta = -0.371, $p < 0.001$), more anxiety (Beta = -0.135, $p < 0.001$), more physical signs (dry mouth, dry axilla, sunken eyes - Beta = -0.204, $p < 0.001$), and more breathlessness (Beta = -0.180, $p < 0.014$).

Conclusions: Hydration status was associated with physical signs and symptoms in advanced cancer. No significant difference in hydration status was noted in dying patients compared to baseline. Further studies can use this work to develop tools to improve personalised hydration assessment, management and communication with patients and caregivers.

P 1.008 Innovative Funding of Palliative Care Services

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Background/aims: HOSPICE Casa Sperantei is the largest foundation in Romania offering free palliative care services, provided in day centres, inpatient and outpatient units, patients' homes, partner hospitals. In its 30 years of existence, HOSPICE has brought comfort and hope to more than 45,000 children and adult patients.

Methods: *The Wishing Tree: Childhood Memories* (2019 – 2022) and *HOSPICE World – An innovative fundraising model* (2022 – 2024) are two of the first projects that embody the strategy through which HOSPICE aims to initiate and develop new funding streams contributing to its financial sustainability. Alongside the primary objective of generating funds for services provided free of charge by HOSPICE, both projects aim to raise public awareness regarding palliative care, not through the classical communication campaigns, but by using the arts of cinema and literature, as well as innovative technologies (a live streaming platform with an integrated donation tool and virtual tours).

Results: *The Wishing Tree: Childhood Memories* project had spectacular results both in terms of raising funds and in terms of raising awareness regarding palliative care: Trailer viewings in cinemas – 637,738 viewers; Viewings in 66 cinemas countrywide- 22,116 viewers, 3rd most watched Romanian film in 2022; *Supererou* (Superhero) music video – 1.276.005 views on YouTube (29.09.2022); Netflix Premiere – 01.09.2022, top 10 most watched films in the children's category; 4,997 books sold, ranked for over 6 months on the bestselling list of the *Humanitas Junior* Publishing House.

Conclusions: Given the strong innovative character of the two projects (the development of new fundraising mechanisms and targeting new groups of donors; the human resources involved – cinema and technical experts; the required infrastructure – film sets, digital platforms), the process of developing these two projects was lengthy and required substantial efforts in securing the necessary support from the organization's leadership.

P 1.009 Insights into the Introduction of an ePRO-based Digital Health Platform in Paediatric Oncology – Focus Group Results from the Clinical MyPal-CHILD Study

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Background/aims: The awareness for electronic patient-reported outcomes (ePROs) is increasing in paediatric oncology and palliative care. As part of digital health innovations, ePROs can facilitate health care professionals (HCPs) to monitor patients' disease progression more seamlessly as an add-on to care to address otherwise missed needs of young cancer patients and their relatives. The underlying motivation is to improve quality of life while facing the life-changing diagnosis of cancer.

The MyPal-CHILD study aims to assess the feasibility of using a novel ePRO-based digital health platform with two mobile applications for young cancer patients and their parents as well as a web platform for their HCPs. During a 6-month participation in a multicentre observational study, participants were encouraged to actively engage through symptom self-reports and diary entries. By empirically examining the platform's usage in clinical practice, we provide first-hand experience on

how to deploy and exploit such innovations to support medical and psychosocial care.

Methods: Besides quantitative data on the platform usage, qualitative data were collected in eight carefully designed focus groups conducted with young cancer patients, their parents as well as the HCPs involved in the study at all three clinical sites.

Results: The focus groups revealed strengths and limitations of the introduced digital health platform across a wide range of topics, e.g. communication, motivation and compliance. Valuable recommendations of the participants provide crucial guidance for prospective advancements of digital health innovations.

Conclusions: Preliminary study results demonstrate that ePRO-based digital health innovations can be valuable under certain conditions. Final discussions on the validity of these findings will be reported in the final project outcomes (December 2022).

Funding: MyPal is funded by the Horizon 2020 Framework Programme of the European Union, Grant Agreement No. 825872.

P 1.011 Design of International Database on Advance Care

Planning Tools

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Background/aims: French policy related to end-of-life care aims to inform people about their rights at the end of life. One of the actions of the last national Plan for palliative care development is to implement the advance care planning (ACP) at the national level. One of the possible levers is to collect tools helping to initiate discussion about ACP. There are many tools available around the world (playing cards, workbooks, websites. . .) and a free online database has been developed for providing people a validated environment aiming to find or inspire them when they want to implement ACP whatever the care setting.

Methods: Tools are identified by two information specialists through a French database related to palliative care (Palli@Doc), websites from the Health Ministry, the medical societies and patient associations (general and by pathology), and the palliative care networks in France and abroad (inclusion criteria will be described). Database was designed from a questionnaire made by an expert and an information specialist, identifying targeted audience, content, format, and tool aiming.

Results: For now, around 100 items are included. The goal of this database is to facilitate the navigation between the tools and to allow people to find the appropriate tool they need. It will be launched in January 2023, available free on the Internet in a French and an English version.

Conclusions: To our knowledge, this is the first database highlighting ACP tools. The willingness of this project is to federate international actors around a unique device in order to better identify and spread tools worldwide. Tools' collection also allowed us to think about the manner these tools are included in the largest process: the most effective tools are designed for creating a consistent ecosystem in which several tools echo each other and respond to all dimensions of ACP: awareness, information, and thinking, writing or communication support.

P 1.012 Patient-centred Supportive Palliative Care Ecosystem for Older Patients with Non-malignant Chronic Conditions

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Background/aims: Technological applications for Palliative Care (PC) can bring information and knowledge at the tip of the finger for patients and their caregivers; they can educate and train medical students and health professionals; they can provide self-care management; reduce stress, and all these in a simple, easy, and fun way. In the context of INADVANCE, a Horizon 2020 project for PC (grant number 825750), several technological tools and applications have been created for older patients with non-malignant chronic conditions, their caregivers, and health professionals. These technological suggestions are

- a) mobile applications for self-management of their disease and everyday life;
- b) mobile applications based on Virtual Patients (VPs) for patients' and caregivers' education;
- c) Virtual Reality (VR) scenarios to train medical students and health professionals in communication skills and empathy; and
- d) VR tools for stress and pain management using 360° videos and mindfulness techniques.

Methods: A co-creation procedure has been followed from the requirements collection to pilot testing with older patients with complex chronic conditions (i.e. chronic obstructive pulmonary disease, frailty, cardiovascular diseases and Idiopathic Pulmonary Fibrosis). A case study is being implemented at two of the Living Labs of the School of Medicine of Aristotle University in Thessaloniki, Greece. Questionnaires, interviews, and observations are used to collect data.

Results: All stakeholders rated the experience beyond interesting and helpful. Patients have been in favor of some applications while finding others not that easy to use. Caregivers were mostly interested in applications that educated them about health issues. Health professionals were interested in all applications and could immediately suggest more uses of these technologies in PC.

Conclusions: Technology and specifically mobile and Virtual Reality applications can be considered a useful tool in the quiver of PC.

P 1.013 Improving the Implementation and Sustainability of the "Living with Cancer" Peer Self-management Support Program

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Background/aims: Patients and relatives are expected to take up responsibility for their health. The "Living with Cancer" program is an innovative, online peer-led peer support program aiming at improving self-management, self-efficacy and health-related quality of life of persons with advanced cancer and their relatives. Sustainable implementation of such programs can be challenging. We therefore applied the NASSS framework to the "Living with Cancer" program. This framework was developed to optimize implementation by identifying and reducing complexity in seven domains: illness, technology, value proposition, intended adopters, organization(s), external context and future perspective.

Methods: We revisited the original dataset (including protocol, manual and interviews) and publications about the pilot study for the "Living with Cancer" program and undertook additional interviews with the study team and other stakeholders, such as an insurer. The total dataset was analyzed using case study methodology to identify any complexities.

Results: Two important complexities were found.

- 1) The online format (Technology domain): this format is inclusive, since very sick people can participate without having to travel. However, online does not allow for one on one conversations and intense emotions can be hard to deal with.
- 2) Funding and continuation after the study phase (Organization domain): longitudinal implementation requires embedding in an organization and support from patient associations by means of informing their members about the existence of the program.

Conclusions: The identified complexities might hinder the sustainability of the “Living with Cancer” program. To improve the chances of a successful sustainable implementation we recommend:

- 1) offer hybrid meetings to combine the pros and cons of online versus face-to-face and
- 2) look for an organization to continue the program.

This research is funded by the Netherlands Organization for Health Research and Development.

P 1.015 Implementation of an Automated Approach to Timely Identification of Patients who Would Benefit from Palliative Care: The Modified Hospital-patient One-year Mortality Risk (mHOMR) Tool

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Background/aims: Identifying those who may benefit from palliative care is a significant barrier to providing timely palliative care. Existing provider-dependent approaches are limited; an improved system would involve accurate, automated tools for identifying patients with unmet palliative needs and triggering a care response. We developed one tool that is integrated into the electronic medical record (EMR) and uses data available at hospital admission to predict one-year mortality – modified Hospital-patient One-year Mortality Risk (mHOMR). mHOMR is accurate (c-statistic 0.89), identifies those with unmet needs, and is acceptable to patients and providers.

Aim: To scale implementation and evaluation of the mHOMR tool to develop a Change Package to support future hospitals in sustainable mHOMR implementation.

Methods: Intervention implementation-evaluation study. Patients with a score >0.21 (sensitivity 59%; specificity 90%) are flagged and clinicians prompted to assess for severe symptoms and readiness to engage in advance care planning. Hospitals develop a tailored implementation plan in 4 phases: needs assessment, EMR integration, mHOMR ‘go-live’, and integrated learning. Implementation and clinical outcomes are assessed via Consolidated Framework for Implementation Research (CFIR) interviews and chart abstraction.

Results: mHOMR is being implemented in 15 hospitals in Ontario, Canada, representing >40% of annual acute care admissions (6 in phase 1; 3 in phase 2; 7 in phase 3). Chart abstraction is underway and results anticipated in March 2023. 15 CFIR interviews are completed; best practices for optimized implementation should consider unique hospital contexts, workflows, and patient populations.

Conclusions: mHOMR is a feasible, scalable tool for identifying patients at increased risk of death with unmet palliative needs. We aim to spread implementation to additional provinces and countries.

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P 1.018 Design, Pilot-implementation and Evaluation of an Interactive Online Toolkit for Optimising Hospice at Home Care Delivery

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Background/aims: For many people, dying at home is an important priority and services called Hospice at Home (HAH) or similar have been developed across England to support people to achieve this. The results from a national evaluation of HAH (Butler et al, 2022) provide evidence on the key factors which need to come together in each HAH to provide the best possible care. It is crucial to translate research knowledge to formats accessible and applicable to diverse stakeholder groups, which has prompted the creation of an online toolkit.

Aims: To design, pilot and evaluate the implementation of an interactive online toolkit for optimising HAH care delivery.

Methods: There are 5 stages to project: (1) Co-Designing the toolkit together with HAH service providers, members of the public, commissioners and wider health and social care professionals; (2) Refining the toolkit based on a qualitative framework analysis of co-production events; (3) Piloting the toolkit; (4) Evaluating the pilot-implementation drawing on Implementation Science (RE-AIM); (5) Further refining the toolkit based on evaluation findings and advertising to diverse audiences.

Results: Qualitative framework analysis guided toolkit design and demonstrated perceived usefulness and user-friendliness of the toolkit. At the time of the abstract submission, the evaluation phase is yet to be completed (due March 2023). Results will focus on toolkit accessibility at lay, operational and strategic levels, relevance and applicability of the strategies generated by the toolkit, impact on piloting organisations, as well as application and sustainability of any changes.

Conclusions: Co-design and co-refinement of knowledge exchange tools is feasible and effective. Once completed, the pilot-implementation evaluation will also provide evidence on the reach, efficacy, adoption, implementation and maintenance of the toolkit, including any impact sustained after the initial implementation.

P 1.019 How Satisfied Are Patients with a Novel Palliative Care Telemedicine Service in a Tertiary Cancer Centre in Singapore?

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Background/aims: The COVID-19 pandemic necessitated the redesigning of outpatient palliative care (PC) services. We piloted a novel nurse-led telemedicine program from June 2020 to October 2021, aimed at allowing patients continued and timely access to PC.

We evaluated the acceptability of the telemedicine service at the end of the project.

Methods: Inclusion criteria for enrolment into the service were: a) advanced gastrointestinal or lung cancer b) prognosis of less than 2 years. Patients known to existing PC services were excluded.

The telemedicine program consisted of a) an initial video consult with a PC consultant and a PC Advance Practice Nurse (APN) b) weekly symptom monitoring for 12 weeks, using a patient self-reported survey (Integrated Palliative Care Outcome Scale survey, IPOS). Identified problems from IPOS were followed up by the APN.

A Client Satisfaction Questionnaire (CSQ-4) was sent to patients after they completed the telemedicine program.

Results: Eighty-eight patients had actualized video consults. A total of 78 CSQ-4 were sent, of which 74 were sent to patients and 4 were sent to caregivers as the patient had demised. Sixty-seven participants reverted, of which 88% reported that most, if not almost all their needs were met, 94% felt the service had helped them to deal more effectively with their problems, 96% felt they would come back to the program if they were to seek help again and 95% were satisfied with the service they received. However, only 46% respondents felt that they would be willing to pay for the telemedicine service.

Conclusions: Our results suggest that telemedicine services are accepted by PC patients, but preferably at no out-of-pocket cost. Future studies could consider further methods of optimizing telemedicine service delivery, in order to continue to deliver good outcomes at a low cost.

P 1.020 How Effective Is Continued Immunotherapy When Melanoma Progresses? A Real-life Evaluation from the Melbase Cohort

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Background/aims: Immunotherapy in metastated melanoma (MM) is associated with distinct types of response, which make it difficult to assess the benefit to the patient. Some clinical trials suggesting a survival advantage of immunotherapy even in the absence of an objective tumour response. The objective of this study was to assess the impact of continuation immunotherapy after progression on overall survival a large multicenter real-life prospective cohort of patients with MM in last line.

Methods: Clinical data from 120 patients with MM were collected via Melbase, a French multicentric biobank prospectively enrolling unresectable stage III or IV melanoma. Two groups were defined: patients continuing immunotherapy at progression in last line (cases) and patients stopping immunotherapy at progression (controls). Primary end-point was OS. Propensity score weighting was used to correct for indication bias.

Results: Among the 120 patients, 72 (60%) continued Immunotherapy. After propensity score weighting, and with a median follow-up of 9,1 months, median OS was 4.2 months (95% CI : 2.6-6.27) in the cases group and with a median follow-up of 4.1 month, median OS was 1.3 month (95% CI 0,95-1,74) in the controls group (p < 0.0001). The calculated hazard ratio was 0.20 (0.13-0.33).

Conclusions: This study shows that patients with MM treated with immunotherapy in last line, continuation after progression is associated with a significant decrease in the instantaneous probability of mortality is on average 5 times lower with continued immunotherapy.

P 1.021 Using Electronic Patient-reported Outcome Measures to Support Care in German Specialist Palliative Home Care:

Acceptability and Perceived Value of the Intervention

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Background/aims: Patient reported outcome measures (PROM) can support symptom monitoring in specialised palliative home care (SPHC)

for patients with complex symptoms. To determine how the eIPOS (electronic version of the Integrated Palliative Outcome Scale) intervention works in German SPHC, and to explore its perceived value.

Methods: A quasi-experimental mixed methods design: intervention group (eIPOS), retrospective/prospective control groups and qualitative interviews with patients. Patients completed the eIPOS on their laptop/tablet. IPOS-values were transferred directly into the electronic patient record. Descriptive and framework analyses were used. Quality of life (QoL) was measured using the EORTC QLQ-C15-PAL before and 2 weeks after using eIPOS. Scoring was performed according to the Scoring Manual, values were compared with the Wilcoxon test, Cohen's d was used for effect size. Multiple imputation (MI) was used as a sensitivity analysis. A symptom/problem was defined as prevalent if patients reported at least "moderate" burden.

Results: 82 patients participated in the eIPOS group (mean age 68.5; 49% female). 470 eIPOS forms were submitted electronically (average 5.7/patient; range 0-15). Missing values in the submitted eIPOS were very low (<5%). The most prevalent symptoms were "lack of energy," "poor mobility," and "family burden". The difference in pre-post QoL score (after MI) was found to be significant (p<0.0001). QoL showed small improvement for the eIPOS group (Cohen's d=0.249). Compared to control groups, the eIPOS group had a significantly lower number of emergency hospital visits (p<0.0001, DF=4, X² statistic=31.22). 23 interviews were conducted with patients using eIPOS. They viewed the questionnaire as appropriate and easy to use. Patients perceived an improvement in care through eIPOS and its use encouraging self-reflection.

Conclusions: The low number of missing values indicates that the eIPOS is acceptable in home care settings. Most eIPOS patients perceived positive effects on their care.

P 1.022 Experiences of Telehealth in Palliative Home Care – Patients' Perspectives

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Background/aims: With a growing world population and increased life expectancies, patients in need of palliative care will increase and many prefer to be cared for in the home. Known challenges are care coordination, care continuity and for patients to maintain governance of their own lives. Also, specialist palliative home care 24/7 may be a challenge, as well as managing care for patients in more remote locations. A suggested measure to counter these challenges is telehealth, which is increasingly used in home care contexts. The aim was to map and assess published studies on the use of telehealth in palliative home care.

Methods: This scoping review was guided by the Arksey and O'Malley framework and the Preferred Reporting Items for Systematic Reviews and Meta Analyses extension for Scoping Reviews (PRISMA-ScR) was used. The databases MEDLINE, PsycINFO, EMBASE and CINAHL were searched for studies between January 1, 2000 and October 16, 2018. Titles and abstracts for 2532 were screened, 100 full-text publications were read and 22 publications were included in the review.

Results: Patients' experiences were that telehealth was useful in declining or poor health and the technology was easy to use. The visual features added dimensions that facilitated communication with visual cues and non-verbal communication for situational awareness, assurance and comfort. The visual aspects facilitated creation of caring relationships and connectivity remotely. Management of troubling symptoms was facilitated by the telehealth resources. Patients described experiences of

having access to healthcare professionals even though they were in their own homes.

Conclusions: Applications of telehealth in the home have potential to promote individualized care and to increase patient participation, and does not seem to add undue burden on patients. Access to specialist palliative care in the home is facilitated, and telehealth may contribute to sustainable development and right to healthcare for diverse patients with palliative care needs.

P 1.023 Patient and Public Involvement: Acceptance of Modern Technologies, a Patient Survey

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Background/aims: Digital solutions for monitoring, treatment and support of patients as well as at-home self-care options grow increasingly important.

In the preparation of intervention studies involving Apps, Wearables and Virtual Reality, we aimed to characterize the experience and acceptability of modern technologies in palliative care patients.

Methods: A questionnaire was piloted and developed with patients and experts. The final questionnaire included 39 questions, 25 of which used the Likert scale and 14 were open response. Patients were recruited at the University Hospital Zurich and Clinic Susenberg Zurich over six months. We evaluated experience, acceptance and opinions in this purposive sample.

Results: 29 adults (69.48 ± 11.80 y, 16 female, 13 male) were included. The majority of patients possessed a smartphone (86%) and a personal computer (83%); just less than 50% owned a tablet and only one patient owned a smartwatch. A majority indicated responses 'interested' (34%) or 'rather interested' (34%) in modern tech generally, whereas experience with tech was more heterogeneous, with approximately 20% of patients in each of the 5 experience levels. Patients spent in average 1.5 h per day on their PC and 2h on their smartphone. No patient owned VR tech, and the majority (86.21%) have no experience with it. A slight majority (38%) stated they 'would not' be interested in using VR during their hospital stay but responses were heterogeneous, with ca. 16% endorsing four other categories, ranging from 'would be' to 'rather not', respectively.

Conclusions: These findings indicate an interest in the use of modern technologies among a palliative care population and suggest acceptance. Intervention studies are under development involving palliative care patients and the public.

P 1.024 Views and Experiences of Palliative Care Healthcare Professionals of Supporting Patients to Manage Digital Legacy as Part of Advance Care Planning

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Background/aims: The need for palliative care is increasing and it is essential to look at how emerging technologies can improve care for palliative patients and their carers in the future. With an increasing use of personal technology, many people are spending time creating their own online content. This online content is often described as a digital legacy, the digital information that is available about someone following their death. There is limited evidence around the experiences of digital legacy amongst palliative care healthcare professionals and the benefits of supporting patients in managing their digital legacy.

This constructivist grounded theory study aims to identify palliative care healthcare professionals' experiences of supporting palliative

patients in managing digital legacy as part of advance care planning discussions.

Methods: Semi-structured interviews were conducted with ten (n=10) palliative care healthcare professionals working in a hospice in the North-West of England. Interviews were recorded and transcribed and data was analysed using NVIVO.

Results: Four theoretical categories emerged from the data describing why palliative care healthcare professionals view digital legacy as an important topic. These four categories; 'accessing digital legacy', 'becoming part of advance care planning', 'impacting grief and bereavement' and 'raising awareness of digital legacy' were found to revolve around a core category 'understanding the impact of digital legacy'.

Conclusions: The emerging theory 'understanding the impact of digital legacy' offers an insight into the knowledge and experiences of healthcare professionals working in a palliative care setting. Further work is needed to explore palliative patients and their carers' views on digital legacy and how they can be supported to manage this better in the future.

P 1.025 Palliative Care Telehealth Innovations in Remote Western Australia

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Background/aims: Western Australia (WA) is the second largest country subdivision in the world with 7 million people living remotely. WA Palliative Care Telehealth goal is to improve equity of access and address the identified gaps due to the remoteness of people and the current demands on the regional palliative care teams. Most importantly, new digital capabilities aim to be responsive to the needs and values of all people, including Aboriginal people, and carers by reducing hospital admissions at end of life. Understanding needs of consumers is a key indicator of optimal palliative care experience.

Aim: This study aims to explore palliative care requests from generalist clinicians, patients and carers from 7 regions of WA. Specifically, how frequently is palliative care telehealth providing support with symptom management, end of life care, goals of care discussion, psychosocial support for patient, carer and support for generalist clinicians.

Methods: This study used a quantitative methodology for data collected from 100 patient's assessments completed by specialist palliative care nurses who used a nationally accepted palliative care outcomes collaboration assessment tool (PCOC). It was also identified which regions of WA interacted with palliative care telehealth services.

Results: The findings suggest palliative care consumers of telehealth service received therapeutic symptom relief, goal of patient care, end of life care discussion, psychosocial support and staff support. Fifty percent of referrals were for patients previously unknown to palliative care services, providing an early pathway to palliative care access.

Conclusions: WA palliative care telehealth supported staff with clinical decision making, better symptom control for patients as per PCOC, end of life care planning, goals of care discussion, psychosocial support for patient, carer and generalist clinicians, and education. Feedback from clinicians, patients and families were positive, reporting they would use telehealth service again.

P 1.026 Translation and Validation of the Person-centred Practice Inventory- Staff (PCPI-S) into Spanish

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Background/aims: Person-centredness, the main focus of palliative care, has become a global movement in healthcare, which is consistent with the development of international healthcare policy. There are few tools to measure person-centredness based on theoretical approaches. The person-centred practice inventory (PCPI-S) is an instrument based on a theoretical framework, the Person-Centred Practice Framework, that assesses the perspectives that health care professionals may have about the development of their person-centred practice.

Aims: To obtain a cultural adaptation and psychometric testing of the PCPI-S to Spanish language.

Methods: First, a translation and cultural adaptation of the PCPI-S from English to Spanish was carried out using the guide of the International Society for Pharmacoeconomics and Outcome Research. Second, the psychometric properties were measured; reliability by the test-retest and the Ordinal Theta (OT), confirmatory factor analysis was also evaluated.

Results: A Spanish version of the PCPI-S was obtained. There were no significant difficulties throughout the translation process and consulting sessions. A sample of 344 health care professionals (physicians, nurses and nursing assistant) participated in the study. All the items showed at least a fair level of agreement in the test-retest. The OT values showed adequate values (>0.69). The model showed good to adequate levels of fit (McDonald and Ho, 2002): CFI=0.89, SRMR=0.068; RMSEA=0.060 with CL90% (0.056-0.063).

Conclusions: The Spanish translation of the PCPI-S is psychometrically valid when tested with Spanish health care professionals.

This study was funded from the national plan of I+D+I 2017-2020 and by the ISCIII-Subdirección General de Evaluación y Fomento de la investigación y el Fondo Europeo de Desarrollo Regional (FEDER) (PI20/01644).

P 1.027 Participatory Action Research to Implement New Technologies in a Chronic Complex and Paediatric Palliative Service

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Background/aims: In the last decades, improvement in survival of severely ill children has led to an increasing prevalence of children with life-threatening illnesses. These children face chronic and complex pathologies along their life, and are dependent of the comprehensive care delivered by their parents and the palliative and complex care paediatric teams.

To preserve patients and families' quality of life efficient home-care plays a key role. Using a participatory action research (PAR) a Chronic Complex and Paediatric Palliative Service (CCPPS) is developing a social robot to monitor children's symptoms and empower parents for taking care of their children at home.

Methods: A PAR methodology has been used to involve the final users of the robot (families and health professionals) in its design. PAR involves 5 phases: Diagnosis, Development, Implementation and interaction, Evaluation, and Decision making.

Results: To date, the first 3 phases have been carried out. In the 1st individual interviews and focal groups with families and health professionals were done to understand their needs and their technological literacy. In the 2nd phase, periodic meetings of design thinking with engineers were carried out until the prototype was obtained, followed by internal and external validation of the chatbot content. In the 3rd phase the robot performed a simulation test with actors playing parent's role in the simulation lab. During the next months a pilot study with some families will start.

Conclusions: The development process of new technologies must be guided by the uncovered needs of patients and families. It is a long way which need to be shared with the final users (children, families and health professionals) in order to obtain a useful and implementable tool in the daily life.

P 1.028 A Digital Health Approach to Facilitate Access to and Continuity of Palliative Care for People with Advanced Cancer in the Bidi Bidi Refugee Settlement in Uganda

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Background/aims: There is an urgent need for feasible approaches to facilitate access to palliative care in humanitarian settings. We sought to co-design and pilot-test a digital health approach to facilitate access to and relational continuity of care for patients with advanced cancer in the Bidi Bidi Refugee Settlement in Uganda.

Methods: A mixed-methods study design was used. Phases included: i) patient and caregiver co-design workshops to gather requirements for a digital health intervention (DHI); ii) DHI prototype refinement led by patient, provider and policymaker feedback; iii) pilot study of routine reporting of palliative outcomes and COVID-19 symptoms data via a mobile phone application and clinician dashboard at the Bidi Bidi Refugee Settlement; iv) qualitative interviews with patient and health provider participants. Descriptive analysis of outcome and symptom data alongside framework analysis to explore patient and staff experience of the DHI was used.

Results: Co-design sessions guided augmentation of symptom reporting to include tuberculosis and hepatitis B due to their high prevalence in the settlement. 35 participants with advanced cancer completed an average of 11/12 (91.7%) scheduled outcome and symptom reports over a 6-week period. Pain, weakness or lack of energy, and poor appetite alongside worry were most commonly reported. The most frequent health provider response following dashboard review of reports was to make contact with a patient. Identified themes included routine reporting as i) facilitating meaningful and valued conversations, ii) retaining patients often lost to follow-up, and iii) balancing the provision of data and efficient care delivery.

Conclusions: A DHI approach is feasible and acceptable to enhance access to and interaction with palliative cancer care in a refugee settlement in Uganda. DHI content refinement and the development of pathways to guide wider scale-up and sustainability across additional settlements in Uganda is underway in partnership with key policy actors.

P 1.029 Democratizing Global Palliative Care Information: An Innovative Interactive Web Tool for All

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Background/aims: Palliative care (PC) development research findings have mainly been visualized through static mapping: regional PC atlases, the Global Atlas, and regional scientific articles. Therefore, new technologies adapted to users are needed to provide social and public health policymakers with easier access to dynamic information on global development. We aimed to improve access to PC data through an interactive, updated, intuitive, and customizable tool.

Methods: Following a direct compilation and an audit review of data presented in the regional and global atlases from 2007 to the present, we designed a webtool combining PC development data (services, use of medicines, education, health policies, research and empowerment of communities) and some World Bank socio-economic variables (gross domestic product, national health expenditure, and population). Specific software like Power BI and Mapbox supported the design process for near eight months.

Results: Freely accessible and interactive web service with information on 169 countries (14609 cells) representing all six world regions is presented. This tool is divided into one dashboard per dimension, all of them showing prominent variables by default, and an interactive filter system allowing customization of maps and graphics according to countries, regions and variable values. We drew up a home page as an overview of the entire project too. Currently, this service is available in English and a demonstration performed live with the EAPC congress attendants could show its potential.

Conclusions: Although this tool already allows a contextualized analysis of existing PC variables, the addition of new variables to enrich possible analysis is desirable. This tool favours the democratization and allowance of universal access to PC data.

P 1.030 Co-producing Resources for Hospice at Home Services:

Framework Analysis of Two Stakeholder Co-production Events

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Background/aims: The results from a national evaluation of Hospice at Home (HAH) services in England (Butler et al., 2022) provide evidence on the key elements and their contextual factors that are required to come together in different HAH services in order to provide the best possible care. Transfer of this knowledge to different stakeholder groups is needed to enhance application of research outputs.

Our aim is to collaboratively design and refine an interactive toolkit based on the Butler et al. (2022) evaluation findings; aimed primarily at HAH service providers, with secondary content for commissioners, and members of the public/patients/informal carers.

Methods: Two online co-production events were held to meet the above aims. Diverse groups of representatives participated in facilitated structured small-group discussions during the co-design and refinement events. Discussions were recorded, transcribed, and then analysed using qualitative framework analysis.

Results: Analysis of stakeholder discussions supported the potential of a toolkit to facilitate knowledge sharing between HAH services, and in turn to adapt and optimise care. Participants also explored ways to inform commissioners, to impact funding, system coordination and external services who work with HAH teams, as well as improving referral quality and accessibility for vulnerable groups. Usefulness and accessibility of the demo version of the toolkit was also discussed.

Conclusions: Approaches taken to facilitate events and perform data analysis enhanced co-production of the toolkit and allowed for inclusion

of stakeholder groups with varying needs and priorities. Proactively considering tensions and challenges of co-production can further enhance the relevance and effectiveness of knowledge transfer outputs (e.g., toolkits).

This project has been funded by the National Institute for Health Research Applied Research Collaboration for Kent Surrey and Sussex and Medway Community Healthcare.

P 1.031 Social Implications of Technology Applications in Palliative Care - Development of a Conceptual Framework

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Background/aims: Applying new smart and sensor-based technology has a high potential to support palliative care (PC), however they may fundamentally change the socio-cultural environment. The PC situation is very sensible and the patients and their families are particularly vulnerable, hence social implications of technology, e.g. potential changes of social interactions in the care context, have to be assessed rigorously in accordance with the PC principles. A framework on how to conceptualize, empirically assess and analyze social implications of using technology in PC is missing.

Methods: Drawing on ideas of *Value Sensitive Design* (Friedman et al. 1997) and *Actor-Network Theory* (Latour 1996) and the findings of a narrative literature review on social interactions and principles in palliative care, technology usage and acceptance models we drafted a framework. Discussions with an interdisciplinary team of palliative care experts, with experiences in technology research, informed the further development of the framework. The elaboration of the framework, e.g. linking appropriate methods, is an ongoing process.

Results: The framework conceptualizes social interactions in PC context and offers a structured procedure to analyze effects technology might have on them, permanently considering their conduciveness to the principles and objectives of PC. Technology interplays with interpersonal interaction and will introduce new human-technology interactions, which both can change the roles, tasks and self-understanding of the involved parties. Stakeholders' characteristics as well as organizational and societal preconditions influence these interactions and are part of the framework.

Conclusions: Our framework intends to inform researchers and developers of technology in PC on the social context of their applications and on technological, training and organizational requirements. Participatory research methods might support research on social implications. Further research is required to validate the framework.

P 1.032 The Changes of Healing State and Symptoms by High-resolution Natural Sound with Inaudible High-frequency Components among Terminally Cancer Patients; An Exploratory Study

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Background/aims: Music has shown positive effects on anxiety, pain and fatigue among cancer patients. Recently, high-resolution natural sound with inaudible high-frequency components (HNIH) has shown a relaxing effect among healthy persons. The aim of this study was to explore the change of healing state and symptoms by HNIH among terminally cancer patients.

Methods: Terminally cancer patients who were admitted into the Palliative Care Unit of our institute were eligible. Patients who couldn't consent and answer questionnaires were excluded. Patients rested for 30 minutes and listened to HNIH for 4 hours in their room. They completed the questionnaires 30 minutes before start of HNIH (T0), 30 minutes after start (T2), 4 hours after start (T3) and next morning (T4). The questionnaires included the healing scale (HS), Edmonton symptom assessment system revised (ESASr-J), patient global impression of change (PGI-C) and satisfaction of sleep. The changes of the healing scale, and their subscales, ESASr-J, PGI-C, satisfaction of sleep were analyzed.

Results: A total of 18 patients were analyzed (12 males and the mean age 69.4). The mean change of HS was 5.3 (95% confidential interval; -1.2 to 11.8, effect size; 0.39) at T2 and 6.6 (1.0 to 12.3, 0.49) at T3. Among the subscales of HS, Relieved Healing, Pure Healing and Refreshing Healing were significantly improved at both T2 and T3. The mean changes of Tiredness, shortness of breath, and anxiety at T2 were -0.6 (-1.18 to -0.04, 0.35), -1.0 (-1.72 to -0.28, 0.42), and -1.2 (-1.99 to -0.34, 0.52), respectively. Additionally, those of anxiety and well-being at T3 were -1.2 (-1.99 to -0.34, 0.52) and -1.3 (-2.58 to -0.09, 0.54). At both T2 and T3, 66.7% of patients felt improvement of their state. At T4, a half of patients rated improvement of sleep.

Conclusions: HNIH showed positive changes on healing, tiredness, shortness of breath, anxiety and sleep among terminally cancer patients. To elucidate the role of inaudible high-frequency components needs further research.

Conflict of interest: This study was funded by JVC KENWOOD.

P 1.033 Individual Voluntary External Clinical Supervision for a Specialist Palliative Care Team

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Background/aims: Clinical supervision is known to support Palliative Care practitioners. There is, however, less evidence of the use of individual voluntary clinical external supervision. Our trust has used this type of supervision for several years now and engagement with this service by the Palliative Care team is very high. However, this service has never been fully evaluated.

The aim of this project was to collect more data from the Palliative Care staff at our hospital and to look at the usefulness of individual supervision versus group supervision. An additional aim was to collect post-Covid resilience data.

Methods: We created a survey with about 15 questions which was sent out electronically to ensure confidentiality. Most questions were on a graded scale from 1-5, as per Likert scale. This survey sent to 10 doctors & 13 nurses. Responses were received from 10 doctors and 12 nurses (96% response rate). The survey also included a well-known resilience questionnaire.

The responses were then collated by an external member of our research group. All data was then analysed and results were then presented to our clinical governance meeting.

Results: Several main results stood out: 1. Individual supervision was seen as extremely important by 100% of respondents. 2. The use of a clinical psychologist external to the team was found to be important/ extremely important for 100% of staff. 3. The fact that supervision in our team is voluntary was seen as extremely important by 68% of respondents. In addition, it was interesting to see what this supervision was used for; for example, 18 staff used it for reflecting on their own professional development.

The Brief Resilience Scale showed that 87% of the team had normal to high resilience post-Covid.

Conclusions: This survey showed that access to individual voluntary clinical supervision provided by an external psychologist has supported professional development as well as personal well-being very successfully; particularly throughout the Covid pandemic.

P 1.034 Telemedicine, a New Technology - Can it Support Quality of Life Despite Serious Illness - The First Experiences

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Background/aims: All statistics show that Danes predominantly wants to die in their own home, despite this fact only a small proportion will actually spend the last time of their lives in their own home.

Aim: This project aims to investigate how palliative nursing professional videoconferencing can promote the quality of life of patients with palliative needs and their families. For palliative patients admitted to municipal temporary nursing home, who face problems of a physical, psychological and spiritual nature associated with serious life-threatening illness, so that they can return to their own homes.

Methods: Prior to the start of the video conferences, the staff at the municipal temporary nursing home are trained as a minimum in the use of SPICt, EORTC-QLQ 15 PAL and relative screening form. Additional training is organized based on the staff's feedback on their skills, and if a need emerges during the project, e.g. lack of CAM screening for delirium.

Video conferences are held with nurses from the palliative care team and at least one nurse from temporary nursing home, with the possibility of video participation by a general practitioner

Results: Preliminary results indicate satisfaction when patients and families meet competent staff.

As a side benefit, it is seen that the competences of primary nurses, social and health assistants and helpers are strengthened, and they improve their ability to identify patients with palliative needs, as well as the competences for palliative care and treatment at basic level are strengthened.

Conclusions: Knowledge and skills are important to be able to take care of the palliative needs of the seriously ill, and these skills are important in order for the patient to spend the last days at their own home. The technology can help to a certain extent, especially where there may be large geographical distances between the patient's place of residence and the specialized palliative care.

P 1.035 Web-based Support for Spouses of Patients with Life-threatening Illness Cared for in Specialised Home Care – A Feasibility Study

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Background/aims: Psycho-educational interventions for family caregivers have been shown to be effective, but not possible for all caregivers to attend, thus web-based interventions may be a complement.

Aim: To evaluate feasibility in terms of usability and acceptability of a web-based intervention, "narstaende.se", from the perspectives of spouses of patients receiving specialised home care.

Methods: In collaboration between healthcare professionals, researchers, a communication strategist and an IT consultant, a website was developed, containing videos with conversations between healthcare professionals and family caregivers (actors), informative texts, links to further information and a chat forum. The website content is theoretically and empirically grounded, built on earlier successful in-real-life interventions and aims to

provide support to promote preparedness for caregiving and death. The study had a descriptive cross-sectional design. Twenty-six spouses answered a questionnaire, before accessing the website and four weeks later, twelve spouses were also interviewed. Data was analysed through descriptive statistics and qualitative content analysis.

Results: Spouses experienced the website as user friendly, warm and welcoming, with relevant and informative content. Spouses would recommend "narstaende.se" to others in a similar situation. Videos were considered to be most easily accessible and contributing to a feeling of recognition and of sharing the situation. The online format was perceived as flexible, but still, not all spouses visited the website, stating the desire for support in-real-life.

Conclusions: A web-based intervention can be feasible for spouses of patients cared for in specialised home care, however, the digital format is not suitable for everyone. Further research is needed to determine the website's potential to provide support and increase preparedness for family caregivers in general.

P 1.036 A 'Digital First' Approach to Death Education and End of Life Planning

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Background/aims: Technology has an important role to play in many peoples care planning journey. MyWishes (UK) goal is to democratise death and dying behaviours through the use of technology, education and support. The aim of this presentation is to highlight how different geographic populations and hard to reach demographics can be engaged with through the use of technology, innovation, collaboration and joined up thinking.

Methods: Following a grant from Masonic Charitable Foundation, content to reimagine hospice wellbeing services at Michael Sobell Hospice and Harlington Hospice was created. A new 'Wellbeing Hub' will host much of the content. By integrating hospice wellbeing content alongside more generalised wellbeing content it is hoped that a theoretical and symbiotic bridge between the two areas is created. Furthermore, it is hoped that by exposing the general public to engaging hospice wellbeing content prior to the need for receiving care, the transition to receiving hospice care will be easier and less daunting in the future.

Compassionate Hillingdon pairs older people living with a life limiting illness and those suffering from isolation wanting to forge a relationship with a 'compassionate friend'. As part of the scope, a digital and non-digital approach to relationship building, information and care planning activities has been adopted. This includes the digital up-skilling the those supported, carers and volunteers.

Results: Bespoke care planning environments have been created for the needs of people living in Hillingdon and different regions in the UK. Each platform has relevant content to local need and supports existing health ecosystems. Modern and engaging content in Hillingdon was co-created with the wellbeing team and validated with existing service users. The results include cost savings, an increased number of Advance Care Plans and a digitally up-skilled population.

Conclusions: The importance of localised, person centred care planning activities and support will continue to increase.

Conflict of interest: I am the founder of MyWishes.

P 1.037 Nature-based Activities Provided to Groups of Patients with Incurable Cancer – A Feasibility Study

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Background/aims: Contact with nature can contribute to mental, physical and social health and encourage patients' coping and creativity. Nature-based interventions to groups of patients with incurable cancer have not been studied previously. Based on the hypothesis that these patients can equally accomplish and benefit from activities based on the surrounding nature's facilities, our Center for Rehabilitation and Palliative Care wished to develop and evaluate a course aimed at this target group. Aim of the study is to investigate the feasibility of a group-based rehabilitation course focusing on nature-based activities, designed for people living with advanced cancer.

Methods: A course of 7-weeks' duration was designed, based on the Center's experience with palliative rehabilitation to people with advanced cancer. Four courses, completed during April to September 2022, formed the basis for the feasibility study. Each course started with 4 days residential stay at the Center, 6 weeks at home practicing, and finalized by 2 days residential stay. Participants, interested in nature-based activities, who were self-reliant and able to walk a least 300 m, were referred by their doctor. Data from validated questionnaires (PRO-data) and from focus-group interviews were collected.

Results: Of 58 participants, who were referred to the four courses, 49 completed; 34 women (mean age; 60) and 15 men (mean age; 68). Cancer types were; breast (12), gastrointestinal (9), hematological (7), prostate (6), lung (5) and other types (10). Data regarding the participants' quality of life, autonomy, and functional capacity, including their feedback on the course and their views on physical testing, are being processed.

Conclusions: Nature-based activities provided to groups of patients with advanced cancer is feasible. Further development of the course is planned, so it can be included as an early palliative care service provided by the municipalities.

P 1.038 Exploring Burdens of Regular Paediatric Epilepsy Monitoring and Potentials of Radar-based Solutions – A Qualitative Approach

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Background/aims: Epileptic seizures are common in paediatric palliative care. Standard epilepsy monitoring implies attachment of equipment to the body, thus restricting the patient's mobility. Innovative touch free sensors offer possibilities for improvement. The purpose of this study is to describe the context of use in paediatric epilepsy monitoring with focus on the characteristics and interactions of stakeholders as well as their requirements on technology.

Methods: Participant observation of routine processes in standard epilepsy monitoring was conducted in a university paediatric ward and outpatient clinic. Episodes observed (n=40) were captured in field notes and protocols, and categorised to characteristics, tasks, interactions and individual burdens of the stakeholders within the current care situation. A focus group with neuro-paediatricians, nurses and physician assistants (n=6) was conducted to discuss the potentials of radar-based technology for epilepsy monitoring as well as potential risks and requirements; analysis was carried out via the mapping method on the potential users' requirements of usage and acceptance.

Results: The observation of the routine processes of standard epilepsy monitoring delivered a differentiated picture of burdens for the stakeholders. For children and their parents, the process can be particular demanding and emotional stressful. For nurses and doctors there is a high workload and physical strain. The focus group indicated that epilepsy monitoring with new radar-based technology can offer relief especially during the night and in the outpatient setting, however applications must be intuitive to use for stakeholders with different technical skills.

Conclusions: Radar-based technology has the potential to support epilepsy monitoring, reduce burden and alleviate quality of life in palliative care. Identified stakeholder-specific characteristics, context variables and usage and acceptance requirements should be addressed from the beginning of the technology development process.

P 1.039 Translation and Transcultural Adaptation of the Person-centred Practice Framework into the Spanish Context

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Background/aims: Person-centred care is a global approach to healthcare organisation and delivery, with a focus on service provision that keeps 'the person' central in complex decision-making. This has led to the development of conceptual frameworks that represent the components of person-centred care. The Person-Centred Practice Framework (PCPF) developed by McCance & McCormack (2021) is an internationally recognized theoretical framework that assists teams to understand the dimensions of person-centredness and how these dimensions can be operationalized in practice. The aim of this study was to create the first version of the PCPF translated and adapted into the Spanish context.

Methods: The PCPF was translated according to the "Translation and cultural adaptation process for patient-reported Outcomes (PRO) Measures" guidelines. A consulting session with experts was also part of the process. Moreover, each domain of the framework was assessed for content validity of clarity and relevance.

Results: There were no significant difficulties during the whole translation process and consulting sessions. There was a general consensus on most items, with the exception of one item, "having a sympathetic presence", which was complex to translate and adapt into the Spanish context. The content was assessed for relevance and clarity by each construct (I-CVI) and for the framework as a whole (S-CVI/Ave). The results showed that the translated PCPF was relevant to a Spanish context and the items were clear and consistent with the original framework ($\geq 0,90$).

Conclusions: The PCPF was translated into a clear, significant, and conceptual Spanish version. The availability of the PCPF in Spanish will allow a better comprehension of the person-centred practice framework in our context and will facilitate the implementation of this approach in clinical practice.

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P 1.040 A Smartphone App for Palliative Medicine Guidance: A Quality Improvement Project

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Background/aims: In keeping with the Irish palliative care competency framework, healthcare professionals should provide a palliative care approach to patient care when required. Education and accessible guidelines can significantly contribute to this delivery of care. The advent of technology means a continual shift towards smartphone-based applications and mobile phone technology to access medical information and as such, it is important that reliable sources are made available to healthcare professionals through modern technological means.

Methods: In our hospital, there is a detailed NCHD (Non-consultant hospital doctor) handbook on symptom control and palliative care in existence. However, at present it is not easily available to all NCHDs and healthcare professionals. The translation of this guidebook into a smartphone application would allow healthcare professionals to have reliable, accessible guidance on-hand at all times.

Results: Pending a current funding application to SPARK seed, we are undertaking the design of a smartphone app of clear, concise user-friendly guidance regarding commonly encountered issues in palliative medicine. This application will contain up to date information and guidance on end of life prescribing and symptom management and draw upon the pre-existing NCHD handbook as a resource. The application will explore the management of common symptoms such as pain, dyspnoea, nausea and vomiting, constipation, delirium in palliative care and respiratory secretions. It will also contain further information on discharge planning, medicines in palliative care, controlled drugs and useful palliative care resources.

Conclusions: It is important to have reliable guidance for healthcare professionals that is accessible and user friendly, with an aim to improve delivery of patient care in keeping with a palliative care approach. Adaptation of pre-existing guidelines to a smartphone application would contribute greatly to this.

P 1.041 OH2 - A Portable Drug Infusion Device

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Background/aims: The design of the syringe driver for the delivery of a continuous subcutaneous infusion (CSCI) has been largely unchanged since the 1970s. It is evident that there is a need for a more robust, cost-effective user-friendly alternative to the current portable CSCI devices. Current CSCI devices are environmentally unfriendly, requiring high levels of disposable battery use.

To develop a new CSCI design with a number of design specifications: to be portable, durable, waterproof, rechargeable and traceable.

Methods: Through interviews with product users in the field of palliative and supportive care an iterative design approach was taken and multiple iterations of the pump developed, manufactured as prototypes and tested to industry standards. Thirty iterations of mechanical and electrical prototypes were developed as part of an undergraduate research project in order to create a small and reliable pump that could deliver fluid at a constant rate, essential for safe drug delivery.

Results: This product has utilised peristaltic flow technology to create a direct replacement for current syringe drivers for use in hospitals, hospices and in the community. This has a worldwide application. Proving peristaltic flow technology could be applied to portable devices was key in getting this product to work. OH2 is capable of infusing up to 50ml of fluid over a period of 24 hours at variable flow rate. The combination of implementing new technologies, adhering to medical device requirements and ensuring continuity of professional user experience has come with its challenges. The infusion device balances innovative design with a familiar operation for professional users. The design can incorporate traceable technology to prevent asset loss for service providers.

Conclusions: It is feasible to develop a portable, durable, user-friendly, rechargeable, waterproof CSCI device at substantially lower unit cost than existing devices. The next stage of this development will be testing its commercial viability.

P 1.042 Wearable Devices Could Reduce the Risk of Injury in Parasomnia Phenotypes

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Background/aims: There are typical patterns - phenotypes - of sleep behaviors by age, and biological sex groups of parasomnia patients where wearable devices could avoid injuries.

Methods: We analyzed public video records on sleep-related behaviors likely representing parasomnias, looking for phenotypes in different groups. We searched public internet databases using the keywords "sleepwalking", "sleep eating", "sleep sex", and "aggression in sleep" in six languages. Poor-quality video-records and those showing apparently faked sleep behaviors were excluded. We classified the videos into estimated sex and age (children, adults, elderly) groups; scored the activity types by a self-made scoring scale; and applied binary logistic regression for analyzing the association between sleep behaviors versus the groups by STATA package providing 95% confidence interval and the probability of statistical significance.

Results: 224 videos (102 women) were analyzed. The odds of sleepwalking and related dangerous behaviors were lower in the elderly than in adults ($P < 0.025$). Females performed complex risky behaviors during sleepwalking more often than males ($P < 0.012$). Elderly people presented emotional behaviors less frequently than adults ($P < 0.004$), and females showed them twice often as males. Elderly males had 40-fold odds compared to adults and children, to perform aggressive movements, and 70-fold odds of complex movements in the bed, compared to adults.

Conclusions: Unlike other groups, the high chances of adults being sleepwalkers and elderly males performing intense and violent movements in bed showed us the importance of developing wearable parasomnia devices to prevent injuries.

P 1.043 Co-design of a Kids Dementia Game

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Background/aims: People living with dementia continue to raise concerns about how they are perceived and that people, including their families and health workers still do not understand their capabilities or how they might continue to meaningfully contribute towards society. Younger people are now experiencing dementia in their family with limited support due to a lack of understanding and/or negative perceptions. Positive education may facilitate a child's understanding and empower them to engage more effectively in relationships with people with progressive illnesses such as dementia. Digital gaming or 'gamification' is becoming an increasingly common way to educate/train.

Aim: To co-design a Kids Dementia Game

Methods: June – December 2021 virtual workshops were held with 10 people living with dementia discussing what children need to know about their condition, and face-to-face workshops were held with 30 primary school students who completed think clouds as prompts for the conversations about what children see when someone has dementia, what they needed to know about dementia and what children might do to help a person with dementia. Data were thematically analysed, then formed into statements to be ranked by children and people living with

dementia. Consensus was then reached on the game content and format.

Results: Three key themes for game content: 1) Children overwhelmingly felt they needed to know more about dementia, 2) Children are aware of the changes that impact on the person with dementia causing different behaviours, 3) children know that dementia is not a normal part of aging but their experience rests primarily with older relatives.

Conclusions: Children in this study categorically wanted to know more about dementia and believed that all children should know about it. People living with dementia also agreed and welcomed the idea of the game to help them explain to children why they might behave as they do due to their dementia. www.kids.dementiagame.com

P 1.044 Point of Care Ultrasound at Home for Palliative Patients Adds Value

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Background/aims: For palliative patients, ultrasound diagnostics are often used to determine common and treatable conditions such as ascites, pleural effusion and urinary retention for optimal symptom relief. Ultrasound examinations are traditionally performed in a hospital setting by radiologists. Point of care ultrasound (POCUS) is performed by non-radiologist physicians and could be used by home care physicians and add a lot of value for palliative patients in their homes.

The aim of the study is to assess the utility of POCUS with portable ultrasound in the diagnosis of ascites, pleural effusion and urinary retention in palliative home care patients and thereby avoid unnecessary hospital visits to maintain or even improve quality of life (QoL). Furthermore, POCUS could as well decrease costs for ultrasound diagnostics at radiology clinics for the home care units.

Methods: In this study we are including 100 patients from an advanced home care unit over 2 years. A pilot study including 30 patients has been performed. We will measure the amount of avoided hospital visits for ultrasound examinations. The patients will estimate their QoL before POCUS and 3 days after.

Results: Preliminary results indicate that POCUS is a safe procedure to perform in home care unit settings and that particularly negative findings in pleural effusion examinations were beneficial for the patients of which 93 % could avoid ultrasound examination at a hospital due to negative findings.

Conclusions: Ultrasound diagnostics at home for palliative patients to examine conditions such as ascites, pleural effusion or urinary retention are safe, cost effective for palliative care units and add a lot of value for the patients regarding quality of life (QoL) and the possibility getting care at home.

P 1.046 Assessment of Activities of Daily Living in Palliative Care with Smart, Sensor-based Devices and Ubiquitous Health: A Focus Group Study

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Background/aims: Health care professionals usually assess activities of daily living (ADL) performance using tools such as the Karnofsky index or the ECOG score (Eastern Cooperative Oncology Group) in palliative care.

From these assessments, consequences for the goals of care and therapy are drawn that complement health status monitoring. The one point in time proxy assessment carries several risks: It does not provide continuous assessment, may be influenced by white coat effect and physician subjectivity. Ubiquitous Health ("smart devices") may be able to provide objective information about ADL performance. It is unclear which ADLs are most promising for sensor-based analysis.

Methods: We conducted an interdisciplinary mini focus group at Erlangen University Hospital. All professions involved in patient care were invited to participate. We collected information about typical patient activities, indicators for health deterioration, current observation techniques, the influence of sensors on patient behavior, patient acceptance, information presentation to staff, and most promising activities for sensor-based monitoring. All participants provided informed consent. Audio was recorded and summarized afterwards.

Results: Three participants (nurse, physician, physiotherapist, all >5 years of professional experience) engaged in the mini focus group. The idea of sensor-based objective measurement was accepted overall. Participants stated tooth brushing, walking, combing, drinking (cup), mobile phone use, sitting, and sleeping as the most promising ADLs for sensor-based monitoring and objective assessment. Attaching passive sensors (e.g. radio-frequency identification) to the patients' body, including wristbands or on shoes, was considered feasible. The presence of sensors was not expected to change patients' behavior.

Conclusions: The use of smart devices is promising for the objective assessment of ADL performance. We started to investigate using a smart toothbrush for this purpose and will report first results soon.

P 2 - Challenges in Symptom Management

P 2.001 Validation of the 4AT for Delirium Detection in Patients Receiving Palliative Care in a Hospice Inpatient Setting

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Background/aims: Delirium is a serious neuropsychiatric syndrome, which is common amongst terminally ill patients. It often goes underdiagnosed and undertreated. Early detection may improve patient outcomes. The 4 'A's Test (4AT, www.the4AT.com) is a brief tool for delirium detection in routine clinical practice. It has been validated in 25 studies involving more than 5000 observations. The test is currently used in specialist palliative care units but has not been validated in this setting. The aim of the study was to determine the diagnostic accuracy of the 4AT against a reference standard in hospice inpatients.

Methods: Test validation study conducted in two hospice inpatient units in Scotland, UK. Participants underwent the 4AT and a reference standard assessment based on the diagnostic delirium criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The assessments were conducted, in a randomised order, by pairs of independent raters, who were blinded to the results of the other assessment.

Results: 148 individuals were recruited, including 14% (19/148) who required a legal proxy to consent on their behalf. 137 participants completed both assessments. Of these, 93% had cancer as their primary diagnosis. Mean age was 70 years and median Karnofsky Performance Status 50%. 5% (7/137) had dementia as a comorbidity. 50% (69/137) of participants died during this hospice admission and 36% (49/137) were discharged home or to another care setting. Three participants with an indeterminate diagnosis were excluded from analysis. 33% (44/134) had delirium according to the reference standard, and 33% (44/134) according to the 4AT. The 4AT had a sensitivity of 88% and specificity of 94%.

Conclusions: The 4AT is a short delirium detection tool that can be used to detect delirium in patients receiving palliative care. Routine delirium screening using the 4AT on admission to a hospice service is recommended.

P 2.002 Oxycodone/Naloxone PR Is Superior for Constipation and Analgesically Non-inferior to Oxycodone PR in Advanced Cancer: First Report of a Multi-centre, Randomised Phase IV Trial

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Background/aims: Opioid-induced constipation (OIC) is a common side effect of Oxycodone. Oxycodone/Naloxone Prolonged Release (OXN PR) contains naloxone, which mitigates OIC as demonstrated in patients with chronic non-cancer pain. In palliative care, the use of OXN PR has raised concerns of poor analgesic efficacy with limited benefit in OIC. We aimed to demonstrate analgesic non-inferiority, and constipation superiority of OXN PR compared to Oxycodone Prolonged Release (Oxy PR).

Methods: This multi-centre open-label randomised controlled trial of OXN PR vs Oxy PR for cancer-related pain was conducted at 5 Australian sites. The primary outcome was average pain difference on Brief Pain Inventory-Short Form (BPI-SF) at 5 weeks. Prespecified equivalence margin was 1. Secondary outcomes were comparison of other pain outcomes (BPI-SF), constipation (Bowel Function Index, BFI), quality of life (EORTC-QLQ-C30), and opioid and laxative dose over 5 weeks. Intention to treat analysis was performed. Participants had moderate-severe pain ($\geq 4/10$), no biochemical liver dysfunction, and usual laxatives were allowed.

Results: 37 of planned 96 patients were recruited with the study stopping early due to the pandemic. Mean age was 63, and mean AKPS 70. Most were male (57%), had solid cancer (87%) and bony metastases (68%).

Average pain was 2.6 (95%CI 1.2;4.0) out of 10 in the OXN PR group and 4.1 (95%CI 2.9;5.3) in the Oxy PR group at 5 weeks, mean difference was -1.5 (95% CI -3.3;4). At each of the 4 timepoints, other pain outcomes (worst pain, least pain, pain now) were always lower in the OXN PR arm.

Mean BFI difference was large, -25 (95%CI -48;-2), p0.03, much lower in the OXN PR arm.

Conclusions: OXN PR is analgesically non-inferior to Oxy PR, and superior in constipation outcomes. This is the first trial examining pain and constipation outcomes between these agents in an advanced cancer population receiving palliative care. These important results suggest OXN PR as choice of opioid preparation in advanced cancer.

P 2.003 Anticipatory Prescribing in Community End of Life Care: Systematic Review and Narrative Synthesis of the Evidence Since 2017

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Background/aims: The anticipatory prescribing of injectable medications is recommended practice in controlling distressing symptoms in the last days of life. Our 2017 systematic review found practice and guidance was based on inadequate evidence. Since then, the evidence base has changed significantly, warranting a new review.

Aim: To review the evidence published since 2017 concerning anticipatory prescribing of injectable medications for adults at the end of life in the community.

Methods: Systematic review and narrative synthesis. Nine literature databases were searched from May 2017 to March 2022, alongside reference, citation and two journal hand searches. Gough's Weight of Evidence framework was used to appraise the robustness and relevance of studies. PROSPERO registration 42016052108.

Results: Twenty-eight papers were included in the synthesis. The standardised prescribing of four medications for anticipated symptoms is commonplace in the UK; evidence of practices in other countries is limited. There is inadequate data on how often medications are administered in the community. The prescribing of anticipatory medications is a significant event for patients and signifies the imminence of death. Prescriptions are accepted by family caregivers despite inadequate explanations, and they generally appreciate having access to medications. Robust evidence of the clinical and cost-effectiveness of anticipatory prescribing remains absent.

Conclusions: Anticipatory prescribing practice and policy remains based primarily on healthcare professionals' perceptions that the intervention offers reassurance and provides effective, timely symptom relief in the community. There is still inadequate evidence regarding which medications and dose ranges are needed. Patient and family caregiver experiences of anticipatory prescriptions warrant further investigation. Urgent research is necessary to investigate the clinical effectiveness, cost-effectiveness, safety and acceptability of different anticipatory prescribing practices.

P 2.004 Association between Electrolyte Abnormalities (EA) and Symptom Burden (SB) in Advanced Cancer: A Cross-sectional Observational Study

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Background/aims: Advanced cancer patients experience multiple distressing symptoms. Impact of symptoms on patients is described as symptom burden. Published reports indicate that electrolyte abnormalities are common, aggravate symptoms, prolong hospital stay and worsen survival in advanced cancer patients in hospitals.

Aim: To determine the prevalence of EA and SB and association between them in advanced cancer patients in hospice settings.

Methods: 208 advanced cancer patients referred to a hospice in New Zealand were recruited between April 2017 and July 2020. Patients' symptoms, performance status and estimated survival was measured using validated tools, and laboratory serum electrolyte (Na, K, Ca, Mg) results collected at the initial assessment. SPSS was used for statistical analysis. Ethical committee approved the study.

Results: Males were 50.1% and mean age was 68 years, range 29-79. Assessment location was hospice in over 50%. The most prevalent cancers were lung, 24% and gastrointestinal 19.2%. Patient's performance status was good in 49% and 18.45% had estimated survival \leq 3 weeks. Median of moderate to severe symptoms reported per patient was 6. 38% had EA of which Na (10.1%) and Mg (7.7%) were most common. A chi-square test determined that there is a statistically significant association between electrolyte abnormalities and symptom severity and whether symptoms were mild or moderate to severe, $\chi^2(1) = 15.151$, $p = .005$. This was primarily between Na and depression, Na and nausea, Ca and dyspnoea and K and depression.

Conclusions: The results highlight that electrolyte abnormalities are less common in advanced cancer patients in hospice settings. However, as the associations between EA and SB noted in the study may impact symptom management, further investigations is advisable.

P 2.005 Transdermal Diclofenac Sodium: Examination of the Usefulness of a New Approach in Palliative Care

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Background/aims: In May 2021, the world's first systemic-acting transdermal diclofenac sodium patch for persistent cancer pain was launched in Japan. We have started to use it since shortly after it was released at our Ashiya Municipal Hospital. Cancer patients often have difficulty with oral intake due to symptoms such as nausea, vomiting, dysphagia, and gastrointestinal obstruction. We retrospectively investigated its efficacy and adverse effects.

Methods: We investigated the use of diclofenac sodium patch preparation at our hospital for one year, from May 2021 to April 2022. We reviewed the medical records and checked age, gender, cancer site, the use of NSAIDs, the combination of opioids, the reason for starting administration, the reason for discontinuing administration, the effect, and adverse effects.

Results: Used by 65 patients (34 women and 31 men), the mean is 73.3 ± 13.3 years. The primary sites were colon in 13 cases, breast in 8 cases, pancreas in 7 cases, lung in 5 cases, and stomach in 4 cases. With 45 patients (69.2%) were used prior NSAIDs and with 48 patients (73.8%) were used opioids in combination. 35 patients (53.8%) had difficulty with oral intake and started using the patch for pain control; pain was relieved in 23 out of 35 patients (65.7%). Antipyretic effect was observed in 10 out of 16 patients (62.5%) with fever of 37.5 degrees or higher. The patches peeled away in 18 cases (27.7%), and skin symptoms as an adverse effect were observed in 5 cases (7.7%).

Conclusions: Although there is a bias in the used situation due to the retrospective observational study at a single facility, our results imply that the transdermal diclofenac sodium is useful in the palliative care setting. The patches easily peel away, and once removed, the adhesive strength decreases. It is also necessary to pay attention to skin symptoms.

P 2.006 Cool Facial Airflow Speeds Recovery from Exertion Induced Breathlessness in People with Chronic Breathlessness

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Background/aims: Evidence supports facial airflow from a hand-held fan (fan) to reduce breathlessness in patients with chronic breathlessness. We tested the effectiveness of different airflow speeds on recovery from exertion-induced breathlessness.

Methods: Repeated n=1 randomised controlled trial with moderate-severe chronic breathlessness (mMRC \geq 3). The order of four airflow speeds and a control (no fan) were randomised for use during 10 minutes' recovery from breathlessness induced by a 1-minute sit-to-stand test (5 tests in total). Numerical Rating Scale (NRS) breathlessness intensity (every minute), facial skin thermal imaging (every 5 minutes), oxygen saturation and heart rate (every 30 seconds) were recorded over 10 minutes. Data were analysed using descriptive statistics, repeated measures ANOVA, with simple contrast analysis.

Results: 10 participants recruited (n=1 withdrawn due to health concerns, and n=1 excluded due to limited exertion-induced breathlessness post exercise test).

8 participants (mean age 65 ± 15 yrs, range 34-82 yrs; 5 men; 7 COPD, 1 Long Covid) completed assessments. An interaction effect for fan speed over time ($p=0.010$, $\eta_p^2=0.192$) suggests that airflow speed impacted breathlessness recovery from exercise. Simple contrast analysis showed a difference between fan and control, reaching statistical significance with fan speed of 2.85 m/s ($p=0.02$, FDR=0.08).

A main effect of fan speed ($p<0.001$, $\eta_p^2=0.758$) and interaction effect of fan speed over time ($p<0.001$, $\eta_p^2=0.686$) indicate that airflow speed reduced skin facial temperature compared with control. A fan speed of 4.91 m/s had the greatest cooling effect but not the quickest recovery and participants stated they found this speed unpleasant.

Conclusions: Facial airflow from a fan improved exertion-induced breathlessness recovery and reduced facial skin temperature. The proposed optimal airflow speed for breathlessness recovery is 2.85 m/s.

P 2.007 Opioid Switching Is Effective in Advanced Cancer Pain and Final Equianalgesic Doses Vary Depending on Opioid Used

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Background/aims: Cancer pain has variable responses to different opioids. Opioid switching is recommended if poor analgesia or side effects are seen, and studies of opioid switching observe improved pain outcomes. This improvement may be caused by change to a more effective opioid and/or higher equianalgesic doses.

We aimed to characterise patients with advanced cancer requiring an opioid switch compared to a control group on stable opioid doses, and to determine doses post-switch.

Methods: This prospective longitudinal study recruited consecutive adult patients from 5 Australian centres. Decision for opioid switch was based on palliative care physician decision. Paired data include pain characteristics, side effects, and treatment efficacy at baseline (T0) and 7 days (T1) using validated instruments. Wilcoxon signed-rank test was used.

Results: 58 patients (24 control, 34 switch) were recruited. At baseline, the switch group experienced more severe pain than the control group (worst pain 8 vs 6/10). Opioid switch resulted in significantly improved average pain (pain 5->4, $p.004$), function (7->4.5, $p.003$), mood (7->5, $p.05$), and sleep (7->4, $p.01$) at T1 vs T0. Clinicians rated superior global improvement in switch group (mean efficacy index 2.22 vs 1.52; $p<0.05$).

To achieve final stable dose, median oral morphine equivalent daily dose (oMEDD) increased by more than two-fold for those switched to hydromorphone (2.2 fold) and morphine (2.1 fold), but reduced for oxycodone (0.9 fold) and fentanyl (0.8 fold). Patients switched to another opioid had a better improvement in pain than control patients. This was particularly true when different SR and IR opioids were used in combination post-switch.

Conclusions: Opioid switching significantly reduces cancer pain and associated symptoms. Final stable switched opioid dose in oMEDD varies between opioids. It is not known whether this reflects a variable effect from opioids or that opioid conversion tables are not accurate in chronic cancer pain.

P 2.009 Guidelines on Sedation in Palliative Care – A Systematic Review from a Clinical-practical Perspective

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Background/aims: Differing recommendations exist on sedation in palliative care (“intentional sedation”, “palliative sedation”). This study gives an overview on clinically relevant recommendations regarding “indication”, “medication”, “risks” and “monitoring”.

Methods: A systematic search was performed for scientifically (pubmed, scopus and google scholar) and on websites of organizations published official recommendations on sedation in palliative care. Quality assessment was made using the AGREE II instrument. A structured content analysis was performed.

Results: Overall, 30 (12 scientifically published) relevant publications were retrieved. Domain with highest mean AGREE scoring was “scope and purpose” (78%), lowest scores were found for “rigor of development” (42%) and “editorial independence” (36%). Mean AGREE-scoring of scientifically published guidelines did not differ significantly from the others.

Intentional sedation (“palliative sedation”) is mostly seen as indicated only in patients with a prognosis of days to approximately two weeks. Main indications for sedative treatment are delirium, dyspnoea and pain. Most recommendations mention existential or psychological suffering as indication with special precautions, only five accept it as an unrestricted indication, two object to it. The majority of recommendations advise to monitor symptom burden and level of sedation. Midazolam generally is first choice for sedative treatment, dosing recommendations start from 0,4mg/h and end at 70mg/h. Risks identified in the guidelines are heterogenous, containing mainly loss of communication skills and autonomy; seven guidelines do not mention any risks.

Conclusions: International guidelines on sedative treatment in palliative care often are not published as scientific articles. The guidelines correspond in many aspects; main differences concern existential suffering as indication. The described risks of sedative treatment vary considerably. New guidelines shall consider treatment risks to support informed consent.

P 2.010 Best Practice Recommendations on the Use of Sedative Drugs in Specialist Palliative Care - Development and Expert Approval

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Background/aims: The use of sedative drugs and sedation in end-of-life care bears clinical, ethical and legal challenges. Nevertheless, this treatment option is of great importance to patients with unbearable suffering in specialist palliative care (SPC). We aimed to develop best practice recommendations on the use of sedative drugs and intentional sedation in SPC and to obtain experts' feedback and approval.

Methods: Step-wise approach on drafting the recommendations, obtaining experts' feedback, applying a single-round Delphi and consecutive consensus conference. The interdisciplinary consortium developed best practice recommendations based on previously published guidance and empirical and normative analyses and relied on experts' feedback. Employing an agreement rate of $\geq 80\%$, experts, including representatives from the patient and public involvement (PPI) groups, consented the recommendations in a single-round Delphi and consecutive consensus conference.

Results: Ten experts commented on the first draft of recommendations. The Delphi panel consisted of 50 experts and PPI participants, the consensus conference of 46 participants. In total, 66 recommendations were approved, on the topics "indication", "intention/purpose", "decision making", "information and consent", "medication and types of sedation", "monitoring", "dealing with artificial hydration and nutrition", "continuing other measures", "accompanying next of kin", and "team support". In addition, the recommendations include suggestions on terminology and comments on legal challenges.

Conclusions: The recommendations and the suggested terminology may serve as a resource for healthcare professionals in Germany on the use of sedative drugs and intentional sedation in SPC and contribute to the international discussion on sedation in palliative care. Implementation, feasibility and effectiveness of the recommendations need further evaluation.

P 2.011 Spiritual Pain and Financial Distress in Advanced Cancer Patients. A Feasibility Study Using the New Spanish Version of ESAS-FS

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Background/aims: Spiritual and also financial distress are important factors contributing to the suffering of advanced cancer patients and their families. In 2012, the Edmonton Symptom Assessment System (ESAS) was modified in its English version, adding scales (0 to 10) for financial distress and spiritual pain (ESAS-FS). Recently, the ATLANTES group of the University of Navarra developed a Spanish version through back translations and a consensus process with professionals that is elsewhere reported.

Aims: a) To determine the feasibility of the Spanish version of the ESAS-FS and to explore the relevance, appropriateness and perceived comfort for Spanish patients evaluated with the new version of the scale.

Methods: Consecutive patients with advanced onco-hematologic diseases were proposed to be evaluated with the new ESAS-FS version. Dichotomous questions about the relevance of the scales, the terms for asking, and, on a scale of 0 to 10, the level of comfort perceived were added after the ESAS. The prevalence and intensity of spiritual or

economic distress were determined. Ethical approval and informed consent were obtained.

Results: A sample of 50 patients were included. One patient refused to participate; 82% (41/50) considered the questions relevant and 94% (47/50) considered the terms appropriate. Only 21% experienced some discomfort answering, at very low levels of 0,68 (CI95% 1,2 - 0,16). In the sample, spiritual pain was 2,7 (CI95%: 3,41 - 2,02) with 36/50 patients experiencing more than 0 pain; financial distress was 2,34 (CI95%: 3,18 - 1,49) with 25/50 affected.

Conclusions: The Spanish version of ESAS-FS was highly feasible. The patients perceived the new scales as comfortable, relevant and appropriate. Spiritual pain and financial distress are common in advanced cancer patients with more than a half experiencing both at some levels.

P 2.012 Effect of Home-based Brain Neuromodulation on Quality of Life in Patients with Chronic Pain: A New Model for the Palliative Care of Pain?

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Background/aims: Chronic pain (CP) is one of the most important public health priorities. Its management continues to be a challenge for palliative care units, due to the inefficacy of current treatments mostly reliant on pharmacology. Transcranial electrical stimulation (tES) may be a useful alternative for correcting defective central pain mechanisms, changing pain perception and improving Quality of Life (QoL), severely impaired in CP disorders. The objective of this study was to determine the effectiveness of a home-based intervention with tES on the QoL (measured by the SF-36) of CP patients and whether this treatment model could be feasible in palliative care.

Methods: In a double-blind, placebo-controlled design (N=40) we randomly assigned CP patients into three groups: active transcranial direct current stimulation of motor cortex (tDCS; 40%), active transcranial alternating current stimulation at 10Hz over parietal cortex (tACS; 40%) and sham stimulation (20%). The patients conducted the 15 daily tES sessions at home, being monitored remotely. We considered the SF-36 (subscales and mean score) as the outcome variables (assessed before and after the treatment).

Results: After the intervention, we found improvements for the SF-36 subscales Physical Functioning, Body Pain, General Health, Vitality, Social Functioning and Mental Health subscales, irrespective of the group. By contrast, for the mean SF-36 we found a significant time (pre-post) x group interaction: active stimulation groups improved significantly more their QoL after treatment; however, the sham stimulation group did not show this improvement.

Conclusions: Our results with the individual SF-36 subscales suggest that the QoL improvements in all groups may be related to positive expectations on the efficacy of neuromodulation. Nevertheless, considering the mean SF-36 score, we found that active tES was more effective than sham. Thus, our research suggests that home-based tES could be implemented in palliative care to improve the QoL of CP patients.

P 2.013 E-StOIC Study: Single Question versus Rome IV Diagnostic Criteria for Diagnosis of OIC

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Background/aims: E-StOIC study is an observational study of diagnostic criteria, clinical features and management of opioid-induced constipation (OIC) in cancer patients from 10 European countries. This abstract describes the results of the Irish cohort.

Methods: Cancer patients receiving opioid analgesics for at least a week were recruited, and asked to complete a questionnaire including background information, single question (Are you constipated?), EAPC definition of constipation, Rome Foundation diagnostic criteria for OIC, and Bowel Function Index (BFI). Rome IV diagnostic criteria are validated in this population.

Results: 120 patients recruited: median age 68.5yr (range 30-96yr); 44% female, 56% male; 27% GI cancer, 21% lung cancer, 16% breast cancer, 12% urological cancer; 47% ECOG PS 2, 23% ECOG PS 3; 35% oxycodone, 28% morphine, 13% fentanyl, 13% oxycodone/naloxone combination.

37% (44) patients self-reported constipation (single question). However, 61% (73) patients met Rome IV criteria for OIC, i.e. 36 (82%) patients reporting constipation, and 37 (49%) patients reporting no constipation.

64% (28) patients reporting constipation agreed that "the passage of small, hard faeces infrequently and with difficulty" described their bowel habit (EAPC definition). However, 43% (33) patients reporting no constipation also agreed with this definition.

38% patients reporting no constipation had a BFI >28, which is indicative of inadequate management of constipation.

Conclusions: Many patients with OIC (diagnosed using the Rome IV criteria) do not consider themselves constipated, and the use of a simple yes / no question to assess OIC is not sensitive.

Conflict of interest: The study was funded by an unrestricted research grant from Kyowa Kirin.

Rome IV diagnostic criteria	Patients with OIC (≥ 2 diagnostic criteria) reporting problem n = 73	Patients without OIC (< 2 diagnostic criteria) reporting problem n = 47
Had to strain during more than one-fourth (25%) of defecations	57	3
Had lumpy or hard stools (BSFS type 1-2) for more than one-fourth (25%) of defecations	46	5
Had the sensation of incomplete evacuation with more than one-fourth (25%) defecations	60	7
Had the sensation of anorectal obstruction / blockage with more than one-fourth (25%) defecations	36	2
Had to use manual manoeuvres to facilitate more than one-fourth (25%) defecations (e.g. digital evacuation, support of the pelvic floor)	5	0
Had fewer than three spontaneous bowel movements per week	36	2

P 2.014 Delirium Prevention in Hospice In-patient Units: A

Focused Ethnography

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Background/aims: Delirium is common and distressing for hospice in-patients. Hospital-based research shows delirium is preventable, but there is little research from hospice settings.

Aims: To explore the behaviours of hospice in-patient staff in relation to delirium prevention, and the influences on them.

Methods: A focused ethnography in two hospice in-patient units used observation, semi-structured interviews and document review, informed by delirium guidelines and behaviour change theory.

Results: 236 hours of observation with 89 participants (multidisciplinary staff, volunteers, patients, relatives) and 10 semi-structured interviews were conducted.

Staff enacted delirium preventative behaviours as part of fundamental care e.g. orientating patients and helping them to eat and drink. This was supported by person-centred essential care being highly valued in hospice culture, adequate staffing levels and multidisciplinary team engagement. However, most staff carried out these behaviours without delirium prevention as an explicit aim. A lack of structured processes limited how systematically some were implemented. With advancing illness, some preventative behaviours, such as mobilising patients, became more limited or required adaptation. Decision-making to balance benefits, risks and patient preferences became more complex. For example, regarding clinically assisted hydration and medication use.

Conclusions: The value placed upon high quality fundamental care in hospices, and corresponding resource provision, supports delirium prevention behaviours but these require adaptation as patients become closer to death. These findings are applicable to seriously ill patients in other settings.

Our findings can be used to inform the development of an intervention which increases staff's understanding of the rationale for delirium prevention and enables systematic implementation of delirium prevention behaviours, tailored to the hospice in-patient setting.

P 2.015 The Health Care Professional's Perception of EORTC-QLQ-C15-PAL in Specialist Palliative Care - Results from a National Survey

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Background/aims: Patient reported outcomes (PRO) have been systematically assessed in specialist palliative care (SPC) in Denmark since 2010 using the EORTC QLQ-C15-questionnaire. However, little is known on how health care professionals (HCPs) use this information. We investigated the perception of PRO data by HCPs in SPC at the first SPC contact.

Methods: A survey was conducted among HCPs in SPC services. The survey included questions on how HCPs experienced using PRO and how HCPs experienced the patient perception of PRO. The questionnaire was initially tested by four HCPs and then sent to all SPC service leaders (N=42) in Denmark, asking them to forward the survey invitation to all HCPs in their service.

Results: The survey was completed by 159 HCPs from 35 (83%) SPC services. Three quarters of HCPs replied that they used the responses from at least 75% of the patients: 61% answered that they used the PRO response in the conversation with more than 75% of the patients, while smaller proportions were presented/discussed the PRO at interdisciplinary conferences and discussed with colleagues. A large proportion of HCPs experienced to some/a high degree that PRO gave them knowledge about the patient's situation (89%), that PRO was meaningful to use (85%) and that they understood how and why PRO was used (93%). The perception of most of the HCPs was that the patients understood why they were asked to complete PRO (83%) whereas 69% of the HCPs experienced that the patients found the PRO completion meaningful.

Conclusions: In Denmark, PRO is integrated in SPC in the first contact with the patients and usually used in the dialogue with the patient. The HCPs found PRO useful and use the information in the contact. Among other data, these results contributed to the development of a 'best practice guideline', with detailed advice to SPC clinicians about how to collect and use PRO data and how to inform patients about the use of PRO; this guideline was circulated to all SPC units after the study.

Fund: Danish Cancer Society

P 2.017 Facilitators and Barriers during Decision Making of Palliative Sedation: Experiences of Relatives and Health Care Professionals

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Background/aims: The decision-making process about palliative sedation can be experienced as very distressing for the relatives. Our knowledge with regard to the decision-making procedure is still limited.

Aims: to learn about the facilitators and barriers for the relatives and health care professionals during the decision-making phase of palliative sedation and to compare the facilitators, and barriers across five European countries (Belgium, Germany, Italy, Netherlands, and Spain)

Methods: Semi-structured interviews were done with relatives and health care professionals of a sedated patient. The data collection started in July 2021 and is still ongoing. The recruitment of the respondents was linked to an observational study in which patients were palliatively sedated. The interviews were held 2-3 months after the death of a sedated patient. NVIVO was used to analyze the data.

Results: In total 40 interviews are held. The preliminary results indicate that important facilitators are: 1) Palliative sedation seen as a relief from suffering, 2) being familiar with the concept of palliative sedation, and 3) a clear request of the patient for palliative sedation. Some important barriers were: 1) family's opinion about palliative sedation, 2) therapeutic persistency (especially in the acute hospital)/ carefulness, and 3) doubts about the efficacy of palliative sedation (e.g., lock-in syndrome).

Conclusions: During the decision-making process some facilitators and barriers are present. A better understanding could help healthcare professionals to respond to the difficulties or barriers related to the decision-making phase, but it is also important to have a good understanding of what facilitates the decision-making process.

P 2.018 Patterns and Costs of Parenteral Opioid Administration – Assessing the Need for Patient-controlled Opioid Dosing in a Metropolitan Palliative Care Unit

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Background/aims: The foundation of pain management for palliative care patients requiring parenteral opioid is a continuous subcutaneous infusion (CSCI), with nurse-administered subcutaneous boluses for breakthrough pain. Patient-controlled opioid dosing (PCOD) allows patient administration of a bolus dose of opioid with optional background infusion.

This study aimed to define the patterns and costs of bolus subcutaneous opioid use in a palliative care unit (PCU) to determine the utility and benefits of introducing subcutaneous PCOD.

Methods: Thirty-three patients admitted to a metropolitan PCU within a one month study period were identified. Data collected retrospectively included patient demographics, duration of hospitalisation, and opioid type and dose given. Linear regression models were utilised to explore associations between clinical variables and breakthrough analgesia use. The time taken for nurses to administer opioid doses was measured prospectively for ten doses. The cost of consumables was also collated.

Results: No correlation was found between disposition, opioid use and any covariate studied, including age, sex and illness type. 347 parenteral opioid doses were administered during the study period, 143 (41.2%) were morphine at a 2.5 mg or 5 mg dosage. [CA1] Mean time for nurse administered analgesia was 12:53 minutes (range = 7:21- 27:46); this delay was essentially eliminated with PCOD. Average patient dose cost comparisons show PCOD provides a 63% cost saving compared to nurse-administered opioid boluses (\$113.75 vs \$310.80). Taking into account the initial cost of the CADD pumps, cost benefits can be demonstrated after 6 months of projected PCOD use.

Conclusions: The introduction of PCOD to a PCU has the potential of being a cost effective method to significantly reduce delays delivering analgesia to patients. In addition, patient care will be improved with analgesia administered more rapidly.

P 2.019 Exploring the Palliative Care Needs of People Living with Frontotemporal Lobar Degeneration (FTLD) Using the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem)

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Background/aims: People with Young-onset Dementia such as FTLD experience symptoms affecting their physical, psychological, social and spiritual wellbeing. Although FTLD is a life-limiting illness, there is little research exploring symptoms from a palliative care perspective and a measure of palliative care needs of people with FTLD is not available. The IPOS-Dem is a comprehensive measure of palliative care needs and may have potential for assessing needs in people with FTLD.

Aim: To explore the palliative care needs of people living with FTLD using the IPOS-Dem.

Methods: Longitudinal, mixed-method cohort study recruited people with FTLD in the moderate-severe stages and their informal carers as proxy where necessary. Participants completed the IPOS-Dem at baseline, 3-months and 6-months.

Results: Assessments were completed with 26 proxy respondents who were all informal carers of people at the moderate (n=11) and severe stages (n=15) of FTLD. People living with FTLD were mostly male (n=16) and aged between 52-80 years (M=66.8). Scores at baseline, 3-months and 6-months indicated increasing needs in physical (M=18.2[10.2], 20.3[7.8], 20.9 [7.6] respectively) and psychological (M=5.8[3.0], 6.6[3.7], 6.1[3.5] respectively) domains. Scores for the social and spiritual domain decreased between baseline (M=3.2 [2.1]) and 3-months (M=2.4[2.2]) but increased between 3- and 6-months (M=3.1[1.9]). Baseline scores indicated high needs in communication (M=2.7[1.5]), weakness or lack of energy (M=1.8[1.4]) and agitation (M=1.7[1.5]). Carers reported high levels of anxiety and worry for the person living with FTLD (M=2.5[1.3]). Missing data indicated that 23% of carers were unable to assess pain.

Conclusions: The IPOS-Dem was found to be acceptable by carers and has potential to be a comprehensive measure of palliative care needs for people living with FTLD. Further work is needed to explore the potential of developing an IPOS-Dem FTLD specific version.

P 2.020 Effect of an Evidence-based mHealth Intervention on Cancer Pain Outcomes among People Admitted to an Inpatient Palliative Care Unit: A Wait-listed Randomised Controlled Trial

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Background/aims: People living with advanced cancer often experience unrelieved pain. Sub-optimal pain screening and assessment are one of many contributing factors.

Aim: To evaluate if a tailored mHealth intervention targeting clinicians' cancer pain assessment capabilities effectively reduced self-reported cancer pain scores by 30%, measured by patients' numerical rated pain scale (NRS).

Methods: A phase III wait-listed RCT of a mHealth cancer pain assessment intervention. Participants were clinicians caring for inpatients with cancer pain in four Australian palliative care units. The COM-B theoretical framework informed the intervention development which integrated several evidence-based elements: 1) spaced learning, 2) audit and feedback and 3) targeted input from site 'clinical Champions'. Participants were randomly allocated to the active or wait-listed mHealth intervention, delivered via an online (QStream) platform to mobile devices over four weeks. Patients' pain NRS scores, pain assessment results and participants' cancer pain assessment knowledge and confidence were collected at three time points. Australian New Zealand Clinical Trials Registry: ACTRN12618001103257.

Results: Ninety-five clinicians completed the trial: intervention (n=46) and control (n=49) groups. While the intervention did not reduce patients' reported pain scores, significantly more patients were screened for pain on admission (p=0.008), had documented pain NRS (p=0.010) and the intervention increased clinicians' cancer pain assessment knowledge (p=0.002) and confidence (p<0.001).

Conclusions: As changing clinician behaviours in complex operating environments is known to be challenging, focusing on collective actions may have been more effective than focusing on individual clinicians. Further research is required to establish the strategies most effective for embedding cancer pain screening and assessment into routine clinical practice.

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P 2.021 Changes in Medication within an Outpatient Palliative Care Population – A Retrospective Analysis of 10,464 Cancer Patients in Germany

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Background/aims: In Germany, the number of specialised outpatient palliative care (OPC) prescriptions increased from 25,937 in 2011 to 79,113 in 2020. The aim of this study was to investigate to what extent medication 12 months prior to OPC differs from medication within 12 months following the first OPC prescription.

Methods: A retrospective database cross sectional study based on the IQVIA Disease Analyser was performed. Cancer patients 18 years or older from 805 general practices within the time frame January 1st, 2018 and December 31st, 2021 were included. Differences between age groups and cancer types were assessed using Chi-squared test (p-value < 0.05). Differences between medication proportion prior versus after the index date were assessed using McNemar's test (p-value < 0.05). Statistical analysis was performed using SAS version 9.4 (Cary, NC: SAS Institute Inc).

Results: The results of this study show that in the context of OPC, there is a significant increase in the prescription of opiates (37.7% vs. 18.3%), sedatives (16.2% vs. 7.8%) and antiemetics (9.7% vs. 5.3%). In contrast, there is a significant reduction in other medications such as statins (21.4% vs. 11.5%), proton pump inhibitors (41.2% vs. 35.3%), or antihypertensives (57.5% vs. 46.6%).

Conclusions: We demonstrate that the involvement of OPC is associated with significant changes in patients' medication. In order to relieve high burden of symptoms the medication profile of cancer patients needs to be adjusted. An overall increase in medication providing symptom relief is shown in our data. At the same time, a decrease in medication not relevant to symptom management, such as statins, can be observed. Differences in medication between general and specialized OPC will be analysed in the near future.

P 2.022 A Case Study of Palliative Immunotherapy Induced Myasthenia gravis and Myocarditis

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Background/aims: Immunotherapy for metastatic disease with palliative intent is increasingly being used. This poses challenges for palliative care providers.

Methods: Case study.

Results: An eighty-five-year-old lady attended the AMU with a one week history of right sided ptosis and dysphonia. She described reduced exercise tolerance, generalized fatigue and shortness of breath over two weeks. She received Pembrolizumab for metastatic melanoma 3 weeks prior. Her medical history was significant for Ischemic Heart Disease with coronary artery bypass grafting thirty years prior, hypertension, hypothyroidism, hypercholesterolemia and cardiac ablation.

Differential diagnoses for her neurological symptoms included progression of malignancy to CNS, subacute cerebrovascular event and immunotherapy induced myasthenia gravis. Differentials for her exertional symptoms included myocardial ischemia, acute heart failure, progression of lung disease or lymphangitis and immunotherapy induced myocarditis. CT brain showed no acute intracranial abnormality nor metastases. Neurology were consulted and a diagnosis of immunotherapy induced myasthenia gravis was made. Cardiac enzymes were significantly raised (troponin 1702) CTTAP showed partial disease response to treatment and following echo and cardiology review a diagnosis of immunotherapy induced myocarditis was made. Oncology team discontinued Pembrolizumab and prescribed high dose methylprednisolone for treatment of severe life threatening dual immunotoxicities. She received intravenous immunoglobulins and IV Pyridostigmine. Unfortunately, she continued to deteriorate with respiratory muscle failure requiring mechanical ventilation in ICU. She died in the ICU two weeks later.

Conclusions: Toxicity from Immunotherapy is challenging to diagnose and management outcomes are time sensitive. Education for patients and palliative care providers in recognizing and managing immunotoxicities is essential. Research is underway to identify those at higher risk of immunotoxicity.

P 2.023 Symptom Clusters of Cancer-related Fatigue in Patients with Cancer Cachexia

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Background/aims: Cancer-related fatigue (CRF) is a multidimensional symptom affecting patients physically, psychologically, and emotionally. Cancer cachexia can cause and exacerbate CRF through disturbed metabolic processes and skeletal muscle loss. However, various other symptoms may contribute to the development of CRF, which may be why no gold standard for its treatment is currently available. Our study aimed to identify subgroups of CRF in cachectic cancer patients to understand contributing symptoms of CRF better.

Methods: We included 122 cancer patients with cancer cachexia (i.e., >5% weight loss or >2% weight loss in patients with BMI <20) and performed a symptom assessment using the Edmonton Symptom Assessment Scale (ESAS, 12 symptom items) during a home-care visit of our local mobile palliative care team (MPT). The assessment took place during the first visit of our MPT. Using latent profile analysis, we then performed a symptom-cluster analysis to identify different subgroups in cachectic cancer patients. To estimate the severity of each cluster, we calculated the ESAS total score (i.e., the sum of all 12 symptoms). Finally, we interpreted the ESAS-item "well-being" as a surrogate marker to estimate the symptom burden.

Results: We found four significant symptom clusters differently impacting the well-being of patients.

Conclusions: All of the clusters included high levels of fatigue and drowsiness but differed in concomitant symptoms. The fatigue-drowsiness-nausea-anorexia-emesis cluster was the most severe concerning impact on wellbeing and total symptom burden. These additional symptoms may worsen CRF and could be a target to influence CRF levels in patients indirectly.

Symptom Cluster (n)	Wellbeing (mean ± SD, ANOVA p=0.044)	ESAS total score (mean ± SD, ANOVA p=0.049)
Fatigue-Drowsiness-Nausea-Anorexia-Emesis (10)	6.20±2.35	58.8±15.01
Fatigue-Drowsiness (73)	3.81±2.19	24.15±9.79
Fatigue-Drowsiness-Anorexia-Depression-Anxiety-Sleep (16)	5.88±2.13	48.88±9.37
Fatigue-Drowsiness-Anorexia-Constipation (23)	5.7±1.96	42.57±13.18

P 2.024 Separating the Wheat from the Chaff: Treatment Recommendations for Off-label Drug Use in Palliative Care - Delphi Process for Consensus Building

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Background/aims: Pharmacotherapy of distressing symptoms is a core element of palliative care (PC). Up to 50% of drugs are used off-label (OLU); yet only a limited part of these uses is supported by official recommendations such as guidelines. In order to provide patients with safe and effective medicines, a risk-benefit assessment should be based on

the best available evidence. Time and resources are often lacking in clinical routine to balance these aspects and OLU treatment decisions are mainly based on own experience.

The aim of this project is to develop consensus-based treatment recommendations for OLU of drugs relevant to PC.

Methods: 1) Systematic literature review for selected drugs, and evaluation of the evidence.

2) Development of therapy recommendations based on the evidence.

3) Internet-based Delphi process for consensus of recommendations with PC experts (physicians, pharmacists, nurses) from German-speaking countries; agreement with the recommendation (required consensus >80%) and certainty of response were queried.

Results: 70/103 invited experts participated in both survey rounds (1st/2nd survey round: 70%/73% physicians, 23%/24% pharmacists, 7%/6% nurses). A total of 40/41 treatment recommendations (15 route of administration, 26 indication) for 15 drugs were consented in 2 Delphi rounds; of these, 32 after the first round, another 9 were rephrased based on participants' comments, 8/9 were consented in the 2nd Delphi round.

Conclusions: The development of consented OLU treatment recommendations based on best evidence can close an information gap and support the provision of effective and safe pharmacotherapy in PC. The recommendations agreed upon in this first Delphi process will be publicly available to professionals in a web-based database accessible free of charge from the end of 2022. Further therapy recommendations are already in the pipeline.

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P 2.025 Update on Prevalence of Pain in Patients with Cancer 2022: Systematic Literature Review and Meta-analysis

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Background/aims: Background: Pain is one of the most common symptoms endorsed by cancer patients. Experiencing pain, and the insufficient relief can be devastating and negatively affect a patient's performance status, emotional well-being, and have a severe impact on a patient's quality of life.

Aims: Developments in oncology like new treatments, adjusted pain management guidelines and aging of the population may have influenced the prevalence of cancer pain, and pain severity in patients. Therefore, the aim of this review is to provide an overview of the prevalence and severity of pain in cancer patients in the 2014-2021 literature period.

Methods: A systematic search of the literature published from January 2014 until December 2021 was performed using the databases PubMed, CINAHL, Cochrane and Embase. Titles and abstracts were screened and full texts were evaluated and assessed on methodological quality. Study, pain and treatment characteristics were extracted from each included study. A meta-analysis was performed on the pooled pain prevalence and severity rates. A meta-regression analysis was used to explore differences between treatment groups.

Results: Of 10,637 studies, 1147 studies were selected for full text evaluation of which 274 studies were included in the study for the meta-analysis on pain prevalence (245 studies, n = 656,445) and pain severity (95 studies, n = 205,417). Pain prevalence rates were 40.3% in treatment naïve patients; 47.5% during curative treatment; 52.3% during palliative treatment; 33.8% after curative treatment; 55.2% in patients with no feasible anti-cancer treatment. Moderate to severe pain was reported by 29.2% of all patients.

Conclusions: This review shows a decrease in both the prevalence of pain, as well as pain severity in the last decade. Increased attention on assessment and management of pain might have fostered the decrease in the prevalence of pain and severity.

P 2.026 Differences in Medication Profile in Hospitalised Patients at the End of Life Receiving a Specialized Palliative Care Intervention

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Background/aims: Patients with advanced disease often suffer from a high symptom burden and are therefore exposed to a high prevalence of polypharmacy. There is growing evidence that polypharmacy is associated with several poor outcomes including falls, cognitive impairment or adverse drug reactions. Little is known about deprescribing in hospitalised patients at the end of life.

The aim of this study is to evaluate the impact of a specialized palliative care intervention on medication.

Methods: We performed a retrospective cohort study examining the medication profile in all patients who died from a non-accident-reason during their last hospitalisation in a large university hospital in Switzerland between January 1st 2016 and December 31st 2020.

Patients were classified as receiving specialized palliative care (SPC) if they had either inpatient care at the palliative care unit or were seen by the palliative care consultation team. All other patients were classified as usual palliative care (UPC).

We retrieved data on medication at two pre-specified time points: at admission and day of death. Medication was grouped in four different categories: symptom-oriented, secondary prevention, disease modifying and others.

Results: Overall, 3196 patients were included in the study. The UPC-group was significantly larger (n=2596) than the SPC-group (n=600).

Patients in the SPC-group received significantly more symptom-oriented medication than the UPC-group (at admission: SPC 91% vs. UPC 77%; at death: SPC 98%, UPC: 82%).

The proportion of patients receiving potentially inadequate medication (PIM) at death was similar in both groups (UPC 30% vs. SPC 35%).

Conclusions:

- Our results show that patients in the SPC-group received significantly more symptom-oriented medication compared to the patients within the UPC-group.
- The high proportion of patients taking at least one PIM underlines the need for a critical evaluation of pharmacotherapy and implementation of a deprescribing protocol in patients approaching the end-of-life.

P 2.027 Final Results of P-move - Impact of Exercise on Physical Function and Quality of Life in Patients Suffering from Advanced Pancreatobiliary Cancers Receiving beyond First-line Chemotherapy

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Background/aims: Patients (Pts) with advanced pancreatobiliary cancers (aPBC) frequently suffer from high symptom burden. Exercise is known to reduce treatment side effects and improve patient-related outcomes (PROMs). However, evidence from prospective studies in the palliative settings are sparse. The primary aim of the prospective, randomized-controlled study is to evaluate the feasibility of exercise therapy (ET) in patients with aPBC beyond first-line chemotherapy. Secondly

endpoints are physical function, quality of life and functional assessment of Anorexia/Cachexia.

Methods: 40 Pt (Stage III/IV) will be recruited beyond first-line therapy. Pts are randomized according to the minimization procedure with strata: gender, age, and loss of body weight in the past six months. The intervention group (IG) completes 3 training units per week for 8 weeks (1x supervised strength sessions, 2x individualized home-based sessions weekly). Control group (CG) receives recommendations on daily activities.

Results: Since study initiation, 194 Pts were screened within the last two years. Of those 153 Pts did not meet eligibility criteria. Of 41 eligible Pts, 33 have been recruited (80.5%). Preliminary data shows significant differences for physical function between groups after 8 weeks in favour of IG. Leg press (t(20)=3.32, p=0.003), Bench press (t(20)=2.25, p=0.036), Sit-to-stand (t(20)=3.27 = p=0.004) and crunch (t(20)=2.62, p=0.016) increased significantly in IG compared to controls. Within group analysis of control revealed a significant decrease in leg press strength during study period (t(10)=2,72 p=0.02). Quality of life in IG increased slightly while CG decreased over study period. Final results will be generated with study completion in April 2023 and presented at the EAPC.

Conclusions: Results state the safety and feasibility of exercise beyond first line palliative treatment. Furthermore P-move indicates some effects of exercise on physical function and PROMs.

P 2.028 Enabling Timely and Effective End of Life Care in Motor Neurone Disease: Results of a Scoping Review

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Background/aims: Motor Neurone Disease (MND) causes progressive degeneration of motor neurones, typically leading to respiratory failure and death within three to five years. Palliative care is critical to MND management, yet related research is limited. When providing high quality end of life care in any illness, timely recognition of the dying phase is vital to guide clinical decision making and communication. Recognition of dying, however, remains challenging for healthcare professionals (HCPs). Our scoping review aimed to explore the recognition of dying in MND to inform the provision of timely, high-quality care at the end of life.

Methods: A scoping review was conducted according to Arksey and O'Malley's framework and Joanna Briggs Institute guidance. Five databases (Ovid MEDLINE, PubMed, PsycInfo, CINAHL and Scopus) were searched. Citations and grey literature were also searched. Screening and full text review were conducted by two independent reviewers and results thematically organized.

Results: From 1067 papers, twelve studies were included. Studies spanned seven countries and included quantitative (n=7), qualitative (n=3), and mixed methods (n=2). Patterns in symptoms and management in the last week of life were described. Although variable, the terminal decline was often rapid and unpredictable. Preserved functional level and repeated episodes of revival were barriers to recognising dying. Unique aspects of dying from MND include withdrawal of NIV, which add complexity and warrant further attention.

Conclusions: Progression towards the end of life in MND is variable, complex, and differs to other life-limiting conditions. Patients often experience a significant symptom burden, and the terminal decline can be rapid, unpredictable, and challenging to recognise. Further research should explore the perspectives of key stakeholders, including patients, carers and HCPs, to enable us to tailor clinical care to the needs and priorities of this group.

P 2.029 Cannabinoids for Vomiting and Nausea in Palliative

Advanced Cancer: A Literature Review

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Background/aims: Vomiting and nausea are one of the most common symptoms in advanced cancer patients receiving palliative care. Besides conventional antiemetic pharmacological treatment, cannabinoids are emerging as a potential candidate group. The aim is to evaluate the level of scientific evidence of the therapeutic effects of cannabis for nausea and vomiting.

Methods: A systematic search was performed on the repositories Psychology and Behavioral Sciences Collection, APA PsycInfo, CINAHL Complete and MEDLINE Complete, through the EBSCOhost database, focusing on and analyzing only articles from 2016 to 2021 in English. They were classified according to their level of evidence following the SIGN criteria and a results table was prepared showing the most relevant data.

Results: 16 articles were included in this study, finding results in favor of cannabinoids for medicinal use. Medications based on synthetic THC, THC-CBD in a 1:1 ratio, CBD and synthetic cannabinoid analogues of THC were highlighted. The studies were of weak scientific quality and in some cases were based on old studies, without comparing them with newer, first-line antiemetics.

Conclusions: There is an urgent need to increase the research on medical cannabis and likewise the quality of these studies in order to start considering them as another option in the treatment of nausea and vomiting in the palliative care setting.

P 2.030 Health-related Quality of Life in Chronic Intestinal

Failure Patients: A Comparative Study

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Background/aims: Chronic intestinal failure (CIF) is one of the rarest organ failures. Although CIF is treatable by provision of long-term parenteral support (PS), there is inequality of access to treatment between and within countries and there is scarce evidence on how the disease burden in CIF compares to other chronic non-malignant conditions. Hence, the aim of this study was to compare the health-related quality of life (HRQOL) of CIF patients with that of patients in hemodialysis (HD) due to kidney failure. These groups were selected for comparison, as they have similar patient and treatment characteristics, but unequal global access to care.

Methods: A cross-sectional design, in which samples of adult CIF and HD patients treated at Rigshospitalet-Copenhagen University Hospital (DK) between 2019 and 2020, were analyzed using the Short-Form 36 (SF-36). Results were compared by Chi-square tests.

Results: 141 CIF patients (39.5% male, mean age 61.4 years) and 131 HD patients (70.2% male, mean age 61.3 years) were included in the analysis. Except for a different gender distribution and higher prevalence of cardiovascular disease in HD patients, the groups had similar characteristics. Both groups reported low scores for HRQOL (score below 50) on

general health, vitality and role limitations due to physical health problems. No significant differences were found between groups for any of the SF-36 domains.

Conclusions: HRQOL was similar and significantly reduced in CIF and HD patients and indicated that palliative care provision is needed in both groups of patients.

Conflict of interest: This study was funded by a grant from the Capital Region of Copenhagen.

P 2.032 Terminological Problem Concerning Sedation in Palliative Care. Results of an Online Vignette Survey among EAPC Members and Experts

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Background/aims: Terminological problems concerning sedation in palliative care and consequences for research and clinical decision-making have been reported frequently. We wanted to gather quantitative and qualitative data on the application of sedation-definitions to clinical cases and to analyse possible implications for high quality definitions.

Methods: We conducted an online survey with international experts involved in the development of guidelines on sedation in palliative care and with members of European Association of Palliative Care (EAPC). Participants were asked to apply four published definitions of sedation practices to four case vignettes. Vignettes and correct applications were developed by an interdisciplinary team of experts. We used convenience sampling. Data were analysed using descriptive statistics and content analysis of free text comments.

Results: 32 experts and 271 EAPC members completed the survey. The definitions were applied correctly in n=2200/4848 cases (45.4%). The mean number of correct applications of the definitions (4 points max.) was 2.2±1.14 for the definition of the SedPall study group, 1.8±1.03 for the EAPC definition, 1.7±0.98 for the definition of Norway and 1.6±1.01 for the Japanese definition. Analysis of free text comments show patterns which provide explanations for the high rate of incorrect answers.

Conclusions: Definitions of sedation in palliative care are frequently not correctly applied to clinical case scenarios under simplified conditions. The data generated in this study may be used to improve definitions as well as accompanying strategies to ensure the correct labelling of clinical cases in clinical practice and research related to sedation in palliative care.

The study was funded by the German Federal Ministry of Education and Research.

P 2.033 Symptom Burden and Quality of Life in Patients with Pancreatic Cancer at Admission to Specialised Palliative Care

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Background/aims: In Denmark, around 1,100 people are diagnosed with pancreatic cancer (PC) annually. Most of these have advanced disease at the time of diagnosis and the prognosis is poor. Within two months from diagnosis 40% of the patients die and less than 10% are alive five years after the diagnosis. Therefore, it is important in large national representative studies with data of high quality to investigate the symptom burden for these patients e.g., at the start of specialised palliative care (SPC). The aim of this study was to investigate symptoms, problems, and quality of life in patients with PC experienced at the start of SPC.

Methods: Data sources for the study were the national clinical databases, Danish Palliative Care Database and Danish Pancreatic Cancer Database, including data about admittance to SPC, date of PC diagnosis, date of death and patient reported outcome questionnaire i.e., the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Core-15-Palliative Care Questionnaire (QLQ-C15-PAL). The study population was patients with PC diagnosed between 2011-18, who died in the same period and were admitted to SPC. QLQ-C15-PAL includes 10 scales ranging 0-100. For the seven symptom scales a high mean score indicates high symptom burden and for the three function scales a low mean score indicates a low function.

Results: From 2011-18, 3,497 patients with PC were admitted to SPC and 58% of these completed the QLQ-C15-PAL. In relation to the symptom scales, patients with PC had a high symptom burden regarding fatigue (mean 76, N=2,000), loss of appetite (mean 68, N=2,010) and pain (mean 56, N=2,025). For the function scales, low physical function (mean 35, N=1,991) and low quality of life (mean 39; N=1,874) were found.

Conclusions: Patients with PC had a high symptom burden and low quality of life at admission to SPC, underlining the need of symptom assessment and palliative care, also before referral to SPC.

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P 2.034 Improving Symptom Change Enhances Quality of Dying and Death for Advanced Cancer Patients: Study from the East Asian Collaborative Cross-cultural Study to Elucidate the Dying Process

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Background/aims: Goal-concordant care is essential for terminally ill patients. Exploring factors associated with the quality of dying and death more than the quality of life may help advanced cancer patients understand the benefits and harms of cancer treatments. This research investigated how symptom changes influenced the quality of dying and death.

Methods: This international prospective cohort study was conducted in Japan, Korea, and Taiwan, specifically known as the East Asian Collaborative Cross-Cultural Study to Elucidate the Dying Process (EASED) from 2017-2019. As a multicenter study, the research included 22, 11, and 4 palliative care units (PCUs) across Japan, South Korea, and Taiwan. Eligible participants were: (1) adults (≥ 18 years of age in Japan and Korea; ≥ 20 years of age in Taiwan) with (2) locally advanced or metastatic cancer. Physical and psychological symptoms were assessed by physicians upon admission and within three days before death. Death quality was assessed using the Good Death Scale (GDS), developed in Taiwan. Univariate and multivariate regression analyses were conducted to identify the correlations between severity changes for the four symptoms and GDS scores.

Results: A total of 998 patients were included in the final analysis. The mean (SD) age was 70.1 (± 12.5) years, with 542 (54.3%) men and 456 (45.7%) women. Persistent dyspnea was associated with lower GDS scores when compared to stable dyspnea (estimated $\beta = -0.427$, 95% confidence interval = -0.783 – -0.071). Worsened (-1.381 , -1.932 – -0.831) and persistent (-1.680 , -2.701 – -0.659) delirium were also significantly associated with lower GDS scores.

Conclusions: This study showed associations of a better quality of dying and death with improved symptom control, especially for dyspnea and delirium. Integrating an outcome measurement for the quality of dying and death is valuable to manage symptoms across the disease trajectory in a goal-concordant manner.

P 2.035 The Genesis of Disparities in the Management of Pain in Palliative Patients: A Review of the Literature

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Background/aims: A insufficient amount of research indicates significant racial and ethnic disparities exist in palliative and end-of-life care (EOC). Pain is the prevalent symptom that is poorly managed in EOC and racial and ethnic minorities experience disproportionate levels of pain. This study aims to identify the genesis of the inequities suffered by minority palliative patients with pain.

Methods: An integrative literature review was developed in 3 steps: Development of the research question, search for scientific articles in the Pubmed database, and critical analysis of included articles. The investigation was conducted in September 2022, and articles between 2008 and 2022 were selected, for a total of 68 articles, of which 13 were used.

Results: The origin of disparities in pain management starts with factors like racial disparities in access to the public health system and are aggravated by ethnic, and socioeconomic factors. The inequities in the quality of pain care are seen for Ethnic and racial minorities when compared with non-Hispanic whites, through the prescription of less effective or underdosed medications. The population most vulnerable to this scenario are African Americans, Hispanics, and Asians, even if pain severity levels are comparable to white people. In addition, the factors that contribute to the inequities present in pain management are due to poor access to coordinated and quality care, cultural and attitudinal differences, bias, lack of language proficiency, knowledge gap, and variability in decision-making.

Conclusions: The pillar of palliative care is the treatment of the individual from a multidimensional and holistic perspective, therefore, disparities in pain management of minority groups such as blacks, homosexuals, and refugees do not fit within the ethical precepts of palliative care. There is a need to change and adapt the individual, the physician, society, and the health care system to improve the management of pain.

P 2.036 Updating the Edmonton Symptom Assessment System (ESAS-FS) into Spanish with the Two New Scales to Explore Financial and Spiritual Distress

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Background/aims: The Edmonton Symptom Assessment System (ESAS) is a widely used tool for the assessment of symptoms in palliative care. The MD Anderson's group recently added to the original version two scales to explore financial and spiritual distress (ESAS-FS). Having the previous Spanish version validated and broadly used, is convenient to update and to be available to the professionals. Spiritual pain and financial distress are highly sensitive topics. An accurate process has to be done to translate and culturally adapt the two new scales.

Aims: Update the ESAS-FS into Spanish with two new scales to explore financial and spiritual distress.

Methods: A preliminary Spanish version will be obtained following the recommendations of the European Organization for Research and Treatment of Cancer (EORTC) to translate health evaluation tools. A consensus process with multidisciplinary professionals of oncology and palliative care will be done exploring perceived relevance, appropriateness and comfort with the two new scales. Consecutive rounds with the same professionals will be done until a consensus of 60% is obtained in all the explored questions.

Results: After ethical approval and informed consent, 34 professionals were enrolled in the survey. In the first round 100% (34/34) considered the two scales relevant, 50% (17/34) stated that the terms were appropriate and 79% (27/34) did not perceive discomfort. With the comments and suggestions received a new version was proposed. In the second round, comfort with ESAS-FS was 97% and appropriateness 94%.

Conclusions: A Spanish version of ESAS-FS was obtained. In the professionals' view to explore financial and spiritual distress is highly relevant. The terms "sufrimiento espiritual" and "preocupación por asuntos económicos" were considered most appropriated for Spanish speaking patients and more comfortable for the professionals. Feasibility studies has to be done requiring the patient's view.

P 2.037 The Effect of the Implementation of Palliative Reasoning on Symptom Management, Communication and Collaboration in Home and Nursing Home Care, a Pretest Posttest Survey Study

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Background/aims: Appropriate palliative care requires multidimensional symptom management, provided by a multiprofessional team. The working method "Palliative Reasoning"(PR), was developed and implemented in primary care and in nursing homes.

Aim: To investigate the influence of the implementation of Palliative Reasoning on symptom management, interdisciplinary collaboration and communication.

Methods: A quantitative observational study with a pretest -posttest design. An online, non-linked survey was completed by health care professionals (HCPs) working in participating teams. The Modified Index for Interdisciplinary Collaboration (MIIC) was used to measure interdisciplinary collaboration. Symptom management, interdisciplinary collaboration and communication with patients&relatives and colleagues were inquired by self-developed surveys. Data analysis was performed using descriptive statistics.

Results: The study samples (n=121 and n=92) contained mostly female nurse assistants and registered nurses. After implementation, participants reported a higher grade of knowledge of palliative care, improved attention to the spiritual domain and estimation of life expectancy, and more frequent execution of all aspects of symptom management. Mean MIIC scores were moderately high and did not improve after implementation. Communication with both patients&relatives and colleague HCPs were generally perceived as high and remained high post-implementation.

Conclusions: Implementation of the working method Palliative Reasoning in primary care and nursing homes resulted in HCPs earlier marking patients with life-threatening diseases, potentially leading to earlier and more appropriate palliative care. Besides, more attention was created for the spiritual dimension. Communication and collaboration remained high.

P 2.038 Experiences from Patients in the Palliative Phase with Symptom Control and Communication in Primary Care

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Background/aims: Appropriate palliative care requires multidimensional symptom management, provided by a multiprofessional team. The working method "Palliative Reasoning" (PR), was developed and implemented in primary care. PR contributes to improved communication and symptom control.

Aim: Insight into the experience of patients with a life limiting illness after with the implementation of PR in primary care.

Methods: Semi-structured interviews were performed with 12 patients in the palliative phase, purposefully recruited from a Dutch home care organization. Outcomes were multidimensional symptom control and communication. This qualitative study included a thematic analysis method.

Results: Four main themes were found, involving wishes and needs, feeling safe, proactivity, and continuity. Patient-related factors can influence the experience of symptom control, such as knowledge, awareness and relative stability of the disease. Healthcare professionals (HCPs) improved feelings of safety through the established relationship, accessibility, and communication. Often, HCPs were proactive in identifying physical symptoms and reacting accordingly. Transparency was achieved through shared decision-making, which contributed to the continuity of care. Communication between HCPs was less visible to patients but was often assumed to be well established.

Conclusions: Patients experienced improved symptom control with a greater knowledge and awareness of their disease after the implementation of PR. The proactive attitude of HCPs, continuity of care, and feelings of safety contributed to symptom control and transparent communication. For clinical practice, the palliative care process can be improved by patient involvement and transparent communication and committed attitude of HCPs.

P 2.039 Comparison of a Novel Methadone Rotation Method with Other Commonly Used Methadone Rotation Methods

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Background/aims: To compare a novel method of methadone rotation with other commonly used methadone conversion methods including Perth rapid titration, Brisbane protocol and 3-day switch.

Methods: Ethical approval was obtained from the local ethics committee. A retrospective chart review of all inpatients prescribed methadone in a Specialist Palliative Care unit (SPC) during 2018/2019 was conducted. Data collected included demographics, opioid requirement in 24 hours prior to rotation and oral morphine equivalent (OME), presence of opioid toxicity, opioid sparing interventions, final stable methadone dose prescribed, length of time to achieve stable dose. Stable methadone dose was defined as a dose that was stable for 5 days or until death/discharge. Using the OME, the expected methadone dose was calculated via rapid titration with both the Perth protocol and 'Brisbane' Protocol, as well as 3-day switch. This data was compared with the results of our study.

Results: 86 charts were identified, 9 were not located, 49 were excluded including methadone use as an adjunct and discontinuation of rotation. 28 rotations were analysed. The final mean methadone dose was 12.6mg using this novel method of rotation. Calculated methadone doses with Perth protocol were significantly higher than doses achieved using this novel method of rotation, with a mean difference of 13.9mg (p value <0.0001). Calculated doses were also higher when comparing the Brisbane method and this novel method, mean difference noted to be 4.6mg (p value 0.0035). No statistically significant difference was found when comparing with the 3-day switch.

Conclusions: Patients rotated to methadone using this novel method received a stable methadone dose lower than they may have received if Perth or Brisbane ratio conversions were used. Methadone rotation remains challenging and further study is needed.

P 2.041 Barriers and Facilitators of Breathlessness Digital Self-management Interventions in Lung Cancer and Chronic Obstructive Pulmonary Disease Patients - A Systematic Review and Narrative Synthesis

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Background/aims: Digital health interventions have the potential to improve symptom management in respiratory diseases, such as COPD (chronic obstructive pulmonary disorder) and lung cancer.

To systematically review published evidence to identify barriers and facilitators to telehealth implementations in managing pain and breathlessness in COPD and lung cancer.

Methods: Standard systematic review techniques were used, following PRISMA guidance, to find evidence on digital health interventions in community-based patients.

The PARIHS (Promoting Action on Research Implementation in Health Services) framework was employed to extract relevant data, following the constructs 'Characteristics of the innovation', 'People's ability to change', 'People's motivation', 'Inner context' and 'Outer context'; results were summarised using narrative synthesis.

Results: 1163 papers were screened, identifying 24 studies for inclusion. Barriers and facilitators were classified in terms of intervention stakeholder relevance, grouped into patient, healthcare practitioners (HCPs) and intervention managers. Issues such as older patient age, low health literacy and lack of trust towards remote interventions were cited as barriers by patients. Excessive workload, low perceived clinical value and lack of continuous resourcing were the main barriers reported by HCPs, whereas intervention managers mentioned lack of awareness as one of

the key issues. Knowledgeable staff, accessible technology and improved patient outcomes were important facilitators reported across populations.

Conclusions: Self-management digital health interventions appear generally appropriate, however no single solution can be recommended for all COPD and lung cancer cohorts. Potentially feasible approaches such as user-friendly interfaces, correct timing of intervention implementation and appropriate use of shared decision-making techniques exist, however important gaps in the knowledge remain.

P 2.042 Patients' Experiences and Medical Personnel Perception: A Comparative Study of Palliative Care Quality

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Background/aims: In this study, we compare the perception of overall palliative care quality in two study groups: palliative care personnel and their patients.

Methods: 60 patients and 60 of their medical staff members participated in a survey study. Participants were asked to answer a questionnaire consisting of palliative care quality determining questions. The research was conducted throughout 2020–2021. The patient group consisted of 38 women and 22 men with a diagnosis of terminal illness, age ranging from 56 to 93 years.

Results: The most significant difference was seen in the incidence and importance of pain. 83.3% of patients indicated that the pain they suffered had a strong impact on their activities and ability to concentrate. Only 43.3% of the medical personnel noted patients to have such levels of pain. According to the data the perception of other diverse symptoms (nausea, cough and constipation) did not seem to differ significantly between the study groups. Terminal disease also affects patients' emotional integrity. Patients experienced anxiety more often (84.2%) than indicated by doctors (60%). It is also important to note a strong link between depression and physical discomfort: patients who answered that life is not worth living, felt strong pain constantly (86.67%).

Conclusions: The greatest difference in responses between patients and their medical personnel was to do with pain control. It is one of the main problems in the care of palliative patients with terminal disease, because it causes the greatest discomfort. Much research has pointed to the need to strengthen communication between medical staff and patients in order to reach optimal pain control results. Furthermore, the anxiety of patients and their relatives is expressed profoundly. This may indicate a psychological need that the personnel require to address. Interestingly, the incidence of patients having spiritual problems is perceived more often by doctors than by the patients themselves.

P 2.044 Clinical Characteristics of Breakthrough Cancer Pain in an Elderly Population: Retrospective Analysis of Patients Treated in a Palliative Care Outpatient Clinic at a Catalan University Hospital

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Background/aims: Breakthrough cancer pain (BTCP), defined as a transient exacerbation of pain that occurs either spontaneously, or

in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain, becomes a subtype of cancer pain with well defined characteristics. It has been established that prevalence and intensity of pain in cancer patients decreases with age. We aim to describe BTcP characteristics in a sample of advanced cancer patients aged > 75 years and to compare the results with a sample of younger patients (≤ 75 years).

Methods: This is a subgroup analysis of a recently completed trial in two subsets of individuals: patients aged ≤ 75 years (low age group) and patients > 75 years (high age group). The study was carried out between January 2014 and December 2015 and patients were recruited at the outpatient palliative care clinic (OPCC) at the Hospital Universitari Arnau de Vilanova (HUAUV) in Lleida (Catalonia). The Davies Algorithm was implemented to diagnose BTcP. Furthermore, the Edmonton Classification System for cancer pain (ECS-CP) was used to determine BTcP added complexities.

Results: 277 patients were included. 100 (36.1%) were > 75 years old. In this subgroup, 66% were men and lung cancer was the most prevalent diagnosis (25%). The number of different types of BTcP was 1.50 ± 0.7 ($p = 0.002$) and the maximum VAS was 5.7 ± 2 ($p = 0.004$). Likewise, the psychological distress component and the addictive personality component were lower in this age group (24.8% and 11.8%, respectively, both with $p < 0.001$).

Conclusions: The population aged > 75 years has clinical characteristics of BTcP that differ from those found in the age group ≤ 75 years.

P 2.045 Cross-cultural Perceptions of Treatments, Symptoms and Palliative Care: A Qualitative Study of Working Age Adults with Myeloma in Poland, Czechia and Germany

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Background/aims: Myeloma treatments are recognised to lead to substantial morbidity. Improvements in survival because of routine use of high-dose therapy, autologous stem cell transplant and the introduction of novel therapies. However, myeloma is still incurable and most patients will relapse and/or become refractory to treatment, with the disease becoming more aggressive and drug resistant over time, with shorter response intervals.

Aim: To understand the symptom and treatment experiences of working age adults living with myeloma in Europe.

Methods: A qualitative interview study with 37 working age people living with myeloma in Poland, Czechia, and Germany. Analysis was inductive and thematic, informed by principles of intersectionality to inform intra- and cross-cultural comparisons alongside consideration of gender, age, and social class.

Results: Analysis indicated that people's treatment satisfaction was affected by what they know about treatment in other countries. Interviewees reported perceptions of treatment hierarchies across different European countries. Analysis identified distinctive patterns regarding the private cross-border purchase of medicines, trust in clinicians and use of relational networks to access preferred clinicians and treatments. Across all three countries, palliative care was not part of the routine dialogue with clinicians, who were focused on short-term treatment goals.

Conclusions: Myeloma is not a unitary disease, nor is its experience singular across three European countries sharing borders with each other. Country-specific differences in treatment access warrant more effort to reduce health disparities. Perception of inferior treatments must be addressed with specific communication when offering treatment lines. Timely integration of sensitive conversations about supportive and palliative care to support all patients living with myeloma.

P 2.046 Is the MYMOP2 Tool a Clinically Useful PROM in Palliative Care Outpatient Clinic? A Single Centre Feasibility Pilot

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Background/aims: The Integrated Palliative Care Outcome Scale (IPOS) is widely used in the UK including at our centre. However the event of COVID-19 and the need for remote consultations has placed a barrier to the use of IPOS: patients don't attend face to face to complete it, proxy-reporting is complicated by not seeing the patients and listing the questions over the phone disrupts the consultation flow.

Aim: To pilot the use of the MYMOP2 tool in measuring patient outcomes including via remote consultation in a palliative care outpatient setting.

Methods: Over 12 months we used MYMOP2 in a palliative care outpatient clinic at a tertiary cancer centre. Each patient was invited to complete MYMOP2 at initial consultation face to face and again at telephone follow up. Uptake at each stage was used as a measure of feasibility. Symptom and activity score change between appointments was analysed to determine clinical impact using Wilcoxon signed rank.

Results: 149 patients were seen in the clinic between May 2021-April 2022. 91 (61%) completed the MYMOP2 tool at baseline. At follow up, 55 patients completed the tool allowing complete records to be analysed for 37% of clinic attenders. The most commonly reported symptom was pain (85/91) and the most common activity patients wanted to address was walking (21/91). Median symptom scores improved from 5 to 2 ($p < 0.001$) and activity scores from 5 to 3 ($p < 0.001$). Median overall wellbeing score improved from 4 to 3 ($p < 0.001$).

Conclusions: MYMOP2 effectively measured symptom, activity and wellbeing change over time for patients. It also provided detail of symptoms and activities the patients wanted to prioritise. However it was ultimately only used by 37% of patients at baseline and follow up, with a 40% dropout when moving from face to face to telephone. This indicates that even though it is shorter and more focused, it still lacks some usability in remote consultations.

P 2.047 Do Patients Receive Too Many Drugs towards the End of Life?

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Background/aims: Prognosticating patients in last phase of life can be difficult. In hospital settings, there is still tendency to continue medications without reviewing those at the end of life. This poses problems as with deranged body functions and organs failure, these drugs can have unwanted effects on dying patients and worsen suffering. Doctors often are hesitant to make decisions to 'deprescribe' towards the end of life. This study looks at the number of medications, we noted that patients were receiving towards the end of life.

Methods: We collected data analysing medication charts of patients in last days of life to review if there are any trends about prescribing. Data was collected retrospectively from an acute general hospital. Charts were prescribed by doctors electronically.

Results: 60 patients' (24 male) data was collected. All patients had cancer (commonest cancer was Lung – 17). Age range was 40 – 98 (mean 77). There were a total of 370 regular medications (6.16 per patient - PP) with 688 doses (11.4 per day) were prescribed seven days before death whereas 200 medications (3.3 PP) with 381 doses (6.35 PP) were prescribed on the day of death. Due to deterioration of patients, a total of 937 doses were omitted (15.6 PP/133.8 per day). All patients had anticipatory medications prescribed 7 days before

death as well with 26 on syringe driver on the day of death. 45 patients received a total of 235 doses of anticipatory medications on the day of death.

Conclusions: Despite deterioration, majority of patients had regular medications prescribed when they were unable to take most doses. Prescription of syringe driver and anticipatory medications implied that the doctors could see that patients were in last phase of life. Deprescribing must be considered on these patients to minimise burden on them.

P 2.048 Effectiveness of Sublingual Fentanyl Tablet for Breakthrough Cancer Pain: Rapid Pain Control and an Improvement of the Quality of Life

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Background/aims: Excruciating breakthrough cancer pain (BTcP) is detrimental to various aspects of patient's life. Sublingual fentanyl tablet (SFT) using a fast transmucosal delivery system seems to be a good option in patients with BTcP, considering the abrupt and short-living nature of the pain. To analyze the effectiveness of SFT in terms of pain reduction, personalized pain goal achievement and quality of life in patients with BTcP.

Methods: The 12-week observational study, conducted in 13 hospitals in South Korea, included 133 opioid-tolerant patients prescribed with SFT for BTcP. Follow-ups were made at Week 1, 4 and 12. SFT doses, diary records of BTcP on numeric rating scale (NRS), achievement of personalized pain goals and Brief Pain Inventory (BPI) scores were analyzed.

Results: Mean age of the patients was 60.4 ± 11.5 years with a higher proportion of male patients (63%). A total of 113 patients were included in the effectiveness analysis. Maintenance dose of SFT was between 100 µg and 400 µg. Maximum intensity of BTcP on the NRS ranged from 7 to 10 (interquartile range: 9-10), and SFT contributed to a significant (p<0.0001) reduction in pain intensity (mean NRS reduction 30 and 60 minutes post-dose by 2.5 and 3.6, respectively). Up to 75% of the patients achieved their personalized pain goals. At Week 4, significant improvements from baseline scores were observed for multiple BPI

interference items, including general activity (7.1 vs. 6.2, p=0.0155), mood (7.1 vs. 5.9, p=0.0045), normal work (7.1 vs. 6.0, p=0.0052), relations with other people (6.4 vs. 5.3, p=0.0152), enjoyment of life (6.8 vs. 5.5, p=0.0041) and sleep (6.0 vs. 4.1, p<0.0001). In the case of sleep interference, the improvements were significant also at Week 1 (5.2, p=0.0402) and 12 (4.7, p=0.0326).

Conclusions: SFT provides rapid analgesia in BTcP, which may exert a beneficial effect on the quality of life.

Conflict of interest: The research being reported in this presentation was sponsored by A.Menarini Korea Ltd. I received personal fees for lectures from Menarini Korea.

P 2.049 Safety First: Body-mind Approaches for Breathlessness-related Distress in Advanced Disease. A Realist Review

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Background/aims: Chronic breathlessness is common in advanced lung and heart disease. Body-mind interventions (BMi) target the relationship between sensory/affective/cognitive aspects of breathlessness but evidence lacks context-specific modifications for implementation. We conducted a realist review to explain how, why, for whom and in what contexts BMi help breathlessness-related distress and to explore implementation barriers/enablers for individuals/institutions.

Methods: Following RAMESES standards we:

- Developed a conceptual platform to map features/mechanisms of BMi in an initial programme theory with an expert advisory group and stakeholders, informed by attachment/affect regulation theories and neuroscience
- Systematically searched 8 databases for primary data to refine and test the theory, plus iteration beyond initial terms
- Successive screening and data extraction, quality/relevance appraisal, retroductive analysis and synthesis working with stakeholders/advisors to explain how BMi work best in different contexts

Results: 61/4466 articles were included. We found that safe relationship was a central context/mechanism interaction promoting self-regulation. Early analysis shows where participants choose a BMi, trust a skilled teacher delivering a tailored intervention and enjoy the social/creative aspect of group practice, embodied resources (movement-with-breath, relaxation, bodily awareness) enable procedural learning ("how to"), new coping skills and the development of breath and body literacy. For people with higher anxiety/symptom burden, mindfulness protocols can be challenging and dysregulating. Lack of evidence in non-White and older populations suggest cultural barriers perpetuated by commercial appropriation of BMi in western contexts. Trauma-sensitive, modified and accessible programmes may increase "reach".

Conclusions: Our findings help us understand how BMi can be embedded into existing care models. Training clinicians in BMi skills may improve access and person-centred care.

Conflict of interest: The first author is a music therapist, yoga and mindfulness teacher.

P 2.050 Low Educational Level Is Associated with a Lower Health-related Quality of Life (HRQOL) in a Cohort of Dutch Dialysis Patients

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Background/aims: Palliative care focusses on the quality of life of patients, which also has become a major topic in the field of Kidney

Replacement Therapy (KTR). KTR is generally associated with a lower health-related quality of life (HRQOL). There is conflicting data from small series on the impact of patient-related factors such as educational level on experienced HRQOL, indicating inequalities within this patient group.

Aim: The aim of this study was to investigate the association between education level and HRQOL in dialysis patients.

Methods: In a single-center retrospective cross-sectional study HRQOL was measured with the kidney disease quality of life SF-36 (KDQOL-SF36) in prevalent dialysis patients. Educational level was categorized into three subgroups of low, intermediate and high education level. Univariate and multivariate regression analysis were performed to assess the effects of age, gender, ethnicity, and dialysis vintage on the association between HRQOL and education level.

Results: 129 dialysis patients were included. Patients with an intermediate education level had significant higher odds on a higher emotional well-being compared to patients with a low education level (OR 4.17 (95% CI 1.83-9.47)). A similar trend was found for patients with a high level of education (OR 2.71 (95% CI 0.79-9.35)), although not significant. Moreover, the odds for women compared to men for higher general health was 2.71 (95% CI 1.25-5.85) and for emotional well-being 2.73 (95% CI 1.24-5.99). Finally, with each year of increase in age physical functioning decreased significantly with 0.94 (95% CI 0.91-0.97).

Conclusions: The current study revealed that patients with a low education level had a lower score on emotional well-being. Males were at higher risk for a lower general health and emotional well-being compared to females. Physical functioning decreased with increasing age.

P 2.051 Gender Differences in Using Complementary and Alternative Medicine in Cancer Patients: A Cross-sectional Study

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Background/aims: Complementary and alternative medicine (CAM) is widely used by cancer patients. Previous studies indicate that women female patients show more affinity to CAM than men. Therefore, we aimed to assess gender differences in the types of used CAM to develop individualized guidance during oncological care for health care practitioners.

Methods: We conducted a survey asking cancer patients about their use of CAM. We grouped the different modalities in five categories according to published literature: Whole medical systems (WMS), Body-Mind-Interventions (BMI), Biological treatments (BIO), Manipulative Treatments (MAN), and other treatments (OTH). Additionally, we assessed the symptom burden using the Edmonton Symptom Assessment Scale (ESAS). We then calculated odds ratios to analyze gender differences in patterns of use and patient characteristics.

Results: In total, 199 patients completed the survey of which 109 patients reported to use at least one CAM intervention. However, only 48% of CAM users discussed their use with a clinical oncologist. 53% of CAM users were women, which were more likely to use WMS (OR 2.99, CI 95% 1.17, 8.50) and BMI (OR 3.48, CI 95% 1.37, 9.83) interventions compared to men. However, men tended to use more biological interventions (OR 1.54, CI 95% 0.72, 3.35, ref.=women) but this trend was not significant. Women also reported significant higher levels of fatigue (4.38±2.56 vs. 3.18±2.55, p=0.019). MAN and OTH interventions as well as all other patient demographics and clinical characteristics were evenly distributed among genders.

Conclusions: Women are more likely to use WMS and BMI therapies and reported greater fatigue than men. The results may indicate a gender bias in the treatment of cancer-related fatigue, leading to a higher

chance of women these CAM therapies. Understanding the factors associated with CAM use can provide the healthcare personnel with the theoretical basis for professional guidance of the patients.

P 2.052 Caring for Patients during Voluntarily Stopping of Eating and Drinking (VSED): Experiences of a Palliative Care Team in Germany

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Background/aims: Palliative care teams are confronted with patients who wish to hasten death. This topic is even more relevant since the ban on assisted suicide intended to be repeated was lifted in Germany in 2020. There still are no definite regulations, which leads to insecurities on the side of both patients and caregivers. An alternative to assisted suicide is voluntarily stopping eating and drinking (VSED). The aim of this study is to determine attitudes, burden and coping strategies of palliative care teams towards VSED.

Methods: The study was carried out anonymously at two instants (T1, T2) one year apart. We conducted a questionnaire for T1+T2, which was complemented by a validated one for T2. 3- and 5-point Likert scales as well as dichotomous answer options were used. Sub-group analysis was performed for nurses and physicians, statistical analysis was conducted using SPSS V. 28.

Results: At both T1+2, 22 team members took part: nurses (T1:40.8%+T2:59.1%), physicians (31.8%+27.3%), psycho(onco)logists (9.1%+4.5%), physical therapists (4.5% T1+2), volunteers (4.5% T1), coordination (9.1% T1), pastors (4.5% T2). Few team members have ethical concerns (T1:4.5%, T2:13.6%). Caring for patients during VSED is a burden for 18.2% (T1) and 22.7% (T2). The most burdensome symptoms staff had to deal with are thirst (T1: 22.7%, T2: 63.3%) and psychological strain (T1:40.9%, T2:31.8%). Ethical case discussions with a trained ethics committee lead to safety for up to 77.8% of the nurses (T2: 53.8%), physicians benefit more from such discussions (T1:100%, T2:83.3%). Professional team supervision is more important to physicians (T1:100%, T2:83.3%) than to nurses (T1:77.8%, T2:53.8%).

Conclusions: Treating patients during VSED can be a burden for palliative teams. Only few team members experience moral concerns, however, medical care of patients who choose VSED is nonetheless challenging due to the symptom burden. Ethical case discussions and team supervisions can be tools to build resilience.

P 2.053 Assessment of Symptom Burden & Quality of Life in Patients of Primary Brain Tumors, Attending a Tertiary Cancer Care Center

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Background/aims: To assess quality of life & symptom burden in patients of primary brain tumors, attending a tertiary cancer care center.

Methods: Prospective observational study using EORTC QLQ C-30 & EORTC BN 20 questionnaires in patients of Primary Brain Tumors, attending a tertiary cancer care center.

Results: 100 patients with radiological or histopathology wise proven primary brain tumors were included in the study, which comprised 61 males & 39 females. Seizures followed by headache & loss of consciousness were the most common presenting symptom of patients. The mean quality of life as assessed in baseline is 78.2907 with a standard deviation of 9.66784 on a scale of 0 to 100 & the brain tumor specific

symptom burden in patients is 46.9 with a standard deviation of 17.95 on a scale of 0 to 100.

Conclusions: This study shall give insight on quality of life & symptom burden in patients of Primary Brain Tumors, receiving treatment in a tertiary care center.

P 2.054 Prevalence and Potential Consequences of Fentanyl-oral Anticancer Treatment Interactions

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Background/aims: Oral anticancer therapy is increasingly integrated into the care of patients (pts) with cancer. Recognition and management of pharmacokinetic/pharmacodynamic drug-drug interactions is critical to provide efficacious and safe anticancer and chronic treatments. We aimed to gain insight into the real-world prevalence of potentially fentanyl-oral anticancer treatment interactions and analyze the potential consequences on their efficacy and toxicities.

Methods: Prospective observational study in an oncohematological hospital October 2020 – April 2022. Pts included were evaluated before start treatment with oral anticancer drug or support treatment. Cancer treatment data were obtained from our prescription software System. Demographic data and concomitant medication were obtained from our electronic medical record software. Micromedex was used to find potential fentanyl-oral anticancer treatment interactions, and were classified as major or moderate.

Results: 2.636 oral anticancer drug or support treatment were started. 651 potential drug-drug interactions were detected and 39 were fentanyl-oral anticancer treatment (6%), 13 men and 23 women, with a median age of 64.8 (range 32.4-88). 33 (84.7%) and 6 (15.4%) drug interactions were classified as moderate and major. The 3 most common cancers were: non-small cell lung carcinoma in 14 pts (35.9%), breast cancer in 12 pts (30.8%) and sarcoma in 4 pts (10.2%). The most commonly drugs were vinorelbine 9 pts (23.1%), osimertinib 8 pts (20.5%), and palbociclib/pazopanib 6 pts (15.4%). Those interactions could lead to higher risk of fentanyl toxicities in 69.2%, lower efficacy of fentanyl 7.7%, and higher risk of QT-prolonged interval 5.1%.

Conclusions: Fentanyl-oral anticancer treatment interactions can play a significant role in fentanyl toxicities or efficacy, specially in lung and breast cancer. Other opioid analgesics or fentanyl monitorization should be considered when hepatic potential interaction drug-drug is detected.

P 2.055 Monocentric Retrospective Analysis of an Abdominal Pleurx® in the Management of Malignant Ascites

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Background/aims: Neoplastic ascites is a frequent development of cancers and there are several management strategies for this symptom, including tunneled catheters. Even if the literature seems to be reassuring, some articles report up to 17% of infections. To date, there are no clear recommendations on the selection of patients who could benefit from this procedure.

Methods: We have carried out a retrospective study of all our patients who have benefited from the placement of a PLEURX® peritoneal

catheter which we will call Ascitx. We included patients who had Ascitx implanted between 2018 and 2022.

Results: Over this period, 47 patients were included with a proportion of 22 women (47%) and an average age of 66.7 years). Most cancers were of digestive (64%) and gynecological (19%) origin. A CT re-reading at the time of Ascitx placement revealed 74% portal hypertension. Of the 47 patients, two were undergoing chemotherapy. All patients had died at the time of analysis. Among them, 40% died at home. The analysis of the files identified 3 withdrawals of Ascitx for leakage (D1), infection of ascites fluid (D6) and compartmentalized ascites (D28) i.e. 6% of the population. Among the population, we identified 3 confirmed infections (6%) of ascitic fluid and 2 suspected infections (fever without a point of call not explored in an end-of-life situation). A device was removed as previously described and other infections were treated with antibiotics. Of the 3 proven infections, one patient was undergoing chemotherapy and one patient had been treated for cholangitis for 4 days. According to the Kaplan-Meier analysis, the median survival is 30.8 days after placement of an Ascitx.

Conclusions: These results are reassuring about the safety of this device and allow patients suffering from refractory ascites to be able to carry out their end of life at home. We recommend selecting patients who no longer have specific treatment for their cancer and who do not have an ongoing infection.

P 2.056 A NICE Accredited Guideline for the Management of Malignant Ascites

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Background/aims: Ascites is the accumulation of fluid in the peritoneal cavity, often associated with a poor quality of life and poor prognosis. There is limited national guidance on management of malignant ascites. This guideline has been produced to enable healthcare professionals to make evidence-based, patient-centred decisions about the management of ascites in patients with life-limiting cancer.

Methods: A comprehensive literature search was conducted, including a key word search in the Cochrane and NICE databases. Articles were graded using SIGN criteria. Surveys of professionals/clinical notes were performed to assess current practice. These were collated and reviewed by the guideline development group (CDG) and a guideline drafted.

Results: Medical management: Evidence for diuretics less clear in malignant ascites. Serum-ascites albumin gradient (SAAG) can be calculated from ascitic tap. SAAG >1.1g/dL most likely to benefit. Spironolactone is first line diuretic, starting at 100mg and titrated to 400mg every 3-4 days as required. If insufficient response, furosemide can be added. Large volume paracentesis (LVP): Accepted standard of care for large volume tense ascites if diuretic resistance/intolerance. Limited evidence to support use of human albumin solution in LVP for malignant ascites. There are limited indications for a drain to be clamped. Drain removal after six hours is recommended. Permanent indwelling peritoneal catheters: May help with symptom control by avoiding repeated LVP. PleurX peritoneal catheter is recommended by NICE as an option to manage refractory malignant ascites. The CDG recommend considering after two LVP. Estimated cost saving of £1051 for PleurX insertion compared to inpatient LVP.

Conclusions: Malignant ascites is a condition that has a significant impact on a patient's quality of life. We have collated a NICE accredited guideline to help consolidate evidence and standardise the approach to management of these patients.

P 2.057 Symptom Profile and Quality of Life in Patients of Cervical Cancer Referred to Specialist Palliative Medicine: A Prospective Observational Study in a Tertiary Cancer Centre

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Background/aims: Cervical cancer ranks 4th among the most common malignancy in women in 2020 worldwide. Approx 84% of all cervical cancers and 88% of all deaths caused by cervical cancer occurred in lower-resource countries. Apart from poor prognosis, patients with advanced cervical cancer experience a gamut of symptoms- physical, psychological, spiritual and social. Integrating dedicated palliative care services into oncological care early in the disease course for patients with advanced cancer had shown improvement in quality of life.

Methods: This is a single-centre, prospective observational follow-up study. The test used were Descriptive test and Pairwise Wilcoxon sign rank test.

Results: 30 female patients with a median age of 51 years were included. 70% were residents from Maharashtra. 66% were married. 56.7% belonged to upper lower class and 36.7% belonged to lower class. The most common symptoms at day 14 were: loss of sleep, loss of wellbeing, loss of appetite. There was significant improvement in pain but increased anxiety, depression, loss of appetite, loss of wellbeing and no change in fatigue. On comparing symptom scores at day 14th and baseline, A statistically significant difference was found between scores for pain, depression, anxiety and appetite loss. For quality of life changes, it showed improvement in role functioning while worsening of cognitive and social functioning. A statistically significant change in score for financial difficulties with worsening towards day 14. The median change was clinically important. There was no statistically significant difference in median scores for GHS/QoL. It also showed a statistically significant change in the median scores for body image and menopausal symptoms with worsening of symptoms towards day 14 with no change in functional items.

Conclusions: This is the first study to highlight characteristics and symptom profile and its effect on quality of life in an Indian setting. It shows significant improvement in pain severity and improved quality of life.

P 2.058 CRP and Skeletal Muscle as Potential Predictors of Outcome in Cancer: A Feasibility Study

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Background/aims: Systemic inflammation, as indicated by raised C-reactive protein (CRP), is associated with high symptom burden and poor quality of life (QoL) in cancer. Systemic inflammation is also associated with loss of skeletal muscle mass and density. CRP and skeletal muscle change could be objective markers to identify patients at risk of high symptom burden / poor QoL.

Aims: To assess feasibility of a longitudinal study of CRP and skeletal muscle measures as predictors of outcomes (QoL and symptoms,

post-operative course) in cancer and explore relationships between CRP, skeletal muscle and these outcomes.

Methods: This was a prospective longitudinal feasibility study, with 3 iterations required for successful recruitment. Rates of recruitment, missing data and study attrition were recorded. QoL and symptoms were assessed (EORTC QLQ-C30) at baseline and 6-8 weeks later, and relationships with CT-measured skeletal muscle metrics and CRP were studied.

Results: 88 patients were included in iteration 3: 35 inoperable lung cancer, 16 operable lung cancer and 37 non-cancer controls. Only skeletal muscle density (SMD) differed between groups at baseline.

Recruitment rate in iteration 3 was 4/week. 60% of the inoperable group were missing at least 1 data point. 19 did not complete the study: 10 too unwell or dead, 6 lost to follow-up, 3 withdrew.

At follow-up, all 3 groups had ongoing symptom/function impairments, significantly worse in the cancer cohorts.

Low psoas muscle index was associated with worse EORTC QLQ-30 at follow up ($p=0.042$) and low SMD with post-op complications ($p=0.045$). High CRP ($>10\text{mg/L}$) was associated with study non-completion ($p=0.026$).

Conclusions: This study demonstrates the challenges of attrition and missing data but highlights the value of a feasibility study and an iterative study design. Novel associations between skeletal muscle measures, CRP and outcomes, including study completion, were identified which should inform future studies.

P 2.059 Is Lacosamide as a Sodium Channel Blocker Effective for Neuropathic Pain in Cancer Patients?

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Background/aims: Sodium channel blockers such as lidocaine and carbamazepine have been used as analgesics. However, their use is limited because the only route of injection, and there are many interactions and side effects. Lacosamide, which has been commonly used as an antiepileptic drug since 2008, has few drug interactions, few skin side effects, and is a highly tolerable drug. Therefore, if lacosamide is effective for neuropathic pain in cancer patients, we thought that it would be a new treatment option for cancer pain, and conducted an observational study.

Methods: From October 2019 to September 2022, lacosamide was used in 27 cancer patients with neuropathic pain. The primary endpoint was the efficacy rate based on pain relief improvement. The secondary endpoint was the amount of change in pain intensity. Statistics used t-test. And skin disorders and neuropathies were investigated for adverse events. Pain intensity was expressed as follows: 0: no pain (NRS 0); 1: mild pain (NRS 1-4); 2: moderate pain (NRS 4-6); and 3: severe pain (NRS 7-10). Pain intensity values were then averaged from the worst three days before and three days after lacosamide administration. A decrease of 2 grades or more was defined as marked improvement, a decrease of 1 grade was considered effective, an increase of 1 grade or more was defined as worsening, and no change.

Results: Twenty-seven patients (40% male) were was 72.5 ± 14.7 years. Concomitant opioid analgesics were Hydromorphone 11, Fentanyl 5, and so on. There were 10 cases of peritoneal dissemination.

The primary endpoint was marked improvement in 17 patients, considered effective in 6 patients, no change in 4 patients, and worsening in 0 patients. Secondary endpoint varied from 2.1 ± 0.8 to 0.9 ± 0.6 ($p < 0.001$).

Conclusions: There were many cases showing efficacy and no serious side effects such as skin symptoms, it is considered to be well tolerated. In the future, more accurate results can be expected by increasing the number of cases.

P 2.060 Characterization and Assessment of Severity of Cancer Induced Bone Pain and its Impact on Quality of Life: A Prospective Observational Study in a Specialist Palliative Care Setting

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Background/aims: Cancer induced bone pain (CIBP) is a complex debilitating cancer pain syndrome. Inadequate evaluation and under utilisation of an integrated palliative care approach can add to significant morbidity.

Aim: To characterize CIBP using clinical descriptors and assess its severity and impact on the quality of life of patients.

Methods: A prospective single centre observational study in patients referred for palliative care in outpatient & inpatient setting having CIBP. Numerical rating scale, Short form McGill Pain questionnaire (SF-MPQ), European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core (QLQ-C30) & Bone metastases module (QLQ-BM22) validated in English, Hindi and Marathi was used. Patients were followed up at day 3, 7 and 14 in person or telephonically. Descriptive statistics were used.

Results: Data from 59 patients (37 male, 22 female), median age of 54 years showed most common cancer types being Lung and breast, with bone involvement at multiple sites, mixed axial & appendicular involvement and lytic type of bone lesions. Other metastatic sites included node, pleura/lung, and liver. Tiring-exhausting, Aching, Heavy, and Tender were most commonly used descriptors on SF-MPQ. Discomforting and Distressing were most commonly used to describe present pain intensity. Baseline median pain scores being 5 with reduction in severity seen in 54 patients by day 3. Improvements in physical ($p=.002$), cognitive ($p=.002$), emotional functioning ($p<.001$), pain ($p<.001$), insomnia ($p<.001$), global health status ($p<.001$) scales on EORTC QLQ-C30. Improvements in pain characteristics ($p<.001$), painful sites ($p<.001$), psychosocial aspect ($p=.02$), & functional interference ($p<.001$) scales on EORTC QLQ-BM22.

Conclusions: Our study highlights the descriptors used for CIBP in an Indian setting. It also shows significant improvements in the pain severity and improved quality of life of patients on an integrated palliative care approach.

P 2.061 Implementation of Palliative Care Protocols - Real World Experience

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Background/aims: The goal of palliative care is to improve the quality of life and relieve suffering through a comprehensive assessment and by offering proper treatment of pain and other distressing symptoms. The paper presents a study designed to explore the specific needs of the oncological patients admitted in palliative care and their management.

Methods: Retrospective study on a cohort of 289 patients hospitalized in the Palliative Care Department of the Regional Institute of Oncology Iasi between January and December 2021. Specific tools were used to assess

the need for palliative care: the questionnaire for identifying the palliative care needs and the palliative case management plan.

Results: Pain represented the main symptom evaluated, 30% of patients – with severe pain (87 patients), 27% of patients - with moderate pain (78 patients), and 43% of patients – with mild pain (124 patients). 202 out of 289 hospitalized patients received opioid-based medication in their treatment plan. 62 patients (21%) were in need to control nausea and vomiting. 38 patients (13%) were diagnosed with delirium and 73 patients (25%) received subcutaneous hydration.

Conclusions: The results demonstrate the importance of applying specific protocols and assessment tools for understanding the problems faced by the oncological patient admitted to the palliative care department. Preventing and managing these symptoms while optimizing the quality of life throughout the disease's pathway is the only way to achieve the goal of palliative medicine.

P 2.062 Risk Assessment for Direct Opioid Challenge in Patients with Opioid Allergy in Palliative Care Setting

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Background/aims: Opioids are the mainstay medication for symptom control in palliative care patients. Its use may be restricted in patients with opioid allergy label, potentially leading to poor symptom control. This is especially so, with the limited alternative drugs available. The usual allergy workup is not suitable for the palliative care population owing to the acute need for symptom control and prolonged investigation time.

Objectives: To create a workflow on risk assessment for the acute use of opioids in palliative care population.

Methods: Literature search in major medical databases were carried out on the following topics - opioid allergy, drug hypersensitivity reactions and allergy workup. Search terms used included opioid allergy including individual drug name, hypersensitivity reactions, adverse drug reactions, anaphylaxis as well as opioid cross reactivity.

Results: True opioid allergy is very rare. Although recollection is limited, previous studies had shown patients were able to recall symptoms and management that generally corresponded with hypotension and angioedema; both associated with high likelihood of true allergy. Using clinical criteria to diagnose anaphylaxis had been demonstrated previously in both prospective and retrospective studies. This allows for risk assessment determination for opioid use in patients with opioid allergy label.

Conclusions: A workflow on risk assessment for opioid allergy for direct drug challenge is created using evidence-based data and patient's recall of index reaction. With this workflow, it is hoped that patients with acute need for opioids can be started on opioids on a timely and safe manner.

P 2.065 "It's Not Going to Happen to Me": A Qualitative Study of Older Adults with Cancer Views and Experiences of Malnutrition, Sarcopenia and Cachexia

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Background/aims: Malnutrition, sarcopenia, and cachexia are highly prevalent, but under-recognised conditions in older adults with cancer. We aimed to explore patients' views and experiences of screening, and their understanding and perceptions of these conditions.

Methods: Eight semi-structured interviews were conducted with patients with cancer, aged ≥ 70 , in a tertiary cancer centre. Participants were screened for the three conditions. Interviews were thematically analysed with a phenomenological lens with feedback loop analysis investigating relationships between themes.

Results: Three feedback loops were identified;

- i) impact of misunderstanding,
- ii) concerned patients feeling they have nowhere to turn, and
- iii) the role of screening for malnutrition, sarcopenia, and cachexia.

A fundamental misunderstanding of the conditions resulted in reduced risk perception. Nutritional or physical function problems were perceived as overlooked by clinicians, overshadowed by the cancer diagnosis, or attributed to other comorbidities or ageing. Tension was seen between participants' experiences of these conditions and their belief that "it's not going to happen to me", whilst also seeing problems as inevitable due to the cancer diagnosis and treatment. This left patients with nowhere to turn when nutritional or functional problems affected anticancer treatment options or quality of life. Screening for the conditions presented opportunities for concerns to be addressed and taken seriously by healthcare professionals, reducing the risk of these conditions being overlooked or overshadowed, and provided opportunities for education and challenging the dissonance of these conditions being seen as expected inevitabilities whilst also being personal impossibilities.

Conclusions: Patients' perceptions, and diagnostic overshadowing, present barriers to the management of these conditions, there is a need to alter patient and clinician attitudes to these conditions to enable successful symptom management in older adults with cancer.

P 2.066 A Case Series of Oral Administration of Parenteral S-ketamine in Wound Care: When 'Conventional' Medication Regimens Are Not Sufficient

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Background/aims: Wound care procedures are often considered painful. Up to 75% of patients report moderate to severe pain. Pain can have severe effects on patients wellbeing and is associated with delayed wound healing. Opioids can be used during wound care, however, their use is not always sufficient or accompanied by unwanted side-effects. Ketamine might be a successful alternative or adjuvant, due to its pharmacological profile and NMDA receptor antagonism which prevents development of increased pain sensitivity. S-ketamine has a higher analgesic potency than the racemic mixture and has less side effects. When administered orally, S-ketamine undergoes metabolism to norketamine, which has anesthetic and analgesic effects of its own.

Methods: In our case series we describe four patients with severe pain during wound dressing changes. They were treated by oral administration of 0.5- 1mg/kg parenteral S-ketamine during wound care on the ward. One patient suffered from wounds due to calciphylaxis, two patients suffered from post-surgical wounds. The fourth had wounds due to an infection with pyoderma gangrenosum. All were treated with S-ketamine as co-analgesic added to their regular medication regimen. Dosage was 0.5 mg/kg for the first patient, and later titrated to 1mg/kg. All other patients were started and maintained on a dosage of 1mg/kg.

Results: In all four patients significant pain reduction was achieved. No serious adverse events or side effects were observed or reported by care-givers or patients. While one patient reported feeling strange after administration, she preferred the use of S-ketamine due to better pain relief.

Conclusions: Oral administration of S-ketamine was successful in reducing pain during wound care in our patients. Pain reduction improves patient satisfaction. Reduced stress and pain might contribute to wound healing. More research in dose, efficacy, long term safety, effects on wound healing and cost effectiveness is needed.

P 2.067 Management of Intractable Bone Pain in Metastatic Renal Cell Carcinoma: A Comparative Case Study

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Background/aims: Renal cell carcinoma commonly metastasises to bone with an increased risk of skeletal related events (e.g., pathological fracture, bone pain). The humeral bone is the second most common location for osseous metastasis. The mainstay of pain management is radiotherapy alongside interventional pain procedures and analgesic medications. Intramedullary nailing or plate fixation is performed in the management of pathological fractures or prophylactically in cases deemed to be at high risk of fracture.

Methods: The medical records for two patients with stage IV renal cell carcinoma and humeral metastases were reviewed. Both patients developed significant neuropathic and inflammatory upper limb pain secondary to localised disease progression.

Results: One patient was initially managed with an intramedullary nail for a pathological fracture and subsequent radiotherapy. Pain remained an issue despite escalating doses of multimodal analgesia, significantly diminishing the patient's quality of life. The second patient experienced similar intractable arm pain with associated loss of limb function despite standard intervention and ultimately proceeded to a palliative amputation. There was a brief period of mild phantom limb pain post-operatively, which was subsequently well controlled with up-titration of pregabalin. Overall, there was a dramatic reduction in the patient's total analgesic requirements.

Conclusions: Adequate control of pain secondary to bone metastasis can be difficult to achieve, negatively impacting a patient's quality of life. Amputation is not commonly performed in this patient cohort due to associated morbidity and their limited prognosis. This comparative case study adds to the limited existing evidence supporting the consideration of palliative amputation in the management of refractory malignant bone pain.

P 2.069 Outcomes and Symptom Burden in Ruptured or Leaking Aortic Aneurysms Unsuitable for Surgical Repair

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Background/aims: This study looks to outline the experience of a palliative care team in a large urban teaching hospital in terms of survival, symptoms and palliative drug use in patients with ruptured or leaking aortic aneurysms.

Methods: A retrospective analysis of the team database of all patients with Ruptured or Leaking Aortic Aneurysms presenting acutely to the hospital was searched using a range of sensitive terms (aorta*, AAA*; aneurysm*) using the team's database of all referred patients; data analysis of electronic records was undertaken to determine symptom burden, outcome and pharmacological management.

Results: 22 patients were seen over a ten year period (2013-2022 inclusive) who were referred to the palliative care team who were not deemed suitable for operative intervention. Of these 4 had thoracic aneurysms (2 ascending; 2 descending thoracic aorta) and 18 had abdominal aortic aneurysms. The outcome was death in all 22 patients (100%) with time to death varying from 1-8 days with a median of 1 day

from presentation to death (where the patient died within 24 hours this was counted as 1 day – in practice the majority of patients died within 24 hours of admission). All patients had pain and all received opiates; a range of opiates was used in a range of doses. The mean oral morphine equivalent was 32.4mg/24h (median 25mg/24hr; range 10-80mg/24h); 14 patients had agitation or distress resulting in the use of benzodiazepine (invariably midazolam - mean dose 8.4mg/24hr; median 6mg/24hr; range 2-12mg/24hr); 2 patients needed levomepromazine in addition to midazolam in doses of 3 and 5mg/24hr.

Conclusions: The palliation of ruptured or leaking aortic aneurysms presents a rapid but symptomatically challenging mode of death for clinicians; opiates are invariably required in moderately high doses; terminal agitation and distress is also common. This data will be used to inform education and guidelines surrounding the urgent management of these patients; a wider study across multiple sites is planned.

P 2.070 Psychomotor Slowing in Patients with Advanced Cancer Not Suffering from Delirium. A Qualitative Study

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Background/aims: In patients with advanced cancer, psychomotor slowing (PS) is observable during hypoactive delirium and in some patients with cognitive and motor symptoms that do not allow such a diagnosis. Current tools used in the context of delirium assessment include cognitive and/or motor items. However, these are only reported in a one-dimensional way, based on the observations of healthcare professionals (HCPs). The aim of this study is to describe the perception and experiences of oncology HCPs related to PS in patients with advanced cancer not suffering from delirium.

Methods: Using a phenomenological approach, four focus groups with 19 HCPs were conducted, fully transcribed, and analyzed using thematic content analysis.

Results: HCPs reported a progressive ("it's progressive") clinical syndrome combining cognitive ("the analysis [of information] takes longer" and "they forget frequently") and motor ("they walk slower than usual" and "we notice slowdowns [. . .] in all tasks : [. . .] talking and eating") symptoms with various underlying etiologies ("related to depressive symptoms" and "drug interactions"), and the need for tools to improve its management ("easily accessible in the patient's file" and "to help the next colleagues adapt their lessons or interventions"). HCPs described various pharmacological ("add drugs like [methylphenidate]") and non-pharmacological ("I repeat myself and I go step by step") treatment options. HCPs recognized the presence of emotional and existential distress in these patients ("It's like mourning" and "loss of hope"). Yet, they reported feeling disengaged ("is this something that absolutely needs to be rectified?") when asked about ways to improve treatment options.

Conclusions: This study will contribute to the development of the first instrument allowing the objective and subjective evaluation of PS, which will facilitate the identification of the population on which it is profitable to intervene and will contribute to a better clinical management.

P 2.071 Which Opioids Are Effective for Cancer Patients with Cancer Pain Including Bone Metastasis? A Comparison of Tapentadol, Methadone, Oxycodone, Fentanyl and Hydromorphone

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Background/aims: Pain caused by bone metastasis of cancer is difficult to treat with opioid analgesics with only μ -opioid receptor stimulating effects, because the sensitization of spinal nerves progresses as the disease progresses. We compared the analgesic effects of tapentadol which has noradrenaline reuptake inhibition and methadone which has N-methyl-D-aspartate receptor inhibition, with hydromorphone, oxycodone, and fentanyl for cancer pain, including bone metastasis pain.

Methods: Cancer patients with bone metastasis who were administered tapentadol, methadone, hydromorphone, oxycodone (all in tablet form), or a fentanyl patch for pain relief in Ashiya Municipal Hospital from January 1, 2013 to October 31, 2021 were enrolled in this study. Numerical rating scale (NRS) scores for pain before and after the administration of drugs (on day 0, 7, and 14) were retrospectively investigated from the medical chart. The primary endpoints were the changes in the NRS scores between day 0 and day 7.

Results: In the 52, 53, 62, 51, and 56 patients enrolled in the tapentadol, methadone, hydromorphone, oxycodone, and fentanyl groups, respectively, the NRS scores (means \pm SD) for pain were 6.65 \pm 2.44, 6.37 \pm 2.12, 6.71 \pm 1.88, 6.36 \pm 2.42, and 6.62 \pm 1.58 before the administration of opioids. The NRS scores on day 7 were 1.29 \pm 1.83, 1.66 \pm 1.88, 4.35 \pm 2.68, 4.29 \pm 2.72, and 4.59 \pm 2.35 in the tapentadol, methadone, hydromorphone, oxycodone, and fentanyl groups, respectively. The NRS reduction at day 7 in the tapentadol group was not significantly different from that in the methadone group ($p = 0.647$) and was significantly greater than that in the hydromorphone, oxycodone and fentanyl groups (all $p < 0.001$).

Conclusions: We suggest that tapentadol and methadone could be more effective than other opioids for cancer pain, including bone metastasis pain. However, because this result may include effects on pain other than bone metastasis pain, further studies are needed.

P 2.072 Pool Training in a Group - Dialogue with Patient According to the Café Model

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Background/aims: Patients who are enrolled in advanced palliative home care (ASIH) Stockholm Södra have the opportunity to participate in group training in the pool. For several years, ASIH has had access to a hot water pool (34 degrees) once a week, for one hour. The goal of the training is to increase well-being and improve the quality of life for the palliative patient. The advantage of training in warm water is that it is gentle on joints and muscles. The training begins with a warm-up, then movement exercises with and without equipment (according to the patients' ability) and "play" with a balloon. Followed by QiGong. Then the patients can decide for themselves whether they want to swim, float or leave the pool.

The aim was to have a dialogue with the patients about their experience of group training in the pool, during and after the visit to the bath, as well as the demand for the patients' suggestions for improvement.

Methods: There were regular short conversations with the patients at the edge of the pool and one day afterwards. Two guiding questions: "How does it feel today?" and "What should we think about?"

Results: The answers were, among other things: "How I've longed!". "So nice", "I feel light", "I can move more pain-free!", "Fun with music", "How we laughed!", "Feeling how my breathing became deeper", "Can relax and focus on myself - we are all sick", "A break in everyday life!". Suggestions for improvement that the patients put forward were, among other things, that the music could be varied more and the demand for an individual time with the physiotherapist to get tips and advice on individual movement or stretching exercises in the pool.

Conclusions: The patients has a positive experience of pool training. They experience improved mobility, breathing and feel more relaxed. Group training with patients in a similar situation means less "stress". Having a dialogue with patients and asking for their views increases patient participation and patients' well-being.

P 2.075 Analysis of Dyspnea in Fibrotic Interstitial Lung Disease and the Impact of Control Measures in Palliative Care Patients

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Background/aims: Dyspnea is a disabling and very common symptom in fibrotic interstitial lung disease (FILD). Although there are several pharmacological and non-pharmacological strategies useful in relieving this symptom, there are still no well-defined guidelines for its treatment.

To analyze the presence of dyspnea, and the impact of treatment on its control in patients (pts) followed by the Palliative Care Service (PC) of a university hospital.

Methods: Retrospective observational study of the clinical records of pts with FILD followed from January 2020 to May 2022. The intensity of dyspnea in the first and last observation, the pharmacological therapy instituted for symptomatic control and its impact on this symptom were evaluated.

Results: We identified 45 pts from different categories of FILD (mean age 73.47 ± 10.43, 57.8% male). In the first evaluation, 18 pts reported dyspnea at rest or on minimal exertion. Eight pts were on opioid therapy (62.5% with morphine) and 22 pts were on psychotropic drugs (54.5% with benzodiazepines, 59.1% with antidepressants and 27.3% with both). Forty three of the 45 pts were under supplemental oxygen at home. In the last evaluation, 4 pts reported dyspnea at rest or on minimal exertion. Thirty-eight pts were under opioid therapy, predominantly morphine and 39 pts were under psychotropic drugs (51.3% with benzodiazepines, 51.3% with antidepressants and 43.6% with both). Fifteen pts died during the period under analysis, 4 were discharged to the home PC team and 22 pts were followed up at the outpatient clinic of the PC Service.

Conclusions: Dyspnea improved in most pts and almost all of them were on opioids and psychotropic drugs, however, more studies are needed to confirm the impact of these drugs on the symptom. The follow-up of pts by multidisciplinary teams, including PC professionals, may allow the early association of pharmacological and non-pharmacological therapies with benefit to pts and their families.

P 2.076 The Positive Impact of a Home-based Palliative Care Team in Symptom Control: A Retrospective Study

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Background/aims: Poor symptom control aggravates suffering and health care services utilization. Changes in symptom intensity are expected over chronic diseases' trajectories. Palliative care (PC) provides strategies to improve symptom control. AIM: To assess the impact of a Home-Based Palliative Care Team (HBPCT) in symptom control. Also, define the population in terms of sociodemographic factors, main diagnosis, complexity and performance status.

Methods: Observational retrospective study of adult patients evaluated by a HBPCT, admitted and discharged between 01/01/2020 and

30/06/2022. The Edmonton Symptom Assessment System (ESAS), the Palliative Care Complexity Diagnostic Instrument (IDC-Pal) and the Palliative Performance Scale (PPS) were retrieved from clinical records. Initial and final ESAS scores were compared to infer the degree of symptom control overtime. A descriptive analysis was performed. The study was approved by the competent organisms.

Results: 135 patients met the inclusion criteria. Mostly were male (55,6%) and had advanced cancer (63,7%); 97,0% were classified as complex or highly complex and 94,8% had a PPS equal or below 50%. Symptom relief was documented for vomiting (100%), nausea (88,9%), depression (85,0%), pain (68,3%), anxiety (67,3%), constipation (59,7%), dyspnoea (50,0%), anorexia (32,9%), fatigue (22,2%) and drowsiness (26,7%).

Conclusions: We conclude that the HBPCT was effective in relieving most of the symptoms, in a variable degree, consistent with previous studies. The small sample size and being uncentric are some of the limitations of this study. Further studies are needed on this topic, such as the analysis of which factors may alter the degree of symptom control in the community setting and in the context of larger sample sizes.

P 2.077 Palliative Care Needs in Patients with Heart Failure – Preliminary Results

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Background/aims: Patients with advanced heart failure have poor prognosis and possibly high symptom burden with no adequate access to specialized palliative care in Denmark. The aim of this study is to identify the prevalence of self-reported palliative care needs, including symptomatology, functional capacity and health-related quality of life in heart failure patients.

Methods: A cross-sectional study using disease specific and generic questionnaires has been conducted since 2020. Sample power calculation was estimated as 400 adult heart failure patients (New York Heart Association Functional Classification - class II, III, and IV), who have an in-/out patient trajectory at the Department of Cardiology. Socio-demographic and clinical data were collected through interviewing the patients. Palliative needs were assessed by HeartQOL, EORTC QLQ-C15-PAL, The Multidimensional Fatigue Inventory (MFI-20) and The Hospital Anxiety and Depression Scale (HADS).

Results: Preliminary results: Currently, 366 patients have been included (206 men, 77 women); response rate 77%. Mean age = 74 years (range 41-94 years). Seventy-two percent has been admitted to the Department of Cardiology within the last 6 months; 75% felt affected by their heart failure and 53% reported their general health less good or bad. Dyspnoea (43%), weakness (39%) and fatigue (37%) were most prevalent symptoms, which were rated from much to very much in intensity. Sleeping problems were reported by 31%.

Conclusions: The preliminary results showed high prevalence of severe symptoms, poor health and health-related quality of life quite similar to findings of palliative needs in cancer patients. This study is delineating the palliative needs of heart failure patients and can assist to adequately plan palliative care services in the future.

P 2.078 Looking beyond the Pain - Assessment of Clinical-emotional Dimensions in Palliative Care

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Background/aims: In palliative care, a clinical-emotional evaluation is essential to identify and relieve the symptoms with a multidisciplinary approach. The aim of this study was to analyze the socio-demographic profile, symptoms and psychological and social counselling referral of cancer patients followed in a palliative care consultation.

Methods: Retrospective observational study of palliative care consultations carried out by an attending physician during three months (July to September 2022). Data was collected by consulting the clinical files.

Results: We reviewed 28 patients, who had 62 total consultations. 68% were female and 32% male, with a mean age of 74 years. 46% had the Eastern Cooperative Oncology Group (ECOG) Performance Status 3. The primary caregiver were spouse (43%) followed by sons (25%).

In the first medical appointments 50% presented pain; 50% sadness; 32% emotional suffering – 18% associated with insomnia. In the follow-up appointments, patients presented pain decreased (71%) as opposed with an increase in patients presented sadness and emotional suffering (35% and 44%). Patients manifesting constipation, tiredness, anorexia, nausea and xerostomia also increased.

28,6% of the patients and 14,3% of the family members were referenced to psychological counselling - among these 18% of the patients and 100% of the family members in follow-up appointments. 39% were referenced to social counselling – 14% in the first encounter.

Conclusions: In this study, psychological symptoms and pain showed an equal significance. With improved pain control, psychological symptoms become predominant. The need for psychological counselling becomes an important need for patients and families. With function decline, the need for social counselling also increased. The identification of these issues allows early referral to a multidisciplinary approach aiming clinical-emotional individualized care.

P 2.079 Reducing Emergency Admissions through Improvement of Adherence to Oral Opioids: A Descriptive Study

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Background/aims: Emergency admissions in cancer patients treated with oral opioids for pain are often due to lack of effectiveness of adequate treatment. Poor adherence to treatment can be a cause of lack of effectiveness. There are medical and nursing interventions aimed at improving adherence to treatment

Methods: Adherence to treatment was measured in cancer patients treated with oral opioids at routine visits to oncology department in a cancer center. Emergency department visits were measured in the following three months. Data about age, gender, type of cancer and type of opioid were also collected for the follow-up.

Results: 36 patients were included, 20 male and 16 female. Median age was 61,73 years. Emergency department visits were significantly higher in patients with low adherence (>1 in the following three months). No significant differences were found in adherence depending on age, gender, type of cancer or type of opioid. Most frequently used opioids were morphine and oxycodone.

Conclusions: Improving adherence to oral opioids through medical or nursing interventions can contribute to reduce emergency and hospital admissions.

P 2.080 Respite Palliative Care in a Lower Middle-income Country: A Single Center Experience in a Tertiary Care Cancer Hospital

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Background/aims: Different models of palliative care (PC) help patients with life-limiting illnesses throughout the disease continuum. The concept of “respite care services” in the context of PC is not uniform worldwide. In the developing countries, it is more of a step-down version of in-patient units. Our institution’s respite palliative care (RPC) consists of a multidisciplinary team providing holistic care to advanced cancer patients. Our study aimed to evaluate the effect of the RPC model on symptom burden and psychological distress.

Methods: We conducted a retrospective descriptive analysis of routinely maintained medical records of all patients admitted in RPC setting over a one-year period. Demographic, clinical and treatment related variables performance status were recorded. Symptom scores on Edmonton Symptom Assessment Scale-r (ESAS-r), Generalized Anxiety Disorder(GAD-7), and Patient Health Questionnaire(PHQ-9) scores at admission and discharge and number of days of admission were noted. Descriptive statistics, chi square tests and paired t tests were used for analysis.

Results: Of 212 patients admitted for RPC, 116(55%) patients were female and 110 (52%) had a performance status of 3. The median age was 46 years. 52 (24.5%), 49(23%), and 42(20%) had gynecological, head-neck and gastrointestinal cancers, respectively. Two-thirds of the patients were not on any cancer directed treatment. The most common reasons for admission were pain (120, 56.6%) and intestinal obstruction (40, 19%). Change in symptom scores from admission to discharge could be assessed in 138 patients. There was a statistically significant reduction in pain, breathlessness, fatigue, loss of appetite, loss of sleep and loss of wellbeing scores and depression and anxiety scores, at discharge. The median number of days of admission was 6.

Conclusions: Respite palliative care in a low resource setting was effective in reducing symptom burden in advanced cancer patients. We need further research to evaluate effect on caregiver burden.

P 2.082 Disparities of Opioid Accessibility for Palliative Pain Management in the Brazilian Amazon

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Background/aims: Opioids are narcotics with sedative and hypnotic effects used to treat moderate to severe pain. In Brazil, opioid consumption has been growing and pharmacy sales recorded an increase from 1,601,043 in 2009 to 9,045,945 in 2015, with codeine being the best-selling and available for outpatient use. However, the availability of these drugs in pharmacies in Manaus is low. This work aims to describe the availability of opioids in the public health service in the city of Manaus and compare the supply between the public and private sectors.

Methods: A cross-sectional, observational, and quantitative study was conducted. For data collection, the authors went personally to the public and private pharmaceutical networks. The opioid analgesics included in the research were as follows: Codeine alone; Codeine in association with Paracetamol; Tramadol; Tramadol in association with Paracetamol; Fast-release Morphine; Controlled-release (CR) Morphine; Methadone; Oxycodone; Fentanyl Patch; Buprenorphine.

Results: The city of Manaus has 2,255,903 people (IBGE, 2010) with a supplementary health system covering only 13% and a good availability of opioids in the public network compared to the private network. In the

monthly stock survey of the Pharmaceutical Supply Center of the public health service, it was described 48.38% of Morphine 10mg; 19.6% of Morphine LC 30mg, 58.68% of Morphine LC 60mg; 77.25% of Morphine LC 100mg; 56.58% of Oxycodone 10mg and 69.53% of Oxycodone 20mg. While less availability of presentations was observed in the private pharmaceutical networks: Codeine 30mg combined with 500mg paracetamol, Tramadol 50mg and 100mg, Morphine 10mg and 30mg, and Methadone 10mg.

Conclusions: Therefore, it is still necessary to study the per capita availability in the city compared to other national capitals, in addition to actively searching for the reasons that imply this divergent accessibility and seeking possible actions to overcome this disparity.

P 2.083 Study of a Supportive Application with Integrated Patient-reported Outcomes in Patients with Advanced Pancreatic or Lung Cancer (BetterEveryDay)

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Background/aims: There is a growing interest in electronic patient reported outcomes (PRO) to facilitate remote monitoring of disease symptoms and side effects. We developed a supportive application (App) with integrated questionnaires. Part A of the study BetterEveryDay tested feasibility of the App in the outpatient setting.

Methods: In Part A of this two-part study (NCT04611867), we included patients with advanced pancreatic cancer (PC) and non-small cell lung cancer (NSCLC) in performance status 0-2, receiving 1st line systemic therapy. Participants were to provide weekly PRO, adapted from the National Cancer Institute, pertaining to symptoms during systemic therapy, and answer to self-reflecting questions. A predefined threshold of severity triggered initiation of extraordinary personnel assistance. The primary endpoint was proportion of participants responding to at least two consecutive questionnaires by 12 weeks. An 80% consecutive completion rate by 12 weeks was considered reasonable to continue with a randomized study (Part B). Secondary endpoints included proportion of participants logged on at least once, recruitment rate, time spent by personnel and satisfaction rate.

Results: In total, 30 participants (PC n=17, NSCLC n=13) were included between August 2021 and December 2021. Most patients were computer experienced (97%). The proportion of participants responding to at least two questionnaires within 12 weeks was 87% (n= 26). 29 participants (97%) logged on to the App at least once by 12 weeks. The recruitment rate was 7 (range 4-11) patients enrolled per month. In total, the personnel spent 621 minutes (mean 20.7 minutes per patient) on phone calls to 14 out of 30 participants. Fifteen participants evaluated the App and the mean satisfaction rate was 77.2%.

Conclusions: The App with integrated weekly PRO and self-reflecting questions was feasible for patients with advanced PC or NSCLC and time spent by personnel was acceptable. The randomized part B is planned to be initiated in 2023.

Conflict of interest: The project is partially funded by Roche.

P 2.084 Monitoring and Management of Symptoms in Palliative Unit: Process to Improve Practice

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Background/aims: Symptom management is one of the essential standards in Palliative Care (PC). Professionals who provide PC need to recognize and respond effectively to their patient's symptoms. This attitude is expected to maximize comfort and minimize the suffering of the patient and family, as well as a process quality indicator.

Aims: Identify and improve the practice of the nursing team in monitoring and managing symptoms in PC units.

Methods: This project is an evidence implementation methodology developed in a PC unit from 9/2021 to 9/2022. The ethics committee approved it.

The sample is intentional and composed of health professionals from clinical practice (n = 22) and patients hospitalized in the PC unit (n = 20) - inclusive criteria were patients with Glasgow ≥ 15 and evaluated with The Edmonton Symptom Assessment System (ESAS) scale.

Data analysis is based on The Joanna Briggs Institute's evidence implementation methodology, characterized by three main stages: 1^o - performance of a baseline audit; 2^o - identify barriers to implementation and development strategies; 3^o - follow-up audit.

Results: Baseline: 9.1% of patients have registration through ESAS; 31.7% of professionals recorded pharmacological and non-pharmacological interventions for symptoms; 0% reassessment of symptom monitoring; 30% of professionals were trained in ESAS and symptom management.

Activities like training sessions, information guides and plasticized scales were created to make them available to the patient and professionals, improving results.

Patients were taught, instructed, and trained to record their symptoms. Improvements were made in nursing records in the comfort focus and the focuses associated with the most prevalent symptoms. Follow-up audit results revealed improvements.

Conclusions: It's essential to standardize care with resources to the best practices available in the area. Strategies implemented in the project were efficient, improving professional practice in monitoring and managing symptoms in palliative care units.

P 2.087 Total Pain in Palliative Cancer Patients: A Qualitative Analysis

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Background/aims: According to the concept of Total Pain proposed by Cicely Saunders, the treatment of pain in palliative patient requires taking into account its multidimensional nature: its physical, social, psychological and spiritual aspects. The purpose of this study was to update the concept of Total Pain through interviews with cancer people in palliative care.

Methods: Fourteen semi-structured interviews were conducted in two French institutions (Mage=68, SD=7.19; 8 women; mean Karnofsky score=50%; disease stage III or IV). The interview guide explored physical suffering (e.g., pain), social suffering (e.g., isolation), psychological suffering (e.g., emotional state), spiritual suffering (e.g., the place of spirituality in the experience of illness), connection to nature, and patients' internal/external resources. Thematic content analysis was used to analyze the interviews.

Results: From the meaningful verbatims, different themes and sub-themes emerged: relationship to pain, appeal to internal resources, impact of pain on relationships (physical suffering); loss of autonomy, social connection as a resource (social suffering); uncertainty and loss of control, movement as a resource (psychological suffering); search for meaning and understanding, transmission of values, end of life, death acceptance but suffering inacceptance (spiritual sphere); ability in savoring « little things », helping memories (connection to nature).

Conclusions: Despite the experience of total pain, some patients mobilize internal and external protective resources in the experience of the disease. These results underline the importance of raising the awareness of the nursing and medical staff to these multidimensional aspects, by considering it as a dynamic process of the individual in connection with his community and environment.

P 2.088 A Limited Systematic Review of the Effectiveness of Interventions in the Management of Patients with Established Opioid Induced Hyperalgesia

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Background/aims: Opioid induced hyperalgesia (OIH) can be defined as, “increased sensitivity to painful stimuli as a result of opioid use”. It is a distinct clinical syndrome from opioid tolerance. Palliative care practitioners are frequently faced with the clinical problem of escalating pain despite escalating opioid doses and distinguishing between OIH, tolerance and disease progression can be a challenge.

Aim: To evaluate the effectiveness of interventions that could be used to treat palliative care patients with an established clinical diagnosis of opioid induced hyperalgesia.

Methods: A systematic review by a single reviewer was performed. EMBASE, OVID-Medline and Cochrane Library were searched using key words like “opioid induced hyperalgesia”, “opioid induced pain hypersensitivity”, “opiate induced hyperalgesia”, “therapy”, “intervention” and “treatment” among others.

Results: 649 titles were identified, 18 underwent full text screening and 3 were included in the final review having satisfied the inclusion/exclusion criteria. One systematic review of case reports and case series by Guichard et al., (2022) outlining the evidence for successful management of OIH (as defined by a reduction in Numerical Rating Scales (NRS) of pain by 30%) using opioid rotation (79%), opioid cessation (57%) and the use of adjuvant therapies (72%) was included. A case series by Walker & Webster (2013) using intrathecal Ziconotide showed a 20-40% reduction in NRS scores in the 4 patients included. A case series by Belgrade & Hall (2010) showed a decrease in oral morphine equivalent use (OME) in 7/11 cases. There were issues with internal validity in all studies and studies were very heterogenous.

Conclusions: It is not possible to make recommendations on most effective interventions for patients with OIH based on this systematic review as there were no experimental studies available. More research is needed, particularly in the setting of palliative care patients where available experimental and observational studies are lacking.

P 2.089 Translation, Cultural Adaption and Response Processes of the Support Needs Approach for Patients (SNAP) in a Swedish Palliative Homecare Context

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Background/aims: Patients (pts) expressed need is key for holistic and supportive person-centred care. We lack tools that enable pts to express their own needs. The Support Needs Approach for Patients (SNAP) includes a tool covering 15 broad questions and a 5-step process for health care professionals to enable pts to consider, identify, and express their support needs and create a supportive action plan together. To translate, culturally adapt and examine response processes of the SNAP Tool among pts and Registers Nurses (RN) in Swedish specialised palliative care (PC).

Methods: Two stage study: (I) translation and cultural adaptation of the SNAP Tool; (II) examination of response processes using cognitive interviews (11 pts) and two focus groups (10 RNs). Stage I was completed by researchers with clinical and methodological experience. Stage II included pts, both men and women with various life-limiting illnesses. RNs had worked as a RN for 22 years (md) and in PC for 8 years (md). Data collection and analysis followed guidelines for information about relevance, clarity, and sensitive content.

Results: Both pts and RNs found the SNAP Tool and its instructions relevant for use in specialised PC. RNs impressions were that SNAP would add to their workload and raise expectations that staff could not meet. RNs queried whether question 5 (about living healthier) could be obtrusive for pts in PC. Overall, pts were positive about the tool and perceived the questions as clear and relevant; timing of use was considered important to them.

Conclusions: The Swedish translation of the SNAP Tool covers relevant and important areas for pts’ support needs. There were some discrepancies between pts’ and RNs’ impressions on question wordings. RN training in SNAP might address this by enhancing their understanding.

P 2.090 Assessment and Documentation of VTE Prophylaxis in a Specialist Palliative Care Inpatient Unit: A Clinical Audit

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Background/aims: Venous thromboembolism (VTE) prophylaxis is an important patient safety strategy in patients admitted to in-patient units. As part of the holistic assessment, all patients admitted should have their risk of VTE assessed to decide whether they may benefit from anticoagulation. The NICE guidelines recommendations to “Assess all patients to identify the risk VTE and bleeding” and to “Balance the person’s individual risk of VTE against their risk of bleeding when deciding whether to offer VTE prophylaxis”. The aims were to assess the quality of our VTE prophylaxis prescribing and adherence to NICE guidelines.

Methods: Standards: Nice guidelines: VTE in over 16s: reducing the risk of hospital-acquired deep vein thrombosis or pulmonary embolism.

Methodology: A Retrospective audit over 3 weeks. Included all admissions to the palliative care in-patient unit during that period. No exclusion criteria. VTE prophylaxis documentation was reviewed and recorded daily. At the end, the data was entered into excel.

Results: A total of 27 patients during the study period. 12 patients were appropriately commenced on prophylaxis, 6 patients were previously on anti-coagulation. 3 patients commenced prophylaxis in the acute hospital prior to transfer. 1 patient had a deferred admission and did not commence VTE prophylaxis until day 2. 5 patients were not commenced on prophylaxis, the rationale was clearly documented in 3 patients.

Intervention: Relevant stakeholders in the in-patient unit informed of initial results and advised on recommendations.

Re-audit: Data recollected after 1 month interval post intervention. A total of 24 patients. 10 patients were appropriately commenced on prophylaxis. 6 patients were previously on anti-coagulation. 6 patients had been commenced on prophylaxis prior to transfer. 2 patients were

not commenced on VTE prophylaxis, the rationale was clearly documented in both cases.

Conclusions: It is important to implement good adherence to the NICE VTE prophylaxis guideline.

P 2.091 Accelerated Repetitive Transcranial Magnetic Stimulation (rTMS) to Treat Existential Distress in Palliative Care: A Phase 2a/2b Dose-finding and Feasibility Clinical Trial

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Background/aims: Nearly 20% of palliative care patients experience existential distress, characterized by feelings of depression/anxiety and loss of purpose – a symptom for which existing therapeutic options are inadequate. Accelerated repetitive Transcranial Magnetic Stimulation (rTMS) is an effective, approved treatment for major depression, but has not been trialed for existential distress.

Aim: Determine the feasibility and therapeutic dose of accelerated rTMS to treat existential distress among palliative care patients.

Methods: Phase 2a/2b open-label, single-arm clinical trial (target n=15 patients). Palliative care patients in Ottawa, Canada with >1 month life expectancy, symptoms of existential distress, and without contraindication to rTMS were eligible. Consented patients received 8 3-minute rTMS sessions daily delivered at 45-minute intervals for 5 consecutive days. 600 pulses of intermittent theta-burst stimulation per session at 80% resting motor threshold targeting the left dorsolateral prefrontal cortex were administered. Hamilton Depression Rating Scale (HDRS) and Hospital Anxiety and Depression Scale-Anxiety (HADS-A) were completed at baseline, each intervention day, and 2- and 4-week follow-up.

Results: Seven patients have enrolled to date; 4 withdrew (3 before treatment start, 1 after day 2) and 3 completed the intervention and 4-week follow-up. No serious adverse events were observed. Overall, HDRS (P01: 13,3,1; P02: 17,2,2; P03: 18,10,12) and HADS-A (P01:5,3,6; P02: 17,4,4; P03: 14,9,8) scores decreased from baseline to intervention completion and 2-week follow-up. 2-week assessment scores were not sustained at 4-week follow-up. All patients qualitatively reported substantial positive impacts on quality of life.

Conclusions: Symptoms of existential distress were managed in a safe and timely way using accelerated rTMS in a palliative context. For those who receive treatment, rTMS is well-tolerated and feasible.

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P 2.092 A Randomised, Double-blind, Placebo-controlled Feasibility Study of Oral Lorazepam for Symptoms of Anxiety in People with Advanced Life-limiting Illness

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Background/aims: Anxiety is common in people with advanced life-limiting illness and adversely affects quality of life. Management in the adult palliative care population often involves drug treatment, most commonly benzodiazepines. However, randomised controlled trial evidence to guide prescribing is lacking. We aimed to determine the feasibility of a definitive phase III trial of oral lorazepam for anxiety in people with advanced life-limiting illness. Primary objectives: To enrol 21 participants in 12 months, with ≥ 80% completing the first week of treatment and assessments.

Methods: Multicentre, randomised, double-blind, parallel-arm feasibility study of twice daily oral lorazepam versus placebo (2:1 allocation ratio) taken for up to 12 weeks with initial dose titration. Participants were palliative care inpatients or outpatients with advanced disease and significant anxiety.

Results: Fifteen participants were enrolled over 12 months (mean age 57.9, 53% female). Over 80% completed the first week of treatment and assessments (87% and 93% respectively). 80% completed 4 weeks of treatment, dropping to 33% by week 8 and 20% by week 12. 93% completed 4 weeks of assessments, dropping to 73% by week 8 and 53% by week 12. At least 73% were still alive at week 12. Of the 10 participants who completed semi-structured interviews, 9 reported they would still participate if given the choice again. The mean burden of participation on a burden rating scale of 0-10 was 0.9. Efficacy and toxicity data analysis is in progress and will be presented.

Conclusions: The co-primary feasibility objective of adherence was achieved. The intervention and procedures were highly acceptable and non-burdensome. However, the recruitment target was not met due to unexpected COVID-19 restrictions. A definitive phase III trial is likely to be feasible without these restrictions, but accrual and retention rates suggest extensive multicentre collaboration is needed.

Funding: Peter MacCallum Cancer Foundation, Bethlehem Griffiths Research Foundation

P 2.093 Association between Changes in Chronic Breathlessness and Health Status: A Swedish Cohort

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Background/aims: Chronic breathlessness is debilitating and increases in prevalence with age. Given the symptom's progressive nature, it is important to understand how perceived changes in chronic breathlessness relate to changes in perceived overall health to help delineate breathlessness patterns longitudinally. This study aimed to evaluate the relationship between self-reported global impressions of change (GIC) in breathlessness and perceived health in older men.

Methods: A cross-sectional postal survey of 73-year-old Swedish men in the VASCOL study about breathlessness assessed using the modified Medical Research Council (mMRC) breathlessness scale, Dyspnoea-12, and Multidimensional Dyspnea Scale; as well as function (World Health Performance Status (WHOPS)), anxiety and depression (Hospital Anxiety and Depression Scale (HADS) and change in breathlessness and health (GIC scales) since age 65.

Results: Of 801 respondents, 17.9% reported breathlessness (mMRC ≥2) with a median duration of 2 years (interquartile range [IQR] 0.0, 5.0), 29.1% reported worsening breathlessness (GIC scale 5-7) and 51.3% reported worsening perceived health. Worsening breathlessness was associated with more limited function (47.2% vs 29.7%; p < 0.0001) and

increased rates of anxiety/depression; and strongly correlated to worsening perceived health, Pearson's correlation coefficient of 0.68 ($p < 0.001$) and Kendall's tau of 0.56 ($p < 0.001$).

Conclusions: Self-reported health status is perceived to worsen as breathlessness worsens. The strong correlation between perceived changes in chronic breathlessness and overall health reflects the pervasive nature of breathlessness across all aspects of a person's being.

P 2.094 E-StOIC Study: Prescribed and Non-prescribed Management of OIC

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Background/aims: E-StOIC study is an observational study of diagnostic criteria, clinical features and management of opioid-induced constipation (OIC) in cancer patients from 10 European countries. This abstract describes the results of the Irish cohort.

Methods: Cancer patients receiving opioid analgesics for at least a week were recruited, and asked to complete a questionnaire including background information, treatment for OIC (prescribed, non-prescribed), Rome Foundation diagnostic criteria for OIC, and Bowel Function Index (BFI).

Results: 120 patients recruited: median age 68.5yr (range 30-96yr); 44% female, 56% male; 27% GI cancer, 21% lung cancer, 16% breast cancer, 12% urological cancer; 47% ECOG PS 2, 23% ECOG PS 3; 35% oxycodone, 28% morphine, 13% fentanyl, 13% oxycodone/naloxone combination. 61% (73) patients met Rome IV diagnostic criteria for OIC.

98 (82%) patients prescribed laxatives: 44 – 1 drug; 44 – 2 drugs; 8 – 3 drugs; 2 – 4 drugs. 9 patients were prescribed a peripherally acting mu-opioid receptor antagonist (PAMORA). 69 (58%) patients took laxatives every day, with 11 taking regularly (but not every day), and 18 taking when they developed constipation. Other interventions to manage OIC included: change diet (32%), increase fluid (53%), increase exercise (15%), over the counter preparations (20%), complementary therapies (8%), opioid reduction (6%), opioid discontinuation (2%), opioid switching (0%), suppositories (33%), enemas (19%), and manual evacuation (4%). 54% patients had a BFI > 28 , which is indicative of inadequate management of constipation.

Conclusions: OIC appears to be sub-optimally managed in this cohort of patients, with many patients resorting to non-prescribed interventions, and many patients requiring invasive interventions.

Conflict of interest: The study was funded by an unrestricted research grant from Kyowa Kirin.

P 2.095 Case Report: Use of Vasodilators to Control Pain in Mesenteric Angina Secondary to Tumor Involvement

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Background/aims: A 45-years-old woman with cervical cancer underwent usual treatment protocol but had no satisfactory response. Six months later, there was evidence of recurrence of the cancer and at this time she underwent a new chemotherapy treatment.

Methods: Even with new chemo, the cancer recurred and the patient required hospital internment due to uncontrolled abdominal pain and weight loss. Tomographic evaluation showed expansive adrenal mass involving the superior mesenteric artery and celiac trunk, which caused partial obstruction of these vessels. Patient had disabling epigastric abdominal pain, triggered by food and an Edmonton Symptom Assessment System (ESAS) rated 9 (where 0 represents absence of pain and 10 the worst).

Evaluation of the Palliative Care Team was requested when patient Palliative Performance Scale (PPS) was 40%. Due to the pain being similar to mesenteric angina, the use of a vasodilator (isosorbide 10mg orally every 12 hours) was associated with the opioid regimen. From then, the patient presented optimal pain control (ESAS 2), better nutrition and reduced opioid doses.

Results: This is the case of patient with a progressive cervical cancer, with no possibility of disease-modifying therapy and with disabling pain. Due to the pain, the patient was unable to carry out her activities. As the metastatic disease reduced the caliber of the abdominal arteries causing pain similar to ischemic arterial disease, vasodilator therapy was started as a therapeutic test. From then, the patient was able to have almost complete pain relief, being able to be discharged from the hospital and improved functionality (PPS 70%).

Conclusions: There are few data in the literature on the use of vasodilators in tumor involvement of mesenteric arteries. This case showed significant symptomatic improvement of the pain, change in PPS in her last months of life and weight gain. It also made possible the reduction of opioid use.

P 2.096 Patient Attitudes towards Opioids in Hospital, Hospice and Community Palliative Care: A Cross Sectional Survey

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Background/aims: Opioids are high risk medications that are prescribed for symptom management in palliative care patients (PCP). Previous literature has focused on doctors attitudes rather than PCP. Recent studies demonstrate increased opioid prescribing prevalence in Ireland over the last decade. Risks of both problematic opioid use and non-compliance have been reported but little is known about the impact of US opioid crisis on patient attitudes in Ireland. Uncovering patient attitudes can focus education programmes and improve safety, compliance and symptom management.

Aim: To investigate attitudes that PCP have towards the use of strong opioids.

To explore patient factors that may influence patients attitudes.

To investigate if attitudes towards opioid are associated with overall distress.

To identify patients preferences for addressing opioid education.

Methods: This observational study was conducted using a cross-sectional 17 item questionnaire of PCP receiving specialist palliative care in a designated cancer centre hospital, hospice and home. Data was analysed using SPSS.

Results: 60 questionnaires completed (33 male, mean age 63). Place of care: hospital 47%, hospice 35%, home 18%. 30% were prescribed opioids > 3 months. Reported fears identified were: sedation 51%, addiction 41.7%, side effects 53.3%, hastening death 33%, sign of worsening disease 58% and due to media coverage 36.7%. Over 80% did not fear opioid misuse, abuse or diversion. Opioid fears were not associated with overall distress scores. 25% reported taking less opioid than prescribed, correlating with patients with third level education ($P < 0.05$).

85% preferred consultation with a health care professional about opioids over a leaflet.

Conclusions: This study suggests there are significant levels of opioid-phobia amongst PCP in Ireland and highlights the need to adequately address these fears with patients while on opioids. Establishing patient attitudes can focus education programmes to improve knowledge, compliance, safety and symptom control.

P 2.097 Functional Status of a Cancer Patient in a Palliative Care Unit
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Background/aims: Functional status translates to an individual's capacity to execute the usual activities required to care for basic needs and preserve adequate health. The increased demands of cancer patients referred for palliative care (PC) lack a correct allocation in differentiated units. There is a need to apply instruments for classifying and evaluating the sick person's abilities, one of them being the status of functionality.

Aims: Identify the socio-demographic characteristics of cancer patients and characterize their functionality status during hospitalization in PC.

Methods: A retrospective observational study included 53 oncological adults admitted to a PC unit. A non-probabilistic sample was collected from March 15 to June 30, 2022. The assessment instruments used were an FIM (Adult Functional Independence Measure), ECOG (Eastern Cooperative Oncology Group) and PPS (Palliative Performance Scale). The FIM applied at admission, on the 14th day of hospitalization and at discharge. Clinical and demographic data were from anonymized integrated medical and nursing records. Data analysis was done with descriptive statistics software.

This study complies with ethical procedures and authorization granted by the institution's ethics committee.

Results: The 53 patients have a mean age of 71 years, most male and with gastric carcinomas. At the admission, there is an average of 65 in the FIM value, 41.1 in the PPS value and 3.3 in ECOG. Patients with reduced FIM values also have low PPS and ECOG values. From admission to 14th day, is a worsening of functionality, and from this date until the moment of discharge, is a slight improvement. No patient was proposed for intervention by the Rehabilitation Nurse.

Conclusions: The results show similarities with the literature, evidencing a decline in functional status between the admission and the fourteen hospitalization days, conditioning and requiring a readjustment of the initial care plan, focusing on constant teamwork, which is one of the standards of Palliative Care.

P 2.098 Bereaved Relatives and their Experiences Participating in an Interview Concerning Palliative Sedation: A Qualitative Study in 5 European Countries

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Background/aims: Qualitative studies about palliative sedation are sensitive research and emotionally distressful for the participant. Previous studies about participating in sensitive research focused on the experience of the participants but lack information about the timing of an interview and the reason why participants refused to participate.

Aims: To explore how grieving relatives experience research participation, the motivation to participate, and the timing of the interview. A second aim is to report information concerning the eligible participants who did not give informed consent, the number of refusals, and the motivation for refusal. The last aim is to compare the responses of the different participants across 5 EU countries.

Methods: Semi-structured interviews were done with relatives of a sedated patient. The data collection started in July 2021 and is still ongoing. The recruitment of the respondents was linked to an observational study in which patients were palliatively sedated. The interviews were

held 2-3 months after the death of a sedated patient. NVIVO was used to analyze the data.

Results: In total 19 interviews are held. The interviews in general were perceived as positive, and amusing. Respondents indicate that one does not often have the opportunity to discuss the end-of-life of the relative, since many people avoid the topic. The motivation why respondents participated was to increase scientific knowledge, to improve care, and a request of the patient. The respondents indicated that a 3-month time lap after the patient passed away, was good.

Conclusions: Participants do not experience any harm in joining this study. Researchers and EC's are more worried about the sensitivity of the topic than the participants.

P 2.099 Exploring End-of-Life Symptoms and Use of "Comfort Kit" for Elderly Individuals Receiving Hospice Care in Long-term Care Institutions in Taiwan

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Background/aims: Veterans in Taiwan are retired service people and considered "honored citizens." A total of 16 Veterans' Homes (VH) represent the largest long-term care service system in Taiwan. Taipei Veterans General Hospital Hospice Home Care Team assists with comfortable nursing care and manages palliative care in VHs. A "Comfort kit" can relieve the acute or dying symptoms and is prescribed to reduce unnecessary emergency room visits or hospitalizations and help veterans fulfill their wishes for a peaceful death at a VH. This study aimed to develop a "Comfort kit" for long-term institutional care practices and provide prompt intervention for terminally ill residents in need.

Methods: This retrospective study examined residents who received hospice care and died in the Taipei Veterans Home or Banqiao Veterans Home from November 2018 to September 2022. Physicians and nurses recorded the data during the visits. The age, gender, main symptoms 72 h before death, drugs preprescribed as a "Comfort kit," and actual use of drugs 72 h before death were analyzed.

Results: The sample was 90 residents (average age 92.0 ± 5.3 years; 96.7% male). Dyspnea was the most commonly observed symptom of patients who were terminally ill (67.8%), and oral morphine was their most commonly preprescribed (82.2%) and used (65.6%) "Comfort kit" medication. In addition to morphine, risperidone oral solution, fentanyl patch, and scopolamine patch were the most commonly preprescribed and used "Comfort kit" drugs. Veterans with a cancer diagnosis had significantly higher rates of increased pain before death than those without a cancer diagnosis.

Conclusions: The primary training courses for the staff in long-term care institutions must include respiratory care skills in palliative care. Additionally, preprescribed drugs in the "Comfort kit" must include the most commonly used medications. Teaching long-term care facility staff how to use these "Comfort kit" drugs promptly is essential in promoting palliative care in long-term care facilities.

P 2.100 Patient-controlled Subcutaneous Opioid Dosing for Improved Symptom Relief

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Background/aims: Advanced cancer and end-stage organ failure are frequently associated with symptoms of pain or dyspnoea, which are managed with opioids. When oral opioid administration is inappropriate, the subcutaneous route is utilised. In a palliative care unit this frequently includes a continuous subcutaneous infusion (CSCI) with subcutaneous

nurse-administered opioid doses for breakthrough symptoms. There are often significant delays between the request for, and administration of, breakthrough doses. There is little evidence of the use of patient controlled subcutaneous opioid dosing (PCOD) to improve symptom management.

Aim: To review the use of PCOD in a metropolitan palliative care unit. The secondary aim was to establish whether nursing and medical staff are satisfied with using PCOD.

Methods: We retrospectively reviewed medical notes from patients who utilised PCOD. Symptom assessment was undertaken using Palliative Care Outcome Collaborative (PCOC) data at three specified time points. Wilcoxon matched-pairs signed rank statistical testing was performed on data. Nursing and medical staff completed an online survey, adapted from a validated questionnaire.

Results: Among the seventeen patients included in the study, there was an improvement in patient reported pain scores 48 hours after the introduction of PCOD ($p=0.0071$). There was an improvement in breathlessness scores at 48 hours ($p=0.019$) for patients commenced on PCOD for management of dyspnoea. The daily dose of opioid increased after the introduction of PCOD ($p=0.0348$). There was no occurrence of opioid toxicity. The healthcare providers who completed the online survey indicated strong satisfaction in using PCOD.

Conclusions: PCOD is a safe and effective method for delivering subcutaneous opioid medication for the management of breakthrough pain and dyspnoea. Health care providers were satisfied with the use of this modality as an efficient and effective method of delivering medication.

P 2.101 Comprehensive Mouth Care in Patients with Advanced Cancer Receiving Chemotherapy

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Background/aims: Oral symptoms are extremely common in patients with advanced cancer, particularly in patients on chemotherapy. Oral problems contribute to morbidity, impact quality of life and may indirectly contribute to mortality. Oral pathology is frequently underreported. Focused oral history and clinical examination is essential to address these conditions. Patients with advanced cancer should be routinely assessed for oral problems and prescribed an oral care regimen. Aims as follows;

To explore mouth-care assessment and management for inpatients who received chemotherapy in the previous three weeks.

To measure compliance with a mouth care assessment tool and anticipatory oral hygiene prescribing.

Methods: The MASCC/ISOO guideline on management of oral problems in patients with advanced cancer states patients should be regularly assessed for oral problems and have a regular oral hygiene regimen. Our hospital has an in-depth mouth care assessment tool.

A seven day retrospective audit of inpatients with advanced cancer who received SACT in the previous three weeks. Anonymised data was collected from nursing, medical documentation, and drug karex. Demographics included age, diagnosis and performance status. Data included documented oral history and clinical exam at admission, whether a mouth-care assessment tool was used, and prescription of anticipatory mouth-care regimen.

Results: Audit intervention phase is underway with education sessions to oncology nurses and doctors relaying the above findings and emphasizing the importance of regular assessment and individualized mouth-care regimens. Re-audit cycle results will be available prior to research forum.

Conclusions: Compliance with mouth-care assessment tool was poor. Documentation of oral history and examination as part of medical admission was poor. Individualized anticipatory mouth-care regimen was rarely documented or prescribed. Further multi-disciplinary

education is required regarding the importance of the above assessment and management practices.

P 2.102 Complementary and Integrative Medicine (CIM) Interventions in a Palliative Care Ward of a Tertiary Care Hospital - A Retrospective Analysis

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Background/aims: Complementary and integrative medicine (CIM) has grown also in palliative care. In 2016, an interview study performed in the palliative care unit (PCU) of a tertiary care hospital (TCH) showed need and feasibility of CIM nursing interventions (CIMNI). In 2017, an expert commission implemented CIMNI into the daily nursing routine in this PCU.

Aim: Retrospective analysis of all CIMI between 2016 and 2020 aiming at a better understanding of process and indications of the CIMNI.

Methods: Manual data extraction from the digital patient records. Analysis of every patient's file for: demographic items, CIMNI, indications. Creation of an excel file, statistical analysis using R Studio.

Results: 784 cases, corresponding to 694 patients, being on average 67 years old. Even distribution of men and women. Average stay in the TCH: 3 weeks, average stay in the PCU: 2 weeks. Half of the patients died in the PCU. Most common main diagnosis: respiratory thorax cancer (23%). General indications for the use of CIM: pain, deterioration of general condition (DGC), GIT problems, breathing problems (BP), fatigue, mental distress (MD), impaired well-being and confusion; pain (40%) and DGC (39%) being most frequent. The most used CIMNI: different types of massages (839 uses, 68%). Massages were the most used CIMNI for BP (64%), pain (59%), fatigue (50%), MD (48%), DGC (37%), well-being (36%) and GIT problems (35%). The second most used CIMNI: wrapping therapy (463 times in 324 cases). Two thirds of the indications (33%): pain and DGC. The most specific used CIMNI: scent therapy with 46%, most often applied in DGC. Scent therapy and massages showed gender differences (women > men).

Conclusions: The most frequent indications for CIMNI in this PCU are pain and DGC. They are mostly addressed by massages and wrapping therapies. Women received more often scent therapy and massages. Further research should include a more standardized documentation of indications and outcomes.

P 2.103 A Case of Subcutaneous Esomeprazole Infusion with Added Low Dose Dexamethasone for Infusion Site Skin Reactions

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Background/aims: Esomeprazole has been administered via continuous subcutaneous infusion (CSCI) in the palliative care setting to optimise symptom control where intravenous (IV) and oral options are not feasible. As this is a novel method of administering esomeprazole, limited data is available regarding tolerability and side effects.

Methods: A 71-year-old woman with oesophageal cancer requiring enteral feeding via percutaneous endoscopic gastrostomy (PEG) described severe discomfort secondary to oesophageal spasm. Trials of proton pump inhibitors (PPI), GTN spray and antispasmodics via her PEG were unsuccessful. She was commenced on a CSCI of esomeprazole 40mg over 24 hours and within days symptoms had fully resolved. Attempts to reduce the dose resulted in re-emergence of symptoms. Over several weeks, infusion sites became problematic with skin inflammation and pump occlusion, leading to frequent cannula re-siting.

Results: Review of the literature identified a recently published case series that demonstrated the successful addition of dexamethasone to an esomeprazole CSCI. An observational study was completed by the Pharmacy department: dexamethasone 0.5mg was added to a solution of esomeprazole 40mg in sodium chloride 0.9%. There was no evidence of physical change e.g. discolouration, clouding or precipitation over 24 hours. Subsequently dexamethasone 0.5mg was added to the CSCI of esomeprazole 40mg. Subcutaneous sites had improved tolerability and less frequent cannula re-siting.

Conclusions: Esomeprazole is alkaline in solution (pH 9-11) and can cause compatibility issues with other drugs. The addition of low dose dexamethasone to CSCI is frequently used to reduce infusion site problems and is alkaline in solution (pH 7-10.5). In general, drugs with a similar pH are more likely to be compatible.

Our case highlights possible side effects of esomeprazole administered via CSCI and supports the use of low dose dexamethasone to increase the tolerability for patients and ensure this a viable medication option.

P 2.104 Evidence for the Use of Patient Reported Outcome Measures in Non-communicable Diseases: A Systematic Review

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Background/aims: Healthcare professionals may overlook and underestimate patients' symptoms and therefore patient reported outcomes measures (PROMs) are used in specialized palliative care (SPC) for screening, dialogue support and decision-making. The use of PROMs may also support symptom-based referral to SPC and thereby include patients with other diagnoses than cancer.

The aim of this study was to systematically review the literature on use of PROMs for screening, dialogue support and decision-making to patients with diabetes, chronic obstructive pulmonary disease (COPD), heart disease, rheumatoid arthritis, and inflammatory bowel disease (IBD) (PROSPERO CRD42021226896).

Methods: Randomised controlled trials were searched in PubMed/MEDLINE, CINAHL, EMBASE, and Web of Science until July 2021. Screening and risk of bias assessment was performed by at least two researchers.

Results: The search yielded 19,699 articles, 626 full-text articles were screened, and 53 original studies were included in the review. The studies included patients with heart diseases (n=15), COPD (n=13), diabetes (n=9), IBD (n=9), rheumatoid arthritis(n=6), and one trial included patients with mixed diagnoses. Endpoints included hospitalisations, mortality, symptoms, and quality of life. No study evaluated the effect on referral to SPC. Twelve studies found a positive effect on different endpoints, and six studies had low risk of bias.

Conclusions: The evidence base for clinical use of PROMs is sparse. The clinical use of PROMs does not appear superior to usual care in the five included chronic diseases on any endpoint. The five PROM interventions with positive effect and low risk of bias are characterized by symptom assessment with predefined cut-offs used for decision and dialogue support. The effect of clinical use of PROMs in palliative care should be further studied.

P 2.105 Evidence of Clinical and Non-clinical Signs that Someone Is in the Last Days or Hours of Life – A Scoping Review

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Background/aims: To identify an approaching death is challenging. The published definitions and signs for the beginning of the final phase differ. The aim is to extract evidence available on clinical and non-clinical signs of impending death of patients with cancer and patients with other life-limiting disease from the current literature and disclose research gaps.

Methods: A scoping review compiled searching in PubMed and CINAHL, using search terms such end-of-life care, terminal care, terminally ill, palliative care, impending death, clinical sign*, prognos*, predictor*, indicat*, identif*, reali*, decision making, clinical decision making, diagnose at 17th Jan 2022. Inclusion and exclusion were independently assessed by two independent researchers. Analysis was done with MAXQDA.

Results: Overall 398 titles/abstracts were checked for relevance. Finally, 21 studies (1998-2021) were considered for full-text analysis. The studies included different settings (hospital, hospice, home, rehabilitation) and study populations (patients, nurses, physicians, relatives). Evidence-based clinical signs identified dyspnoea (n=14), fatigue (n=13), delirium (n=12), pain (n=7), skin change (n=7), anorexia (n=7), dysphagia (n=6), reduced urinary excretion (n=6), no pulse of the radial artery (n=4). Non-clinical indicators are the loss of interest in liquid & food intake (n=9), social withdrawal (n=9), depression/hopelessness (n=5). Meanwhile non-clinical indicators such as insomnia (n=1), statements of the patient (n=1), intuition (n=3), fear/anxiety (n=3), increased spiritual needs (n=3), change of the gaze and eyes (n=3) are hardly ever studied scientifically.

Conclusions: Surprising was that fear or anxiety seems to be not well evidence based. Change of the gaze and eyes could be discussed for further research. The results could be used to develop training material in addition to the German S3 Guideline Palliative Care.

P 2.106 Opioid-induced Hyperalgesia: A Diagnosis Not to Be Missed

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Background/aims: Opioids are frequently used for symptom management in patients receiving palliative care. Opioid-induced hyperalgesia (OIH) is an uncommon, but important adverse effect to recognise, as it will influence ongoing pain management.

Methods: An 84 year old gentleman with a new diagnosis of metastatic gastro-oesophageal junction cancer was admitted to a hospice inpatient unit for management of severe pain, odynophagia, nausea, fatigue and psychological distress. He had upper abdominal lymphadenopathy and diffuse hepatic metastases and was not a suitable candidate for oncological treatment. He was initially admitted to hospital, where sequential strong opioids via continuous subcutaneous infusions were used as pain management; including oxycodone, morphine sulphate and alfentanil. He also commenced opioid-sparing adjunct medications. On hospice admission, he described mixed nociceptive and neuropathic pain, which was partially opioid-responsive. Marked allodynia was noted.

Results: Opioid-induced hyperalgesia was diagnosed. Management included discontinuing his subcutaneous alfentanil infusion and reducing his breakthrough morphine dose. His severe upper abdominal pain persisted, therefore regular methadone 2mg twice daily orally was prescribed, with oral methadone 1mg-2mg as required for breakthrough pain. His pain responded to methadone and his allodynia became less pronounced. His overall condition deteriorated five days after hospice admission. There was no reversible cause determined and he entered the

terminal phase. His oral methadone dose was converted to a continuous subcutaneous infusion equivalent. He died peacefully in the hospice, just three weeks following his diagnosis of extensive malignancy.

Conclusions: OIH is a recognised adverse effect of opioids and can be difficult to diagnose. Treatment options include use of co-analgesics, causal opioid reduction and rotation to methadone for ongoing pain control, as in this case. Clinicians should have a high index of suspicion for diagnosing OIH.

P 2.108 Retrospective Descriptive Study of Deep and Continuous Sedations Maintained until Death Performed at the Patient's Request in Palliative Care Units

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Background/aims: Since the evolution of the legal framework and recent national guidelines, continuous deep sedation until death (CDSUD) forms an effective part of palliative care in France. Midazolam is the most commonly used drug in such situations, but neuroleptics and propofol are also used in second intention. Nevertheless, few studies report descriptive elements on CDSUD at the patient's request, in palliative care units.

Objective: To describe local practices of CDSUD at the patient's request in the context of refractory suffering or after a request to stop life-sustaining treatment. In particular, we have sought to evaluate the duration of CDSUD and the dosage of the sedative treatments involved.

Methods: This study included patients hospitalized from January 2020 to December 2021 in Palliative Care Unit in Nantes University Hospital. Preexisting medical conditions were assessed, as well as the biological parameters and the treatments administered. Data related to the request and implementation of CDSUD were collected: reason for the request, duration of sedation, doses of sedatives, etc.

Results: Among the 42 patients who had CDSUD in this study, 79% of them occurred in a context of refractory suffering. This was mostly a global suffering (67%). In the cases of sedation following a request to stop life support (38%), high-dose corticosteroid therapy was the most frequently involved life-sustaining treatment. The first-line sedative used was midazolam. To maintain a deep level of sedation, it was necessary to add chlorpromazine in 79% of cases and propofol in 40% of cases. The average duration of sedation was 37 hours.

Conclusions: This provides new descriptive elements on the use of second-line sedative molecules in cases of failure of sedation with midazolam, based on a sedation protocol set up locally. It seems necessary in a second step to conduct a larger scale observational analytical study to distinguish patient profiles likely to require recourse to second-line sedative molecules like propofol.

P 2.109 Palliative Sedation at the End-of-Life: Family Caregivers and Health Care Professionals' Distress

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Background/aims: The process of palliative sedation in an end-of-life context can be an emotionally distressing experience for healthcare professionals and relatives of the patient.

Aims: The present study focuses on which situations are experienced as distressing by relatives and healthcare professionals. We will also look for experiences that lowered distress, thereby we will take into account the care setting and the country of the cases.

Methods: Semi-structured interviews were done with relatives and health care professionals of a sedated patient. The data collection started in July 2021 and is still ongoing. The recruitment of the respondents was linked to an observational study in which patients were palliatively sedated. The interviews were held 2-3 months after the death of a sedated patient. NVIVO was used to analyze the data.

Results: In total 40 of the 100 planned interviews are held. The preliminary results indicate that the following situations cause distress:

- 1) The patient develops an unintended consciousness during sedation;
- 2) There are sometimes difficulties to get the patient sedated,
- 3) The double role of being a relative and a healthcare professional, and
- 4) uncertainties related to palliative sedation.

The following situations were lowering the distress:

- 1) being able to discuss the distressful situation with peers,
- 2) a clear request of the patient for palliative sedation, and
- 3) being able to ask questions to the healthcare professionals.

Conclusions: A determining factor for the level of distress in both the family and health care providers during palliative sedation is the wish of the patient and the experience that the patient is comfortable. A good understanding of which situations cause distress and what lowers distress is important to improve the care for sedated patients and family relatives, but also to enable the health care professionals to cope with such a distressful situation.

P 2.110 Ensuring Safe Use of Opioids for Cancer Pain: A Decade-long Experience

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Background/aims: Opioids must always be available in order to effectively treat pain, provide palliative care, and control opioid dependence. This study intends to examine the patterns of morphine usage and the use of safety protocols for opioid prescriptions in a tertiary oncology hospital in India.

Methods: Using retrospective analysis of medical and pharmacy records, we looked at the distribution and consumption trends of oral morphine from 2008 to 2020.

Results: From 2008 to 2019 there was a continuous rise in the number of new cancer patients attending the hospital, the number of these patients returning, and inpatient admissions to palliative care services, with a sudden decline in 2020 due to the COVID pandemic. The amount of oral morphine consumed annually increased steadily from 4.89 kg in 2008 to 11.53 kg in 2019 before declining to 5.68 kg in 2020. However, the average amount of oral morphine prescribed per patient every visit showed a trend of slight growth from 1.1 grammes in 2008 to 2.06 grammes in 2012, then a steady reduction to 0.89 grammes in 2020. There was no evidence of opioid diversion.

Conclusions: Effective palliative care integration and comprehensive therapies, together with safety measures for opioid prescriptions, can help avoid opioid misuse problems.

Table 1. Patient registrations and Morphine consumption.

Year	New Cancer patients (n)	New patients registered with Palliative care team (n)	Revisits per year to the cancer hospital (n)	Revisits per year to the Pain clinic (n)	Admissions in Palliative care ward (n)	Oral Morphine consumed per year (kgs)	Oral Morphine consumed per visit (gms)
2008	8793	295	74280	4457	-	4.89	1.1
2010	8679	408	82597	4906	603	8.1	1.65
2012	9059	410	91100	6030	494	12.44	2.06
2014	11000	362	138125	10539	619	10.15	0.96
2016	12372	671	157884	14443	908	13.84	0.95
2017	13260	725	171778	15530	1022	9.37	0.6
2018	13186	963	181566	17240	1227	9.6	0.56
2019	13008	1120	178700	17587	1514	11.53	0.65
2020	7093	723	82392	6398	479	5.68	0.89

P 3 - Caregivers

P 3.001 Dyadic Appraisals, Coping and Quality of Life in Patients with Pancreatic Cancer and their Caregivers: An Actor-partner Interdependent Mediation Model

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Background/aims: Pancreatic cancer (PC) have the worst survival prognosis of any cancer due to its difficult to detect early and there are limited treatment options for it. PC diagnosis and treatment takes substantial distress for both patients and their family caregivers. The purpose of this study was to investigate symptoms and quality of life (QoL) experienced by PC patients and caregivers whether each affects the other and the mediating effect of coping on these relationships.

Methods: This longitudinal study was conducted on 120 of undergone PC resection patients and family caregivers. Spanning two times measurements over four months after surgery, dyad reported on their symptoms, coping, and QoL. Using the actor-partner interdependence mediation model, the mediating effect of coping and its interdependence on the relationship between symptoms and QoL were identified. Changes in symptoms, coping, and QoL over time were analyzed using repeated measures ANOVA.

Results: Caregivers' depression negatively affected patients' emotional QoL. The mediating effect of caregivers' emotion-focused coping on this relationship was significant (95% CI: -0.137, -0.002). Patients' pain interference and fatigue symptoms affected their mental QoL and caregivers' depression, anxiety, and fatigue symptoms had actor effects on their emotional QoL ($p < .05$). Over time, only patient anxiety affected their physical QoL ($p = .002$). Caregivers' depression and pain interference affected patients' mental QoL. Pain interference symptoms showed interactions with patient and caregiver groups and time ($p = .011$). Changes in fatigue symptoms ($p = .043$) and physical QoL ($p < .001$) over time were different between dyads.

Conclusions: The interdependent relationships found in this study raise important awareness of the role of illness appraisals and coping strategies within dyad for mental QoL of PC patient-caregivers. Emphasizes the importance of early palliative interventions of a family-oriented approach to improve their QoL.

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P 3.002 Caregiver Views and Expectations about the Use of Artificial Hydration in the Management of Dying People with Advanced Cancer: A Questionnaire Study

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Background/aims: Evidence for the use of artificial hydration (AH) in people dying with cancer is inconclusive, which creates challenges for healthcare professionals. These situations can be distressing for family caregivers, who may have unmet information needs. Better understanding of caregiver perspectives about AH in the dying, can potentially help healthcare professionals to identify information needs to improve support for caregivers. This study aimed to examine caregivers' beliefs, experiences and information needs about AH use in people dying with advanced cancer.

Methods: Questionnaire study of the caregivers of people with advanced cancer, who were participants on a research study (evaluating the association between hydration status with clinical cancer outcomes). Caregivers were recruited from 3 UK study sites, consisting of 2 hospices and 1 hospital palliative care inpatient unit.

Results: 52 caregivers participated. Most participants were female (N=38, 73.1%) and aged between 50-59 (N=12, 23.1%) and 60-69 (N=13, 25%). Most participants (N=33, 63.5%) said they were not aware of the term 'artificial hydration'. Most (N=35, 67.3%) believed that AH represented good care for the patient, with the majority stating that AH improved thirst (N=33, 63.5%) and dry mouth (N=30, 57.7%). Most participants did not believe AH affected prognosis, with 11 (21.2%) stating that AH prolonged life and 8 (15.4%) indicated that prognosis would be shorter without AH. Most expected AH to be available for patients in hospitals (N=42, 80.8%), hospice (N=43, 82.7%), nursing home (N=37, 71.2%) and home (N=31, 59.6%) settings. Most participants believed patients had the right to demand (N=39, 75%) or refuse (N=48, 92.3%) AH in the dying phase.

Conclusions: Our study provides information about caregivers' views and expectations of the use of AH in dying cancer patients. Further work should explore how healthcare professionals can better identify and address unmet information needs of caregivers, concerning the use of AH in the dying.

P 3.003 Experiences of Being a Severely Ill Parent of Dependent Children and Receiving Care at Home – Hopes and Challenges

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Background/aims: In multiple studies, it has been found that severely ill parents face an especially difficult situation as they have parental responsibilities while also facing the demands related to their illness. Two trends in the care of the severely ill are that patients live longer with their illness and that they are increasingly being cared for at home. Few studies have focused on the thoughts and feelings of parents of dependent children during palliative home care. Hence, the aim of this study was to explore the experiences of being a severely ill parent during palliative care at home.

Methods: This qualitative study derives from a pilot intervention study, the Family Talk Intervention (FTI), in specialized palliative home care. FTI is a psychoeducational support program with the main goal to increase family communication about illness-related topics. This study is based on field notes from 104 sessions with 20 parents taken by an interventionist during intervention delivery. The field notes were analyzed using the principles of qualitative content analysis.

Results: Parents with severe illness who were cared for at home, face many challenging situations. First and foremost, communication with the children, about their illness and prognosis. Parents also expressed feelings of guilt and grief for being unable to fulfil their different roles; as parents and partners. Existing family conflicts seemed to escalate with the severity of illness, according to some of the parents. Despite being affected by illness, parents kept hope, if only for small things – such as a period of normal family life.

Conclusions: Severely ill parents in specialized palliative home care seek support regarding how to communicate and stay connected to their roles in the family, to maintain normality and hope for as long as possible. Communication with children is vital and needs to be brought to the attention of health care professionals. A family-centered focus, involving both parents and children could be considered helpful.

P 3.005 Healthcare Professionals' Barriers and Facilitators to Deprescribing at the End of Life

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Background/aims: Polypharmacy or the use of 5 or more medications, is frequent at the end of life. Many of these medications have questionable benefits in this situation and can be deprescribed.

This study aimed to explore healthcare professionals' barriers and facilitators to deprescribing for people at the end of life and to examine their knowledge about existing tools and guidelines regarding deprescribing.

Methods: A descriptive qualitative study was conducted using a semi-structured interview guide. Nursing home (NH) nurses, and physicians and community pharmacists linked to NH were interviewed until data sufficiency was reached. Data were analysed inductively, using open codes, which were summarized in subthemes and themes.

Results: Five key themes were extracted from 28 interviews:

- (1) organizational characteristics,
- (2) healthcare professionals' vision and attitude,
- (3) collaboration, multidisciplinary and with the resident and his family,
- (4) communication, and
- (5) shared decision-making.

Barriers frequently reported were the lack of:

- (1) a clear framework and guidelines regarding deprescribing,
- (2) dialogue between the different actors and

- (3) clarity of everyone's role.

Moreover, discontinuity in communication and collaboration between physicians and between physician and resident hindered deprescribing. Acting from a holistic view and involving the resident and his family in advance care planning facilitated deprescribing. Despite limited cooperation and role ambiguities, participants agreed that the focus of care at the end of life should be on residents' quality of life.

Conclusions: The complexity of the various actors and themes, such as role ambiguity and resource constraints complicate deprescribing. Further research is important to formulate clear recommendations, develop practical deprescribing guidelines and reduce polypharmacy at the end of life.

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P 3.006 Hospital Nurses' Views on the Timing of Initiation of Palliative Care, a Descriptive Qualitative Study in Flanders, Belgium

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Background/aims: Despite increasing recognition that initiation of palliative care early in the disease trajectory is beneficial for patients with a life-limiting disease, palliative care is still introduced rather late or not at all.

This study aims to explore nurses' views on early initiation of palliative care for patients with a life-limiting disease.

Methods: A descriptive qualitative study was conducted using a semi-structured interview guide until data saturation was reached. Hospital nurses presented and discussed a patient for whom palliative care was initiated too late. Nurses working on oncology, haematology or palliative care units were excluded. Data were analysed inductively, using open codes, which were summarized in subthemes and themes.

Results: Five key themes were extracted from 15 interviews: (1) communication, (2) fear, (3) religion, (4) time restraints and (5) enablers. Early initiation of palliative care was hindered by disagreement between healthcare professionals on the timing of this initiation. This timing was often postponed due to therapeutic obstinance, a lack of experience or hierarchy. Nurses were confronted with fear of taking care too little and not being able to let the patient go. This disrupted communication with patients and their family. According to the nurses, patients' religious beliefs often hindered the use of sedatives or morphine which led to discomfort. Due to time restraints nurses were not always able to develop a relationship of trust needed for end-of-life conversations with their patients. A palliative support team in hospital, advance care planning and creating moments for patients were enablers for early palliative care.

Conclusions: Healthcare professionals, patients and their families are confronted with the same barriers to early initiation of palliative care. All actors should be brought together to elaborate on the enablers of early palliative care in order to achieve optimal care at the end of life.

P 3.007 Using the Lens of Complexity Science as a Guide towards New Insights into Resilience in Advanced Cancer Patients' Intimate Partners

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Background/aims: Those caring for a patient with advanced cancer are at risk of depression or anxiety. Yet most informal caregivers appear to be protected from these disorders by resilience, a process promoted by

certain individual characteristics, and by the availability of a support network, a group striving towards the same goals. Such a network may be considered a complex adaptive system (CAS), a concept stemming from complexity science.

Aim: to gain insight into the way a support network may promote resilience by studying the behavior of it through the lens of complexity science.

Methods: A framework analysis was conducted on nineteen interviews with members from the support networks of eight intimate partners by: (1) deductive coding using the CAS principles as a coding framework, (2) inductive coding of the quotes under each principle, (3) ordering the codes into themes to concretize behavior patterns, and (4) charting the codes into a matrix to identify intra- and inter-CAS similarities, differences, and patterns.

Results: The network's behavior adapts dynamically to the changing circumstances as the patient's prognosis worsens and is based on internalized basic rules, (e.g., reassuring availability), attractors (e.g., feeling appreciated or connected), and the history of the support network. However, the interactions are non-linear and often unpredictable.

Conclusions: Analyzing the data through the lens of complexity science has provided us insight into the behavioral patterns of the intimate partners' networks and how these refine the characteristics needed to enable resilience.

These new insights allow healthcare professionals (HCPs) to understand the dynamics of a support network. HCPs should allow these networks to evolve and adapt as a system rather than focusing on the individual actions. Moreover, it is crucial to recognize the networks' emerging internalized basic rules. Furthermore, endorsing the attractors might motivate the network members to persevere in order to maintain positivity.

P 3.008 Barriers and Facilitators to Implementing Family Carer Decision Support Intervention Using Family Care Conferences in Nursing Homes: mySupport Study

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Background/aims: Decision making regarding end-of-life care for people with advanced dementia presents a significant burden for family caregivers. Family Carer Decision Support (FCDS) is an educational intervention which helps staff in nursing homes in involving family carers in advance care planning (ACP) using family care conference and the provision of a Comfort Care Booklet. The aim of this study was to screen barriers and facilitators in the process of implementation of FCDS in nursing homes.

Methods: This was a transnational multidisciplinary implementation study which used multiple case study approach. FCDS was implemented in 16 nursing homes across 6 countries. Data were collected using semi-structured interviews and questionnaires with care home managers, staff, and family carers before implementation (environmental scan) and after (follow up). Data were analyzed using thematic analysis.

Results: Based on the environmental scan we identified anticipated barriers among staff (motivation, lack of training in communication), in family carers (motivation, readiness, conflicts) and logistics (scheduling difficulties, lack of staff). Anticipated facilitators were also among staff (organizational culture, good communication, beliefs in positive outcomes of FCDS) and in family carers (motivation, relationship). Follow-up interviews identified other perceived barriers among family carers

(involvement) and in logistics (covid, research demands) as well as additional facilitators among staff (role-play based training, support). The crucial facilitator for implementation was trusting relationships between family carers and staff.

Conclusions: Involving family carers in ACP is essential in residents with advanced dementia and it is very important to have a good trusting relationship with them. Strengthening the motivation of staff and introducing palliative approach in the organization culture can further improve implementation of interventions such as FCDS.

P 3.009 Associations between Preparedness for Caregiving and Preparedness for Death and Related Factors among Family Caregivers in Specialised Palliative Home Care

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Background/aims: Family caregivers' preparedness for caregiving and death is crucial both during caregiving and for their future life. Preparedness include physical, emotional and social aspects and has been confirmed to improve wellbeing.

Aim: To explore associations between preparedness for caregiving and preparedness for death among family caregivers of persons with life threatening illness cared for in specialised palliative home care. A further aim was to explore associations of communication and support with preparedness for caregiving and death.

Methods: This correlational study was conducted at five specialised home care services for patients with palliative care needs, providing 24-hours-a-day care. Participants were spousal caregivers taking part of the web-based supportive intervention "närstående.se". For this study data was collected through a baseline questionnaire, including demographics, the Preparedness for Caregiving Scale, and single items about preparedness for death, received support, information and communication about life-threatening illness. Data were analysed using descriptive statistics and Spearman correlations.

Results: Altogether 39 family caregivers participated. The median age was 61, 67% were women, 49% were employed and 64 % were involved in caregiving on a daily basis. A significant association was found between preparedness for caregiving and preparedness for death ($r_s=0.51$, $p < 0.001$). Further, received support and communication about life-threatening illness with health-care professionals and/or one's spouse were associated with higher levels of preparedness for caregiving ($r_s = 0.34-0.39$, $p < 0.05$) and preparedness for death ($r_s = 0.39-0.52$, $p < 0.05$).

Conclusions: This study acknowledges the association between preparedness for caregiving and death. Further, it contributes with knowledge about factors of importance that could guide healthcare professionals when supporting family caregivers to improve their preparedness and promote wellbeing.

P 3.010 Informal Long-distance Caregiving at the End of Life: Results of a Scoping Review

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Background/aims: In our increasingly mobile society, more people than ever are providing end-of-life informal care to their loved ones from a geographical distance. To our knowledge, no literature review has yet focused on experiences and support needs of long-distance caregivers in end-of-life situations. The aim of this review is to map the available evidence and identify research gaps with regard to experiences and support needs of informal long-distance caregivers in end-of-life situations.

Methods: A scoping review based on Arksey and O'Malley's (2005) rigorous five-stage framework was conducted as part of the research project "LoCatE—Long-distance caregiving at the end of life (2021-23)". The scoping review provides a narrative account of literature and research, outlining research trends and key concepts. PubMed, CINAHL, PsycINFO, Web of Science Core Collection, and Google Scholar were searched from inception to 8 November 2021. Two researchers independently assessed 3,752 articles.

Results: Nineteen scientific papers were included in the review; the majority (n=10) of the reported studies were located in the USA. The review identified five major themes: 1) long distance as a barrier to care provision, 2) communication difficulties and the role of (video-)telephony, 3) burdens and benefits, 4) interaction and conflict with local caregivers, and 5) specific support needs. Long-distance caregivers frequently feel insufficiently involved in the coordination of care and local caregivers' decisions. The studies also showed that health care staff can bridge the geographical distance.

Conclusions: Qualitative studies with larger samples, quantitative, and mixed-methods studies are needed to generate more comprehensive information about the experiences and needs of long-distance caregivers and to develop specific support measures for this group. Future research should focus on the diversity amongst informal caregivers providing end-of-life care over geographical distance.

P 3.011 Bereaved Family Members' VOICES of Support and Care during the Last Three Months of Life for People with Advanced Illness

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Background/aims: There is a need for studies with an extended perspective, focusing on the content and quality of palliative care for all patient groups with potential palliative care needs, and on the care received in several care places, targeting the perspective of bereaved family members. The overall aim of the thesis was to investigate bereaved family members' experiences of support and care during the last three months of life for people with advanced illness.

Methods: The thesis encompasses four studies; in study I the VOICES (SF) (Views of Informal Carers – Evaluation of Services (Short Form)) questionnaire was validated, and in studies II-IV a survey design was employed using VOICES (SF). The survey sample consisted of 485 bereaved family members (20-90 years old, 70.7% women) of people who had died in one of four hospitals, in two Swedish healthcare regions, between August 2016 and April 2017.

Results: The care place/care service was central for family members' experiences of care and support. The importance of that the ill persons received care according to their needs was stressed, but the delivery of the care was equally important. Most of the family members were satisfied with the care; however, about a fifth were not. The type of care, diagnosis, length of illness, educational attainment, and the relationship between the deceased person and the family member, influenced the experiences of care. End-of-life communication and the support given to family members was not experienced as optimal.

Conclusions: This thesis project has provided novel and important knowledge about the content and quality of care in different care places

during the last few months of life, for all groups with potential palliative care needs. Family members expressed dissatisfaction with care, communication and support, hence care at the end of life can be improved and there are potential inequalities in care at the end of life.

P 3.012 Family Caregivers' Experiences of End-of-Life Caregiving in a Home Care Setting: A Qualitative Study in the Faroe Islands

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Background/aims: Although part of the Danish realm, the Faroe Islands is not a member of the EAPC. This might be one reason why the Faroe Islands do not meet the EAPC's standards for palliative care in some areas. There is, for instance, only access to home care services around the clock in the larger communities, and the palliative care team does not have an outgoing function. Despite this, 12% of people die in private homes. The aim was to provide inside into conditions that make home death possible in a small-scale society and describe family caregivers' experiences of providing end-of-life care within a private home setting.

Methods: The study is qualitative. A phenomenological approach, inspired by Giorgi, was applied. Thirteen caregivers were interviewed about their experiences with end-of-life care.

Results: Two essential structures captured the experience of caring at home until death: 'Managing end-of-life care' and 'meaningfulness in a time of impending death'. It was mainly the family and family members with a health professional background and district nurses who supported the caregivers in end-of-life care. By fulfilling their relative's wish to die at home, the caregivers found their caring task meaningful and experienced a closeness among family members during the palliative course. For caregivers in areas with no home care during night hours, this caused caregivers to feel insecure, especially about being able to relieve their relative's pain sufficiently.

Conclusions: The willingness among family members to conduct end-of-life care for a relative is great despite limited structural conditions to support them. A way to increase the number of home deaths could be if home care around the clock was nationwide and an outgoing palliative team was established. An application for membership in the EAPC would commit politicians and professionals to further the development of palliative care in the Faroe Islands.

P 3.014 The Impact of the mySupport Intervention on Family Caregivers' Perceptions of Decision-making and Care for Nursing Home Residents with Dementia: Pretest-posttest Study in Six Countries

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Background/aims: The mySupport intervention was originally developed and evaluated in Northern Ireland. Family caregivers of nursing home residents with dementia received an educational booklet and family care conference with a trained facilitator to discuss their relative's future care.

Aims: To investigate the impact of mySupport adapted to six countries and complemented by a question prompt list on family caregivers' uncertainty in decision making and satisfaction with care. Second, to investigate if it affects residents' hospitalizations and advance directives.

Methods: In Canada, the Czech Republic, Ireland, Italy, the Netherlands and the UK, two nursing homes participated in the pretest-posttest

study. Family caregivers' scores on the Decisional Conflict Scale and Family Perceptions of Care Scale before and after the intervention were compared in linear mixed models. The number of documented advance decisions and residents' hospitalizations were compared with McNemar tests.

Results: In total, 88 family caregivers completed baseline, intervention and follow-up. They reported less decision-making uncertainty (-9.6, 95% CI: -13.3, -6.0; $p < .001$) and more positive perceptions of care (+11.4, 95% CI: 7.8, 15.0; $p < .001$) after the intervention. The number of advance decisions to refuse treatment was higher after the intervention (21 vs 16); the number of other advance directives or hospitalizations did not change.

Conclusions: The mySupport intervention may be impactful in countries beyond the original setting.

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P 3.015 Robbed of Making Memories: The Impact of the COVID-19 Pandemic on Care at the End of Life amongst Hospice Staff and Informal Carers

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Background/aims: Family caregiving is burdensome with many carers experiencing burnout, isolation and financial challenges. During the covid-19 pandemic, the number of carers supporting people at the end-of-life increased. This research investigated the impact of the covid-19 pandemic on family carers and hospice health and social care staff at a time where formal care services were reduced and pressures for care at home increased.

Methods: A qualitative study was conducted under a critical realist approach. Interviews across a virtual platform were conducted with 37 participants (15 carers and 22 staff) recruited via hospice services in England and Scotland, UK. Interviews explored the experiences of care, services, impact of the pandemic and formal and informal support. Data was managed using framework methods and analysed thematically.

Results: Great sacrifices were made by hospice staff and family carers to offer high quality end-of-life care but many experienced challenges which negatively impacted on wellbeing and for carers; the ability to grieve. Three key themes are identified;

- (1) Missed Opportunities for memory making related to not being there and not having others around;
- (2) The Lone Carer during a period of high care intensity, reduced service-led home support was challenging, but also which enabled quality time for some;
- (3) Procedure Vs Person-centred Care resulting from changing rules and restrictions and prioritisation of regulation over essential palliative care.

Conclusions: This study is the first to report the experiences of the hospice workforce and carers during the pandemic but has global implications for all involved in end-of-life care. Despite continual efforts to provide dignified care; holistic components of 'palliative care' were

jeopardised. Important lessons can be learned from how health and social systems and society reacted to the pandemic; the longer-term impact of such is likely to be seen in unresolved grief and suffering for many people in our communities.

P 3.016 What Do Family Caregivers of Patients with Life-threatening Diseases Need from Healthcare Professionals?

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Background/aims: Support for family caregivers is an essential component of palliative care. A better understanding of what family caregivers need from healthcare professionals in a wide array of circumstances is fundamental to providing adequate support.

This study explores what family caregivers need from healthcare professionals from different healthcare settings during and after the patient's illness trajectory.

Methods: Interviews with family caregivers were transcribed and analysed with reflexive thematic analysis. An inductive approach was used with preliminary code categories based on the research question. Open and axial coding was done in ATLAS.ti to determine domains and develop themes.

Results: Sixty-one family caregivers of patients with life-threatening diseases were interviewed, of whom 53 individually and 8 in focus groups with 4 participants. Of the patients, 34 (56%) had been ill with Covid-19 and 27 with other life-threatening diseases. Forty-six patients (75%) had died. The patients had been treated in hospitals, nursing homes, hospices or at home. The needs were categorised in six domains: "The relationship with the patient", "Practical and emotional support", "Information", "The relationship with healthcare professionals", "Care for the patient" and "Communication with healthcare professionals". Three themes were developed that transcend the categories: "To feel seen and valued by healthcare professionals", "Trust in healthcare professionals", and "Experiencing some sense of control".

Conclusions: Healthcare professionals' awareness of the themes and corresponding needs presented in this study can help to offer family caregivers adequate support before and after the patient's death. As needs differ between individuals and can change over time, it is important to tailor support to each family caregiver's specific needs and circumstances.

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P 3.017 Emotional Functioning of Relatives of Patients with Advanced Cancer: A Longitudinal Analysis of the eQuiPe Study

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Background/aims: Advanced cancer has major impact on both patients and relatives. Quality of life of relatives might vary along the illness trajectory, as they are involved in all different phases of the disease, from diagnosis to end-of-life care. This study aims to give insight in the course of the emotional functioning of relatives of patients with advanced cancer during the last year of the patient's life.

Methods: A prospective, longitudinal, multicenter, observational study on quality of care and quality of life of patients with advanced cancer and their relatives was conducted (eQuiPe). Emotional functioning was measured with the EORTC QLQ-C30. All questionnaires completed by relatives in the last year of life of the patient were analyzed (T1 = 9-12 months before death; T2 = 6-9 months before death; T3 = 3-6 months before death; T4 = 0-3 months before death). A linear multilevel model was used.

Results: 409 relatives completed one or more questionnaires in the last year of the patient's life. Their mean emotional functioning decreased significantly over time (T1=73.9, T2=69.5, T3=67.2 and T4=64.6) ($p < 0.001$). 119 relatives (57%) had a decrease in emotional functioning towards the patient's death. In the last three months, 55% of the relatives had a clinically relevant low emotional function (< 71), indicating emotional problems, based on the thresholds of Giesinger. Relatives of patients with lung cancer (OR = 3.6, 95%CI [1.3–10.0]) and prostate cancer (OR = 6.0, 95%CI [1.4–25.7]) had higher odds of having a decrease in emotional functioning compared to relatives of patients with colon cancer (corrected for age and gender).

Conclusions: The emotional functioning of relatives decreased in the last year of life of the patients, with more than half of all relatives experiencing emotional problems in the last three months. Especially relatives of patients with lung and prostate cancer seem more vulnerable for a decreasing emotional functioning and might therefore need more attention.

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P 3.018 A Qualitative Study of Mutual Support between Patients and Family Caregivers in Palliative Care

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Background/aims: Mutual support between patients and family caregivers in palliative care is under-researched. Little is known about how patients and family caregivers reciprocate in support of one another.

Aims: To identify

- 1) key actions and behaviours which comprise mutual support between patients and family caregivers in palliative care; and
- 2) factors that enable or restrict mutual support between them.

Methods: Thirty in-depth qualitative interviews focused on the topic were conducted with patients with advanced illness (n=15; cancer n=13, neurodegenerative n=1, cardiovascular n=1) and their family caregivers (n=21) recruited from a large regional-based hospice. Data were collected and analysed in line with the grounded theory method.

Results: Patients and family caregivers supported each other by counselling one another, remaining positive for one another, making

decisions together about future care, and by collectively preparing for the financial implications of the patient's impending death. Despite patients' inability to reciprocate in the form of physical support, the majority felt they provided emotional support to their family caregiver through expressions of encouragement and appreciation. Open disclosure between the patient and family caregiver enabled patients and family caregivers to support one another. However, mutual concealment of pain and distress, discordance between patient and family caregiver perspectives on their situation, family caregiver burnout, and a lack of support from the wider family to the patient and family caregiver, limited patients' and family caregivers' ability to be mutually supportive to each other.

Conclusions: Patients and family caregivers in palliative care have capacity to support one another during the advanced stages of patient illness. The findings serve to inform the development of psychosocial interventions in palliative care focused on supportive relations between patients and family caregivers.

P 3.019 Factorial Structure of Satisfaction with End-of-Life Care: A Systematic Review

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Background/aims: The Family Satisfaction with End-of-Life Care (FAMCARE) is a widely applied scale for measuring satisfaction with care and has been applied internationally to assess satisfaction with palliative care. The main objective of this study is to gather, analyse and systematise the available evidence on the factorial structure of FAMCARE instrument in palliative care population.

Methods: A systematic review was conducted following the PRISMA 2020 statement, by date 27/07/2022 within the Scopus, MEDLINE® and PubMed databases. A standardised data extraction form was developed to extract study characteristics and tested using three randomly selected studies. The results of interest consisted mainly of the factors obtained from the different factor analysis techniques applied and the interpretation made by the authors. For studies in which two or more analyses were conducted, separated by subsamples, number of items or factor structure, only the analyses that obtained the best goodness-of-fit statistics were selected.

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Results: Searches of scientific databases identified n=40 records. In the screening phase, n= 5 articles were reviewed and finally included. All studies administered FAMCARE family questionnaires, but the versions varied between the original FAMCARE questionnaire (n=8), FAMCARE-Patient (n=4), and FAMCARE-2 (n=3). Several studies administered or validated shortened versions of the questionnaires (n=6).

The most frequent analysis technique was PCA (n=9), followed by CFA (n=7) and PAF (n=3). In several cases (n=4), PCA was accompanied by CFA to assess the goodness-of-fit of the resulting model. Only in one case was it used to reject the alternative model.

Conclusions: Most factor structures differ markedly from the initial proposal of Kristjanson 1993. It should be noted that while the method used by the author was based on cluster analysis, subsequent research has employed factor analysis techniques.

P 3.020 Singularities of Lived Experience of Accompaniment of Spouses of Young Adults at the End of Life

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Background/aims: Studies on young adults' (YA) spouses with end-of-life cancer are scarce, and little is known about how they experience caregiving.

Aims: To understand the lived experience of the phenomenon of accompaniment for YA at end-of-life by their spouse.

Methods: This is an interpretive, phenomenological-hermeneutic study, guided by the conceptual premises of Heidegger and Gadamer. The participants were intentionally selected from a Portuguese Public Oncology Center. Phenomenological interviews were carried out with seven spouses (aged 33 to 45 years) from six heterosexual couples and one homosexual, whose data analysis followed the Gadamerian perspective.

Results: The phenomenon of accompaniment was revealed along eight topics common to the participants (Neves et al., 2022), disclosed as singularities of the spouse's lived experience, present in the common topics that emerged in the subtopics 'Feeling discriminated against'; 'Feeling the loss in marital intimacy'; 'Living with the uncertainty'.

Conclusions: During the accompaniment, the spouse felt their presence by the YA was limited by the stigma of homophobia, suggesting prejudice related to sexual orientation and showing inequities in health care. The experience of marital intimacy, namely the expression of sexuality, underwent alterations, which were not the focus of attention by health professionals, indicating that, apparently, this dimension is overlooked in end-of-life care. Living with uncertainties related to the threat of the YA's death, caused the interruption of achievement of common projects, such as parenting, indicating that the preservation of fertility, protection and accomplishment of the parental project are concerns for these spouses, which must be the targets of attention and intervention. These results suggest that the YAs, despite being a minority population, have specific needs that require a timely, integrated and differentiated intervention by the Palliative Care teams.

P 3.021 Predictors of Death-preparedness States for Family Caregivers of Terminally Ill Cancer Patients

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Background/aims: High-quality end-of-life (EOL) care may facilitate family caregiver preparedness for their patient's death to avoid negative caregiving and bereavement outcomes. But, studies examining predictors of caregiver death preparedness are primarily cross-sectional, and focused on demographics. We aimed to broadly examine factors predicting caregivers' death preparedness over cancer patients' last 6 months.

Methods: For this cohort study, associations of death-preparedness states (no-, cognitive-only-, emotional-only-, and sufficient-death-preparedness states) with socio-demographics, physician prognostic disclosure, patient-family communication on EOL issues, coping capacity, and perceived social support were examined among 336 Taiwanese

caregivers by a hierarchical generalized linear modelling using the no-death-preparedness state as reference.

Results: Caregivers with financial hardship were less likely to be in the emotional-only- (adjusted odds ratio [95% confidence interval]=0.09 [0.01, 0.78]) and sufficient-death-preparedness (0.06 [0.01, 0.35]) states than the reference state. The better the patient-caregiver relationship quality, the higher the odds for caregivers to be in the emotional-only- (5.87 [2.15, 16.02]) and sufficient-death-preparedness (6.15 [2.73, 13.89]) states. Physician prognostic disclosure facilitated being in the cognitive-only- (14.89 [6.36, 34.86]) and sufficient-death-preparedness (22.39 [9.05, 55.39]) states, whereas the greater the tendency to communicate EOL issues with their loved one, the lower the odds for emotional-death-preparedness-only state membership (0.48 [0.27, 0.86]). Stronger coping capacity predisposed caregivers to the emotional-death-preparedness-only state, but perceived social support was not associated with state membership.

Conclusions: Caregivers' death-preparedness states are associated with socio-demographics, physician prognostic disclosure, patient-family communication on EOL issues, and personal coping capacity.

P 3.022 Care during the Last Two Days of Life for People with Advanced Illness – Bereaved Family Members' Experiences

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Background/aims: The aim was to investigate how palliative care needs were met during the last two days of life for people with advanced illness – from bereaved family members' perspective.

Methods: A retrospective survey design using the VOICES (SF) questionnaire was employed, in a sample of 485 family members (aged: 20 - >90 years, 70% women) of individuals who died in hospital (aged 40 - >90, 50% men). Descriptive statistical analyses were performed.

Results: A large majority of the bereaved family members reported that the ill person had been treated with dignity and respect during the last two days of life (always 67% and most of the time 20%). Help with personal care (75.8%) and medication (78.4%) was reported as satisfactory by a majority, but pain relief (74.2%) and symptom management (58.1%) were reported slightly lower. Regarding having received sufficient help with spiritual needs during the last two days, more than half (67.1%) of the family members reported that they did not know, or that it was not applicable, and almost half (47.6%) reported that they did not know, or that it was not applicable for help with emotional needs (Table 1).

Conclusions: Dying people are treated with respect and dignity in care during the last two days of life according to family members' reports.

Table 1. Level of help for different areas received during the last two days of life.

Items	Strongly agree % (n)	Agree % (n)	Neither agree nor disagree % (n)	Disagree % (n)	Strongly disagree % (n)	Don't know % (n)	Not applicable % (n)	Missing n
There was enough help with personal care the last 2 days in life	35.4 (167)	40.3 (190)	4.9 (23)	3.0 (14)	1.5 (7)	8.5 (40)	6.6 (31)	13
There was enough help with nursing care e.g. medication the last 2 days in life	38.1 (180)	40.3 (190)	5.9 (28)	3.6 (17)	1.3 (6)	6.8 (32)	4.0 (19)	13
The bed area and surroundings gave enough privacy the last 2 days in life	51.9 (244)	32.6 (153)	4.3 (20)	3.6 (17)	1.9 (9)	3.2 (15)	2.6 (12)	15
There was enough help with pain relief the last 2 days in life	36.9 (174)	37.3 (176)	4.7 (22)	2.8 (13)	1.3 (6)	7.8 (37)	9.3 (44)	13
There was enough help with other symptoms the last 2 days in life	28.4 (132)	29.7 (138)	7.3 (34)	4.3 (20)	2.2 (10)	15.9 (74)	12.1 (56)	21
There was enough help with spiritual support the last 2 days in life	5.7 (26)	6.2 (28)	11.9 (54)	4.0 (18)	5.3 (24)	24.2 (110)	42.9 (195)	30
There was enough help with emotional support the last 2 days in life	12.3 (56)	19.2 (87)	13.9 (63)	2.9 (13)	4.2 (19)	30.6 (139)	17.0 (77)	31
There was enough help to stay where he/she wanted to be the last 2 days in life	19.9(93)	19.7 (92)	10.0 (47)	3.0 (14)	2.8 (13)	25.2 (118)	19.4 (91)	17

Pain- and symptom relief at the end of life were mostly satisfactory, but there is room for improvement. The availability, implications and meaning of help and support with spiritual and emotional needs might benefit from being clarified.

P 3.023 Family Caregivers: Needs Assessment and Support Interventions Apparent in Patient Records of Palliative Home Care Services

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Background/aims: The Carer Support Needs Assessment Intervention (CSNAT-I) is a person-centred intervention to support family caregivers providing end-of-life care at home. It consists of the CSNAT, an evidence-based self-assessment tool comprising 14 support domains, and a person-centred process of assessment and support. The intervention proved to be effective, however, links between the assessment of caregiver needs and support measures in palliative home care services where CSNAT-I is applied regularly need to be researched. An intervention study of CSNAT-I in an Austrian region provided the context for the exploration of this issue.

Methods: Retrospective analysis of electronic patient records from 7 specialised palliative home care teams in Austria (50 nurses) covering 21 months. Quantitative and qualitative analysis of 484 documented CSNAT conversations included prioritized support domains, key issues of conversation with family caregivers, and corresponding support interventions.

Results: The following domains among caregiver support needs were documented most often: "Having time for yourself in the day", "managing your relative's symptoms", and "dealing with your feelings and worries". Various types of support measures were identified, most of them counselling interventions, like listening, encouraging, informing, and giving advice, directly provided during the individual assessment conversation with the family caregiver. Some shortcomings in documenting caregiver support regarding wording, completeness, and documentation of the person-centred process became apparent.

Conclusions: With a focus on conversations with family caregivers support measures seemed to respond adequately to documented support needs according to the CSNAT-I. There might be a gap between what was documented and what was done, however, results serve as a basis for addressing the important issues of caregiver support in palliative home care.

P 3.024 Enabling Professional and Personal Growth among Home Care Nurses through Using the Carer Support Needs Assessment Tool Intervention - An Interpretive Descriptive Study

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Background/aims: The Carer Support Needs Assessment Tool Intervention (CSNAT-I) can provide guidance for discussions with family caregivers in

specialised home care concerning their specific support needs. Little attention has been paid to how nurses experience the use of the intervention in their everyday practice.

Aim: To explore nurses' experiences of supporting family caregivers in specialised home care while learning to use the CSNAT-I.

Methods/Design: This longitudinal study adopted an inductive qualitative approach using interpretive description.

Methods: Interviews were conducted at two time points. A total of 22 interviews took place with 12 nurses, recruited from six specialised home care services. Data were analysed using interpretive description. The COREQ checklist was used in reporting the study.

Results: Findings: Nurses' everyday clinical practice changed while learning to use the CSNAT-I and they experienced professional and personal growth. Their assessments and supportive inputs shifted from being reactive towards being more proactive. Their approach changed from taking on great professional responsibility, towards a more collaborative approach with a shared responsibility with family caregivers. The support altered from ad hoc contacts in the hallway, often in passing, towards scheduled trustful conversations. Nurses were concerned about the amount of time and energy this kind of support might require. They pointed to the importance of holding good nursing skills to conduct this new way of having conversations.

Conclusions: Nurses' everyday clinical practice can be further developed through use of the CSNAT-I. Nurses may develop both professionally and personally, increasing their ability to provide person-centred support. With the use of CSNAT-I, nurses may create trusting conversations with spouses of patients with life threatening illnesses cared for in specialised home care.

P 3.025 Increased Preparedness among Family Caregivers through Use of the Carer Support Needs Assessment Tool Intervention (CSNAT-I) – An Evaluation Study

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Background/aims: The Carer Support Needs Assessment Tool Intervention (CSNAT-I), that has been developed to support family caregivers in palliative care, consists of two parts; an assessment tool and a five-stage person-centred process. It has internationally shown to improve caregiver outcomes but has not been tested in a Swedish context.

Aim: To explore potential effects of CSNAT-I on preparedness, caregiver burden and quality of life among family caregivers in specialised home care.

Methods: Pre-post intervention design, conducted at six specialised home care services in Sweden, providing 24-hour care, for patients with palliative care needs. Spousal caregivers completed a questionnaire package, including the Preparedness for Caregiving Scale, Caregiver Burden Scale, and Quality of Life in Life-Threatening Illness – Family caregiver version, at two time points (baseline and follow-up after one intervention). Descriptive statistics and Wilcoxon signed-rank test was used for analyses.

Results: Altogether, 33 family caregivers completed the baseline and follow-up assessment. The mean age was 69 years, a majority were retired (81%) and women (58%). Preparedness for caregiving was

Table 1. Effects of the CSNAT-I.

	Baseline Mdn (q1–q3)	Follow-up Mdn (q1–q3)	p-value
Preparedness for caregiving	18 (15–20)	20 (17–22)	0.002
Caregiver burden			
General strain	2.4 (1.8–2.6)	2.3 (1.8–2.6)	0.740
Overall quality of life	6.0 (5.0–8.0)	6.0 (5.0–8.0)	0.645

significantly increased between the baseline and follow-up (Mdn = 18 vs. 20, $p = 0.002$). No significant changes were found on caregiver burden or overall quality of life (Table 1).

Conclusions: The results add to knowledge regarding CSNAT-I's potential to improve caregiver outcomes. The factors affecting family caregiver outcomes in a stressful life situation are complex. It will be important to understand how interventions such as CSNAT-I may affect outcomes.

P 3.026 Predictors of Informal Care Costs in the Last Year of Life in England

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Background/aims: Previous estimated predictors of informal unpaid end-of-life care costs are based on decedents known to palliative care teams or, if nationally representative, with cancer only, and in the last 3 months of life. We aimed to explore predictors of informal care costs in the last year of life.

Methods: Population-based survey (age 16+), England. End-of-life carer questions were included in the 2017 Health Survey for England: i) if someone close to them had died of a terminal illness within past 5 years, ii) if they had provided hands-on personal care, and iii) estimated hours of care (last year). Homecare worker unit cost was applied (~£24/hour). Multivariable linear model findings are shown (Table 1). Length and intensity of care were not included in the model as costs were calculated from these variables, but Spearman rank correlations with costs were conducted.

Results: 521/7997 (6.5%) respondents provided care. We estimated maximum care costs of £11,469,648. Care duration was strongly (0.88), and intensity moderately (0.46), correlated with costs. Increasing age was related to increasing costs; compared to carers aged 16–24 years, costs for carers aged 65–74 or 75+, were 4.0 (95% CI: 1.6 to 10.0) and 6.7 (95% CI: 2.5 to 17.7) times greater respectively. Costs were greater for carers who had lived with the decedent; carer costs of those dying at home (but did not live with them), hospital or hospice, were 72.2% (95% CI: 87.1 to 39.9), 61.1% (95% CI: 81.4 to 18.8) and 66.2% (95% CI: 85.5 to 21.6) less respectively. Costs were greater for more (vs least) deprived carers (quintiles 4 and 5: 2.10; 95% CIs 1.15, 3.79; $p = 0.016$ and 1.42; 95% CIs 0.78, 2.58; $p = 0.245$) respectively.

Cautious interpretation of religion and ethnicity findings is needed due to small numbers other than white/Christian.

Conclusions: Costs of care in the last year of life are greater for: older adults; those caring for someone who died in their mutual home; longer care duration and intensity, and greater carer deprivation.

P 3.027 Interview Study on the Care and Support Needs of Adolescents and Young Adults Who Have a Parent with (Advanced) Cancer

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Background/aims: Parental cancer brings changes and challenges which affect the whole family. Evidence shows heightened psychosocial risk among their children. However, little is known about their needs, which is crucial for developing appropriate support. Our aim was to gain insight into 1) the perceived needs of adolescents and young adults who have a parent with cancer (AYA) and 2) their use of formal and informal support and their experienced barriers.

Methods: We conducted semi-structured interviews with 17 AYA who have a parent with cancer, 12 parents with curative/non-curative cancer, and 18 healthcare providers (HCP). Content analysis was used for data analysis.

Results: (Preliminary findings - final findings are expected in early 2023) Most AYA expressed a need for honest and clear information from parents and HCP (e.g. clinicians). AYA want confronting information to be told patiently in a private room. Some AYA find it hard to ask questions or talk about their worries to their parents, out of fear of evoking intense negative emotions. In daily life, AYA experienced that parental cancer has an impact on their well-being, school experiences, family roles and relationships, which goes along with psychosocial and practical needs. They mostly used support from their informal network compared to formal support. On the one hand, they appreciate others being proactive, starting conversations about parental cancer, listening and validating their emotions. On the other hand, they also expressed a strong need for normality, distraction, and fun. AYA expressed barriers in seeking, finding, and accepting formal support such as a lack of information about what's there for them, or fear of worrying the parents.

Conclusions: AYA expressed informational and communication needs. They mostly make use of their informal network for support. Although there are needs regarding formal support, AYA expressed several barriers to getting in touch with HCP. With this information, more suitable support can be offered.

P 3.028 Strategies and Checklist for Designing and Conducting Palliative Care Research with Family Carers: EAPC International Expert Elicitation Study

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Background/aims: Palliative care services seek to improve the wellbeing of family carers of people living with serious and life-limiting illness. To

help achieve this goal, systematic reviews have recommended priority areas for family carer research and the need to improve the quality of study design. Policy makers have also advocated for enhanced family carer support. However, there are specific methodological considerations and challenges in designing and conducting carer research conducted during the course of the serious illness trajectory and in bereavement.

Aim: To develop strategies to improve the design and conduct of research with family carers.

Methods: Expert elicitation study using an adapted version of the 'Identify, Discuss, Estimate and Aggregate' elicitation protocol, supplemented with strategies from peer-reviewed literature. Participants included 9 members of the management committee of the European Association for Palliative Care's Reference group on family carer research, comprising international senior research academics in family caregiving.

Results: A compilation of recommended strategies and checklist was created to: (a) help researchers plan research involving family carers focussing on: preparation, conduct and dissemination and (b) assist ethics committees and funding bodies to evaluate proposals. The EAPC board approved the process and outcomes.

Conclusions: The strategies and checklist for conducting research with family carers may enhance methodologically rigorous research. Consequently, researchers, practitioners and policy makers will not only gain a more comprehensive understanding of the unmet needs of family carers but also promote the development of empirically sound interventions.

P 3.029 Predictors of Resilience among Family Caregivers of Patients with End-of-Life Cancer

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Background/aims: The family caregiver has the obligation and responsibility of supporting the patient especially, under Traditional Chinese Confucianism. Despite the stress of caregiving, FCs experience positive feelings of attachment, reward, responsibility, and pride. The comprehensive factors of resilience among the FCs of patients with terminal cancer are still uninvestigated. This study aimed to investigate the resilience of the FCs of patients with end-of-life cancer and determine the predictors of their resilience.

Methods: This descriptive, cross-sectional study was conducted from August 2020 to October 2021. The inclusion criteria were (1) a relative of a patient with terminal cancer who only lived <1 month and (2) a person who was extensively involved in actual care, as considered by the patient. Resilience Scale for Adults, Positive Aspects of Caregiving, Caregiver Self-efficacy Scale, and Caregiver Reaction Assessment were employed for data collection. The nine variables that were significantly associated with the outcome in the univariate analysis ($P < 0.05$) were included in the stepwise multivariate analyses.

Results: Of the 228 originally enrolled FCs, 186 provided consent to participate in the study. The results indicated that the family caregivers of patients with terminal cancer had satisfactory resilience scores. High self-affirmation, outlook on life, self-esteem, and financial capacity were the promoting factors of the resilience among these family caregivers. In conclusion, increasing the positive aspects and self-esteem may improve the resilience of FCs.

Conclusions: High resilience was found in FCs with higher educational level, greater positive aspect, higher self-esteem, and lower financial impact when caring for patients with terminal cancer. Comprehensive support should also be provided to FCs when dealing with a patient with terminal illness. This support must include improving their personal strength, meaning of life, uplift, gratification, reward, growth, and satisfaction.

P 3.030 Decision-making and Advance Care Planning for High-Grade Glioma Patients in Japan: A Qualitative Study of Bereaved Families' Needs and Preferences through Experiences as Surrogate Decision-makers

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Background/aims: Although respect for patients' autonomy is essential in decision-making, it has been reported that patients with high-grade glioma (HGG) may not be fully engaged in decision-making or advance care planning (ACP). Specific strategies for how healthcare professionals (HCPs) should support HGG patients' ACP and their families' decision-making have not been identified. Therefore, this study aimed to obtain bereaved families' perspectives on what aspects of HCPs' support were needed during the provision of decision-making and ACP.

Methods: Semi-structured interviews were conducted with 15 bereaved family members between August 2019 and February 2020. Participants' narratives were analyzed using content analysis.

Results: Four themes addressing aspects of support needed from HCPs were identified:

- 1) Participants wanted HCPs to allow families to determine whether to let the patient participate in decision-making;
- 2) Participants wanted HCPs to support patients' ACP or their surrogate decision-making;
- 3) Despite being upset by patients' sudden deterioration and uncertainty, participants needed HCPs to understand the family's commitment to seek the best possible treatment and care; and
- 4) Participants desired psychosocial support to be able to meet the patient needs and assist in their fight against the disease.

Conclusions: The study revealed that families, while overwhelmed by their loved one's rapid deterioration, have a dire need to play a role in seeking what is best for the patient with the support of HCPs, while maintaining control over their engagement in the decision-making of the HGG patient. The key to decision support that respects the autonomy of the HGG patients and simultaneously meets the needs of their families is for HCPs to reflect patients' wishes in their practice. Setting up opportunities for the HCPs to introduce ACP discussions early stage will ensure that patients' and families' needs for information and engagement in decision-making are met.

P 3.031 The Family Caregiver Journey: Development of a Workshop for Healthcare Providers to Explore How Support for Family Caregivers Can Be Improved

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Background/aims: To develop a workshop for healthcare providers to explore the gaps in their current practice of supporting family caregivers and to find ways to overcome these. The workshop outcomes serve to be translated into a tailored action plan to improve structural support for family caregivers.

Methods: The patient journey's concept was developed into a workshop to stimulate reflection, discussion and collaboration among participants, as well as their ownership of an improvement program within their

organisation. Different possible workshop methods were tested by healthcare providers to decide on its final form. The workshop materials' content was based on interviews with family caregivers and healthcare providers and tailored to specific healthcare settings (hospital, nursing home, hospice, home care).

Results: The workshop consists of four steps: 1.) Establishing the family caregivers' journey within the healthcare organisation by chronologically placing 'activity-cards' (e.g. 'providing practical support to the family caregiver'). 2.) Establishing what needs of family caregivers are sufficiently and insufficiently met, using 'needs-cards' (e.g. 'being involved in medical decision-making'). Together, participants choose 3-5 needs of family caregivers that they would like to better fulfil. 3.) For each chosen need, participants decide where in the journey (step 1) this need is particularly unfulfilled (red sticky note) and where it is going better (green sticky note). 4.) For each red sticky note participants brainstorm on how the need could be better met.

Conclusions: The workshop was well-received in 19 healthcare organisations. It brought participants to discover successes, but also gaps in their current practice, including ways to overcome these. When conducting the workshop, we recommend bringing different perspectives together by engaging a diverse group of participants.

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P 3.032 A Prospective Observational Study on Implementation of FAMCARE-2 Questionnaire in a Palliative Care Unit

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Background/aims: The FAMCARE-2 questionnaire is a widely used tool of family satisfaction with the health care received by both patient and family in Palliative Care (PC).

Family caregivers are a pivotal source in quality of life and assistance and investigating their satisfaction can be a part of quality and tailored assistance improvement, both for patients and caregivers.

Methods: The study was approved by the local Ethics Committee.

Research question was: "The implementation of FAMCARE-2 questionnaire is able to identify pitfalls or care issues in patients and family caregivers referred to our Inpatients hospice and PC home service?"

Between one to two months after patient's death, the research team sent (after collecting an informed consent by a phone call) the Italian validated form of the questionnaire to inpatients hospice's and home care's caregivers by e-mail or mail. We collected them in the same ways.

Results: From October 15th 2021 to April 15th 2022, 232 questionnaire were sent and we received back 67 of them. Six caregivers did not give consent to the research.

Overall and single-item satisfactions were really high both in hospice and home settings.

The data did not show any significant relationship between assistance timespan and overall satisfaction.

Conclusions: FAMCARE-2 questionnaire is an easy and effective tool to evaluate family satisfaction in PC services; data collected could help professionals to improve care.

The major issue for future research is the low rate of questionnaires collected.

P 3.033 The Experiences of Family Members Witnessing the Diminishing Drinking of a Dying Relative in Hospital: A Narrative Inquiry

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Background/aims: Family members commonly witness their dying relatives drinking less and less and express concern about the management of this diminishing drinking, particularly in hospital. This study explored the experiences of family members when witnessing the diminishing drinking of a dying relative in order to identify how professional support might be improved.

Methods: The research used Narrative Inquiry methodology derived by Clandinin and colleagues from Pragmatism. Thirteen family members who had witnessed the diminishing drinking of a relative dying in hospital in England were recruited. Their experiences were gathered through in-depth narrative interviews undertaken within 4 months of the death. The interviews were transcribed verbatim and areas of resonance were analysed.

Results: All participants understood diminishing drinking as an unfolding process associated with advancing illness. They all monitored the reducing liquid intake and believed it to be detrimental. Three groups of responses were identified: promoting, accepting and ameliorating. These responses were determined by participants' beliefs and values. Most, but not all, participants' responses fluctuated with their understanding of their relatives' dying trajectory. Supportive professional strategies were facilitating family members to help their relatives drink and communicating with family members about prognosis. Tension between professionals and families arose over different approaches to managing aspiration risk and clinically assisted hydration.

Conclusions: Professional support of family members witnessing the diminishing drinking of a dying relative in hospital could be improved by: re-conceptualisation of diminishing drinking at the end of life as the culmination of ongoing decline; consideration of the determinants of family members' responses; enhanced communication with family members about dying trajectory and supporting the agency of family members within the management of diminishing drinking at the end of life.

P 3.034 Experiences and Perceptions of Nurse Assistants on the Emotional Impact of Providing Palliative Care. A Qualitative Interview Study

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Background/aims: Providing palliative care (PC) to nursing home residents can be both fulfilling and emotionally challenging for healthcare professionals. In this setting, nurse assistants are most involved in providing primary PC to residents and often develop a close relationship. Despite their prominent role, little is known about the emotional impact of providing PC among these professionals. The aim of this study was to gain insight into the emotional impact of providing PC among nurse assistants in Dutch nursing homes, their strategies and needs in coping with this impact.

Methods: Seventeen semi-structured interviews with nurse assistants working in Dutch nursing homes were conducted. Participants were recruited via personal networks, social media and snowballing technique. Interviews were audio recorded, transcribed and open coded following a thematic analysis approach by two independent researchers.

Results: The perceived emotional impact of providing PC in nursing homes related to: 1) Situations (e.g. unexpected deaths, seeing residents suffer), 2) Interactions (e.g. developed relationship, gratitude from family), and 3) Reflecting on provided care (e.g. feeling inadequate in caring or fulfilment by being able to care). In coping with the emotional impact, nurse assistants used several strategies including emotional processing activities, attitude towards death or gaining experience in dealing with

the emotions or certain situations. However, nurse assistants reported a need for more education in practical and socio-emotional skills in PC and organised peer group meetings.

Conclusions: Perceived emotional impact of providing palliative care is related to situations, interactions with the resident and their family, and by how the nurse assistants reflect on their contribution to the provided care. Although nurse assistants themselves already undertake various activities to reduce the emotional impact, employers should be aware of the unmet needs in this area and the responsibility they have in this regard.

P 3.035 Needs of Carers and Care Recipients with Severe Dementia upon Hospital Discharge

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Background/aims: A randomized clinical trial titled the *Carer End of Life Planning Intervention (CELPI) in people dying with dementia* evaluated the effect of additional carer education and support about palliative care. We present a pre-planned qualitative analysis of data collected during the CELPI trial in which the needs of carers randomized to the intervention were assessed using a novel instrument (Carer Needs Directed Assessment in Dementia (CANDID)).

Methods: The CANDID tool identified the needs and experiences of primary carers and of their care recipients during the last 12 months of the carer recipient's life. The tool consisted of 33 open-ended questions evaluating: symptom assessment, symptom management, emergency contacts, advanced care planning, the carer's perception of the care recipient's future needs, the carer's current needs, and a proposed current and future care plan. Qualitative data collected during interviews using the tool were thematically analyzed in five steps: compiling, disassembling, reassembling, interpreting, and concluding. An interpretation of participants' reality emerged from their common experiences and the subjective meanings assigned to actions attached to the phenomena studied.

Results: Thirty carer participants were included. Analysis identified three major themes: carers' perceived stressors, systemic barriers to care provision, and future planning. Issues identified included barriers to accessing supports, carer health, and division between roles, financial burden, familial conflicts, adequate care in hospital and aged care facilities, concern about future needs, and end-of-life discussions.

Conclusions: The CANDID tool provides a detailed evaluation of carer needs and concerns. A referral to palliative care services provides this level of management and may therefore be beneficial for the person living with dementia and their primary carer.

P 3.036 Children as Next-of-Kin – How Did We Care for Them during the Pandemic?

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Background/aims: Follow up of children as relatives is a statutory and important task for the health care service. In our hospital, health care professionals are required to complete a standardized checklist of the patient's family if they have children under the age of 18. This checklist includes information on the child and the follow up of daily activities. Children need conversations about the situation they and their family experiences. During the pandemic several restrictions regarding

relatives visiting patients were initiated. However, the management at our hospital decided to prioritize children visiting their parents.

Aims: To investigate whether the follow-up of children as relatives of patients in a palliative inpatient unit was affected by the restrictions during the pandemic.

Methods: This was a non-empirical, retrospective study at an inpatient hospice/palliative care unit. Data were collected in 2019 and in 2021. The completed checklists "Children as next-of-kin" were obtained from medical records.

Results: Of 339 patients admitted to the unit in 2019, 14 patients had children younger than 18 years of age. Eight children were followed up with a conversation in the unit, whereas 4 teachers and 3 school nurses were contacted for follow up of daily activities. In 2021 twenty-five of 340 inpatients had children. Twenty-one children were followed up with a conversation, and 13 teachers and 9 school nurses were involved.

Conclusions: This study shows that next-of-kin children received similar follow-up during the pandemic as prior the pandemic. More patients with children were admitted to the inpatient unit during the pandemic. The pandemic with its restrictions did not lead to a loss of focus on the importance of follow up children. This result may be related to committed childcare workers who have followed up the work over many years, with teaching and weekly interdisciplinary meetings. A key to success has been to anchor the work in hospital management.

P 3.037 Coping with Advanced Cancer Together Dyadic Strategies of Patients with Advanced Cancer and their Relatives in the Netherlands

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Background/aims: Advanced cancer impacts the entire lives of both patients and their family caregivers, as they spend 95% of the time outside the health care system. We aimed to identify how patients with advanced cancer and their family caregivers work together in managing the disease and its consequences.

Methods: Secondary analysis of interviews with patients with advanced cancer and their family caregivers (SMART study). Transcripts were analysed inductively, deductively and thematically, focussing on dyadic strategies and using the 'Live with love' framework.

Results: Interviews with 38 dyads of patients and family caregivers were analysed. Dyads described dyadic strategies within several domains: medicine and pharmacology, lifestyle, mental and spiritual well-being, social support, knowledge and information, navigation and coordination, and dealing with the future. Strategies used included:

- efforts to adhere to prescribed medication schedules;
- engaging in as many joint leisure activities as possible (walking, going on vacation, visiting museums);
- ensuring a shared positive attitude and staying hopeful;
- seeking social support from family, friends and healthcare professionals;
- joint visits to healthcare professionals.

Conclusions: The dyadic strategies identified in this study were typically aimed at being able to maintain a normal life together with limited involvement of healthcare professionals. It is important for patients with advanced cancer and their family caregivers that healthcare professionals acknowledge the dyadic nature of the experience of having advanced cancer. Identification of what is important for dyads to live with this life limiting disease and providing them with dyadic support contributes to high quality care.

P 3.038 Caregivers' Absenteeism and its Association with Health Shocks and Functional Impairment among Persons with Severe Dementia

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Background/aims: We quantified employed caregivers' absenteeism days assessed the association of PWSDs' functional impairment status and health shocks with absenteeism, and determined the characteristics of caregivers who do not experience absenteeism in the presence of PWSDs' health shocks and high level of functional impairment.

Methods: In a prospective cohort of family caregivers of community-dwelling PWSDs in Singapore surveyed every four months for one year, we calculated absenteeism days due to caregiving and calculated the corresponding absenteeism cost among 119 caregivers employed at baseline.

Results: Nearly four-fifth (79%) of employed caregivers experienced absenteeism at least once over the one-year period. On average, in a month, they experienced 2.3 (SD 5.9) absenteeism days and incurred S\$758 (SD 2120) in absenteeism cost due to caregiving. Those caring for PWSDs with high level of functional impairment, incurred an additional 2.5 absenteeism days and S\$788 absenteeism cost compared to caregivers of PWSDs with low level of functional impairment/no impairment. Caregivers whose PWSDs experienced a health shock incurred an additional 1.8 absenteeism days and S\$772 absenteeism cost compared to caregivers of PWSDs without a health shock. Caregivers not co-residing with PWSDs and with an adaptive coping style were less likely to experience absenteeism when caring for PWSDs with a health shock.

Conclusions: Caring for PWSDs impacts their caregivers' employment in terms of missed work days. Workplaces need to be mindful of this impact, and design policies and programs to reduce caregiver absenteeism.

P 3.039 End-of-Life Conversations about Death and Dying from Volunteer Perspectives: An Interpretative Phenomenological Study

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Background/aims: Volunteers are essential in end-of-life care. At the end-of-life, most people are community-based and so seldom see their doctor, a nurse, or another healthcare professional. They are more likely to talk to their family members, neighbours, or community organization volunteers, about their impending death, and other related matters such as a desire to die. The aims of this study were:

- to explore the nature of end-of-life conversations (i.e. death and dying, and the desire to die) between hospice patients and hospice volunteers and
- to explore facilitators or barriers of these conversations.

Methods: We conducted semi-structured interviews using an interpretative phenomenological analysis. We recruited hospice volunteers in Calgary, Edmonton, and Red Deer in the province of Alberta (Canada). The inclusion criteria were 18+ years old, fluent in English, active hospice care volunteer, and signed informed consent. The exclusion criterion was cognitive or emotional instability.

Results: We recruited twelve hospice volunteers. The analysis identified 137 codes that were grouped into categories, and classified into four themes: hospice as a safe place to facilitate conversations, conversations

about death and dying, communication facilitators, and impact of end-of-life and desire to die conversations on volunteers.

Conclusions: The safe environment of the hospice, the commitment of confidentiality to hospice clients, the ability of volunteers to meet the needs of the patients or simply be there contributed to open conversations with volunteers about death and the final dying process, including the desire to die. These conversations provide a transformative context for both clients and volunteers.

P 3.040 What Do You Really See as Important? Understanding and Promoting Carer Wellbeing

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Background/aims: There is growing evidence of the role of formal and informal community support in the support of carer wellbeing, utilising a public health approach. However, admission to palliative care support often occurs after a long period of uncertainty and life schedule interruptions. Many carers are therefore financially disadvantaged, fatigued with navigating systems and isolated from community involvement. Our aim was to ask the carer's what their priorities were and to adapt our service design to provide for and support their needs.

Methods: Participants were recruited utilising two data sets obtained from the electronic clinical record used by the service. The carer needs survey was a combined online, in-print, telephone and in-person survey conducted by the project team.

Results: Results were drawn from 104 bereaved carers that completed the survey tool. Although 25% of respondents identified that they wanted more assistance. Key areas of carer support that was required: 92% wanted to be more heard and consulted with respect to their concerns, 80% wanted more training in practical care 96% wanted more *help to keep the person's symptom's manageable* 86%grief and loss counselling 85% more understanding how to adjust to the changing circumstances 89%information on illness, process of dying, how to prepare for loss, Self-care The second group of participants, who were currently caring for a client on the service also identified 0% wanted more help to keep the person's symptom's manageable, 55% wanted overnight practical nursing/carer assistance in the home 68% wanted more understanding how to adjust to the changing circumstances.

Conclusions: While the service receives such positive feedback from individuals receiving clinical care, this research identified that there is a significant need in the carer population that is not being met. There are opportunities for partnership and advocacy to support this in the future. The benefits of using this data to drive strategy, decisions and clinical practice.

P 3.041 Perceptions and Challenges Regarding Social Support: A Qualitative Study among Terminally Ill Patient

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Background/aims: To understand the type of social support networks existing for patients with a terminal illness and their care providers in rural Rajasthan.

Methods: Detailed Interviews were conducted with community-dwelling adults living with advanced life-limiting illness and their main caregivers. They were inquired about the type of social support networks available around them and the support obtained. The inquiry was also made regarding specific challenges faced by these patients or care providers in availing of different types of support.

Results: A total of 26 patients on end-of-life (EOL) care and their caregivers were interviewed. Family relatives (8 participants) and friends (2 participants) were reported as the most availed social support by the

participants followed by colleagues (1 participant), and social security schemes (1 participant). Most of the participants did not feel the need of seeking social support during the time of EOL support (12 participants). The social organizations played a minimal role in providing support to these families. Regarding financial support for these patients, family support played a key role in the majority of the instances. Four of the participants reported financial support from social security schemes, while 2 respondents reported incomplete support from these institutions. Three of the respondents replied dependent on money lenders for financial support. The majority of support after hospitalization came from doctors and family members. Almost all (19 participants) of the participant felt the role of the caregiver in decision-making, and only 3 participants reported the role of the patient to be substantial in the process.

Conclusions: No community-owned systems of social support for terminally ill patients in rural Rajasthan are present as both patients and caregivers identify family and friends as predominant sources of social support. Building community networks in this regard can bring instrumental change in strengthening end-of-life care in this region.

P 3.042 Deathbed Etiquette – The Guide: A Qualitative Study Exploring the Views of Practitioners on its Introduction into End-of-Life Care Settings

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Background/aims: It is common for relatives to feel uncertain about what to expect at the bedside of a dying loved one. The Centre for Art of Dying Well together with clinical, academic and communications experts created a 'Deathbed Etiquette' guide offering information and reassurance to relatives. The study aims to explore the views of practitioners with experience in end-of-life care on the guide and how it might be used.

Methods: A qualitative research design Three online focus groups and nine individual interviews were conducted with a purposive sample of 21 participants involved in end-of-life care. Participants were recruited through hospices and social media. Data was analysed using thematic content analysis.

Results: Discussions highlighted the importance of effective communication that normalises experiences of being by the bedside of a dying loved one. Tensions around the use of the words 'death' and 'dying' were identified. Most participants also expressed reservations about the title, with the word 'deathbed' found to be old-fashioned and the word 'etiquette' not capturing the varied experiences of being by the bedside. Overall, however, participants agreed that the guide is useful for 'mythbusting' death and dying.

Conclusions: There is a need for communication resources that can support practitioners in having honest and compassionate conversations with relatives in end-of-life care. The 'Deathbed Etiquette' guide is a promising resource to support relatives and healthcare professionals by providing them with suitable information and helpful phrases. More research is needed on how to implement the guide in healthcare settings.

P 4 - Palliative Care for Older People

P 4.001 How Reliable Is Staff Proxy Assessment in Clinical Care? – Inter-rater and Test-retest Reliability of the Integrated Palliative Care Outcome Scale (IPOS)

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Background/aims: Measurement of patient-centred outcomes has been successfully implemented into clinical palliative care in the UK. Reliability in clinical practice needs further study.

Aims: To 1) determine the inter-rater and test-retest reliability of IPOS in clinical care, and 2) explore any heterogeneity in reliability estimates.

Methods: Secondary analysis of clinical data (collection funded by UK NIHR RP-PG-1210-12015) in 4 acute care trusts and 8 hospices covering inpatient or community/respite services. Independently completed patient and staff IPOS at entry, end of each episode of care, and at change in palliative Phase of Illness together with patient characteristics were collected. Prevalence and biased adjusted kappa (PABAK), intra-class correlation coefficients (ICC), Bland-Altman analysis plus mixed-effects analysis of variance were used to test reliability.

Results: 309 patients (mean age 67 years, 55% female, 20% non-white ethnicity, 78% cancer) were included. Complete IPOS data with no delay between independent patient and staff assessments gave 224 matched pairs. Of the 17 items, 5 had good agreement, *Drowsiness* had poor (ICC 0.39) and the remaining 11 items fair agreement (ICCs: 0.44 to 0.59). The IPOS physical subscale score had fair agreement (ICC 0.53); with IPOS emotional subscale high agreement (ICC 0.66). Overall, patients reported higher item prevalence than staff. Highest agreement for each item was found at the second assessment per episode with disagreement becoming more pronounced at the 4th to 7th assessment per episode. Hospital or respite setting, dying Phase, living alone, and non-white ethnicity led to overestimation of IPOS total and emotional scale scores by staff. Underestimation by staff was present with higher distress and poorer quality of life.

Conclusions: With careful implementation, clinical staff across a range of UK specialist palliative care settings can reliably use IPOS to assess symptoms and concerns, with fair to good agreement for all IPOS items except drowsiness.

P 4.003 D-PaP Score (Delirium Palliative Prognostic Score) Estimates Short-term Survival in a Cohort of Hospitalised Geriatric Patients

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Background/aims: Providing palliative care to elderly people regardless diagnosis and prognosis is a concept emphasised by recent reports from W.H.O, E.A.P.C. and E.U.G.M.S. D-PaP score is recommended by E.A.P.C. for its high accuracy in predicting short-term survival in hospitalised terminal cancer patients. The aim of this prospective study was to assess the feasibility and accuracy of D-PaP score in a cohort of geriatric in-patients.

Methods: This was a prospective observational cohort study on survival prediction based on the D-PaP score and routinely collected clinical data. Individual D-PaP scores were calculated for 250 geriatric patients admitted to two acute hospital wards between July and September 2021. D-PaP score is a multidimensional score based on dyspnea, anorexia, KPS, Clinical Prediction of Survival (CPS), total WBC, lymphocyte percentage and delirium. The D-PaP score assigns patients to three different risk groups according to a 30-day survival probability: group A, >70%; group B, 30%–70%; group C, <30%. The CPS item was estimated three days after the admission by the physician who was taking care of the patient, the delirium item was assessed with the CAM algorithm.

Results: In this study 250 geriatric patients were enrolled, of which 90,3% had a non-cancer diagnosis, 52,8% had dementia. At the 30-days follow-up 32 patients (15,9%) had died. The three groups, divided based on different ranges of D-PaP, had significantly different survival curves (long rank test $\chi^2= 111$ $p<0,0001$), with 30 days actual survival (AS)

rates of 93,3% (A group), 65,2% (B group), and 21,7% (C group). Sensitivity was 84,45%, specificity was 74,4%, PPV was 94,7%, NPV was 46,7% and accuracy was 82.2. The multivariate logistic regression model confirmed D-PaP as the independent variable with the best statistical significance ($p=0,0001$).

Conclusions: These data suggest that the D-PaP scoring system is a reasonably robust method for prognostication in hospitalised geriatric patients and can help physicians with ACP.

P 4.004 Empowering Better End of Life Dementia Care (EMBED-Care): Co-design of a Digital Framework for Integrated Palliative Dementia Care to Support Holistic Assessment and Decision-making

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Background/aims: People with dementia experience a variety of palliative care needs which they cannot always express and therefore go unmet. We must optimise how we deliver palliative dementia care and empower people with dementia, carers and professionals to better assess, monitor needs, and manage distressing symptoms. Aim: Describe the co-design process and components of a framework for integrated palliative dementia care to support holistic assessment and decision-making for community and care home settings.

Methods: Using a systematic approach we co-designed the EMBED-Care Framework. Using framework analysis we synthesised data from evidence reviews, large data, and a cohort study to identify unmet palliative care needs of people with dementia. We presented the data in workshops, using nominal group with people with dementia, carers, and health and social care professionals, to construct the components, design and implementation requirements. User testing identified changes needed and refinements to the framework for clinical practice.

Results: The Framework was co-designed for delivery on an app, comprised four main components: 1) holistic assessment of needs using the Integrated Palliative care Outcome Scale-Dementia(IPOS-Dem); 2) IPOS-Dem scores inform priority setting and goals of care; 3) evidence-informed clinical decision-support tools automatically linked with identified needs to manage care; 4) priority setting and decision-support tools to facilitate shared decision-making between the person with dementia, carer and practitioners. The app generates automated alerts, linked with resources, and facilitates interprofessional working and communication to manage care.

Conclusions: Our framework is ready for evaluation in a feasibility and pilot trial. This is the first intervention to link the IPOS-Dem with practical decision support to empower people with dementia, carers and professionals in providing care and supporting users to understand and provide evidence-based palliative dementia care.

P 4.005 Dependence in Activities of Daily Living in the National Multicentre Cross-sectional Study of the Elderly Population in Georgia

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Background/aims: The prevalence of dependence varies in the elderly population. The aim of the study were to identify which socio-demographic and medical characteristics were associated with dependence in older Georgian population.

Methods: A national multicentre cross-sectional study was conducted in outpatient primary care settings from 2018-2020. Elderly patients (65+) with Montreal Cognitive Assessment scores of ≥ 16 were included. Healthcare providers recorded disease-related characteristics, while patients registered socio-demographics, Geriatric Depression Scale (GDS), Activities of Daily Living scale (ADLs), and Instrumental Activities of Daily Living scale (IADLs). Factors associated with dependence were evaluated in multivariate logistic regression analysis.

Results: 878 questionnaires were filled in 18 centers from 5 different regions in Georgia. 71% of the patients were female and the mean age was 75 years (SD 6.7). The prevalence of dependence was 16% and 39% on ADLs and IADLs, respectively. Dependence in ADLs was associated with age 75-84 years, < 10 years of education, being single, diagnosed with pulmonary disease, receiving outpatient home care service, having mild dementia, depression, and ≥ 6 symptoms (OR 6.15; CI 2.26-16.77). IADLs was associated with female gender, older age (85+), having primary diseases such as arthritis and other, receiving outpatient home care services, living outside of the capital, having mild dementia, depression, and ≥ 6 symptoms (OR 4.94; CI 2.88-8.49).

Conclusions: A relatively high number of elderly patients in Georgia are dependent according to basic and instrumental ADLs. Common factors associated with dependence in ADLs and IADLs were age, diagnosis, receiving home care services, mild dementia, depression, and ≥ 6 symptoms. It remains a health problem associated with adverse outcomes and poorer quality of life among older people. Therefore, promoting healthy aging may lessen the need for long-term care.

P 4.006 What Does a Good Death in Dementia Look Like?

Comparing the Views of People with Dementia in Brazil and the

UK: Qualitative Study

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Background/aims: Few studies have directly asked people living with dementia (PLwD) about their views regarding a good death taking into account their diagnosis or compared their perspectives cross-culturally. We aimed to compare the meaning of a good death for PLwD in Brazil and the UK.

Methods: A convenience sample of 32 PLwD (16 each in Brazil and the UK) took part in semi-structured interviews between Jul 2019 and Aug 2021. A co-developed topic guide was used in both countries. We assessed all participants for cognitive capacity to give informed consent. Two teams of interdisciplinary researchers independently analysed transcripts for their country, using inductive thematic analysis, followed by jointly developing overarching themes on the contrasts and similarities across the two countries.

Results: We identified 3 main themes: Choice and Control; Spirituality; and Fears and Wishes. Whereas in the UK, a good death with dementia

was defined by (having) choice and control, in Brazil participants believed that choice/control over the circumstances of one's death was inconceivable and not an aim at all. In Brazil a good death was inextricably related to spirituality and defined by being 'on good terms' with God. In the UK the Spirituality theme was much less prominent and, when present, focused on the afterlife. Participants in both countries shared fears of 'becoming a burden' to their loved ones and wished to die quickly. However, interviewees in the UK feared losing their identity and receiving insufficient public (health)care, which were not voiced in Brazil.

Conclusions: Designing culturally-sensitive approaches in palliative dementia care has to take into account how PLwD define both what a good death is and what helps to achieve it. Our findings also raise caution around replicating palliative care initiatives (e.g., on advance care planning) between countries without adapting its goals and means to achieve them so they are culturally meaningful.

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P 4.007 5,000 Extra Deaths at Home for People with Dementia in 2021 in England - Increasing Challenge for Community Palliative Care

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Background/aims: During the first year (2020) of the COVID-19 pandemic, the number of deaths of people at home and in care homes increased dramatically compared to 2019 (+29.3% and +21.1% respectively). However, while the number of care home deaths reduced back down to pre-pandemic levels in 2021 (110,563 deaths compared to 111,186 in 2019), the number of deaths at home in 2021 was even higher than in 2020 (157,312 deaths and 155,787 deaths respectively).

Aims: To investigate the pattern of home deaths for people with Dementia or Alzheimer's (D&A) in the second year of the pandemic and compare with other key causes.

Methods: ONS mortality data for England Jan 2019 to Jul 2022 was used. 2019 was considered the baseline year for comparison. D&A deaths include any mention of the ICD-10 codes F01- vascular dementia, F03- unspecified dementia or G30- Alzheimer's disease in any position on the death certificate.

Results: Home remained the third commonest place of death in 2021 for people with D&A, there was a significant increase in % deaths compared with 2019 (+4.5pp to 15.7% of all deaths) equalling an extra 4,768 people dying with D&A at home. The % increase in deaths at home was much higher for people with D&A (+46.7%) albeit from a lower baseline, than for cancer by (10.6pp to 41.6%).

The higher level of deaths at home for people with D&A has continued into 2022 although there is evidence that this trend is starting to reverse. Comparing the numbers of D&A deaths at home in first seven months of 2022 with 2021 and 2019 (January to July), there has been a small drop between 2022 and 2021 (-6.2%) but the latest number is still 43.6% higher than in 2019.

Conclusions: The 2021 increase in deaths at home for people with D&A is significant and proportionally greater than for other main causes. This may be a post-pandemic move away from care homes by families. While absolute numbers are lower than cancer, D&A deaths at home presents significant community palliative care (CPC) complexities for patients and their families.

P 4.008 Understanding Chronic Pain, Opioid Use and Cognitive Adverse Effects: A Qualitative Study with Older Adults at Risk of Severe Frailty and their Informal Carers

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Background/aims: Opioids are used to manage moderate to severe pain, but older frail populations may be more at risk of adverse effects. Cognitive adverse effects can be distressing but there is limited evidence to inform our understanding. This study aimed to explore the experiences, perspectives and concerns of older adults at risk of severe frailty and their informal carers regarding chronic pain, opioid use, and cognitive adverse effects.

Methods: Semi-structured interviews with community-dwelling older adults (≥ 65) and their informal carers. Inclusion criteria: risk of severe frailty, opioid prescribed over the past year, and reported chronic pain and cognitive adverse effects from the opioid(s) prescribed. Reflexive thematic analysis was used to analyse the data, guided by Corbin and Strauss' Illness Trajectory Framework and Horne's model of adherence.

Results: 18 older adults and 14 informal carers were interviewed. Chronic pain creates insurmountable 'work', including chronic pain work (the tasks necessary to manage pain), everyday life work (managing daily activities) and biographical work (managing self-concepts). This work is impacted by internal (e.g. adverse effects) and external (e.g. family) influencing factors. Chronic pain is challenging to manage; multiple approaches are adopted but were often ineffective. Cognitive adverse effects associated with opioids are distressing, especially for informal carers who felt helpless observing the event. Timely access to support and reporting issues are limited by how primary care is structured (e.g. booking appointments). Loss was common, with changes in abilities to complete daily activities and reliance on informal carers.

Conclusions: Older adults need more timely access to chronic pain support, with careful consideration of opioids prescribed and frequent review of what would be useful/meaningful. Informal carers play an important role in pain management but need to be empowered to do so, especially in managing pain medication and cognitive adverse effects.

P 4.009 Development and Validation of a Clinical Prediction Tool to Estimate the Risk of 1-year Mortality among Hospitalized Patients with Dementia

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Background/aims: Advance care planning (ACP) has an established benefit among dementia patients though occurs infrequently, which may contribute to goal-discordant care at the end of life. A prognostic tool could serve as a trigger for ACP. We sought to develop and validate a clinical prediction tool to estimate the risk of 1-year mortality among hospitalized dementia patients.

Methods: Population-level data in linked health administrative databases in Ontario were used. The derivation cohort comprised patients hospitalized from Apr 1, 2009 to Dec 31, 2017. Predictor variables were fully pre-specified based on existing tools, a review of etiological studies, and subject-matter expertise. The outcome variable was mortality within 1 year of hospitalization, such that a logistic regression model was estimated. The validation cohort comprised patients hospitalized from Jan 1, 2018 to Mar 31, 2019. Model performance was assessed in terms of predictive accuracy, discrimination, and calibration.

Results: The derivation and validation cohorts comprised 235,667 and 62,909 patients, of whom 35.0% and 33.5% died within 1 year of hospitalization, respectively. The model includes 76 predictor variables (186 degrees of freedom) capturing information about sociodemographic factors, comorbidities, previous interventions, functional status, nutritional status, admission information, and previous healthcare utilization. The model demonstrated good predictive accuracy (Nagelkerke's $R^2=0.35$), acceptable discrimination (c-statistic=0.80), and good

calibration in the validation cohort (mean relative difference = -3.29%) and in subgroups defined by age, sex, living status, and comorbidity. There was no overfitting.

Conclusions: Our model for hospitalized dementia patients could be integrated into electronic medical records as an automated prognostic tool, which could prompt ACP. Before implementation, the model requires external validation and study of its potential impact on clinical outcomes and healthcare costs.

P 4.010 The Psychological Impact of Living with Chronic Breathlessness and Experiences of Identification and Assessment of this Symptom in an Older, Frail Population in Primary Care

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Background/aims: Little is known about the experiences of older people with frailty and chronic breathlessness to explore the experience of older adults with frailty and chronic breathlessness, their carers, and healthcare practitioners (HCPs) about i) the psychological impact and ii) how chronic breathlessness is assessed and supported in the primary care setting.

Methods: Qualitative study using semi-structured in-depth interviews with community dwelling older adults at risk of severe frailty (>65 years; eFI >0.36), family carers and HCPs. Data were subjected to Thematic Analysis.

Results: 20 participants (9 females), their carers (n=5; 4 spouses, 1 child), and HCPs (n=10; 5 GPs, 3 Advanced Clinical Practitioners, 2 Nurses) were interviewed. Four main themes were identified: 1) The widespread impact of chronic breathlessness on patients and carers; chronic breathlessness affected all aspects of a patient's life, and that of their carer, including their mental health. 2) Barriers to optimal health-seeking behaviour and the identification of chronic breathlessness; adequate identification and assessment are limited as breathlessness is 'one of many' symptoms, and in the context of 'one appointment, one problem' within the primary care setting. Patients conflate breathlessness with underlying disease/illness and lack awareness of symptom specific treatments. 3) Clinical management of chronic breathlessness is limited; few are offered evidence-based treatments (e.g. handheld fan) and patients find their own coping strategies. 4) Need for education and information about chronic breathlessness; HCPs reported feeling helpless about management of breathlessness other than pulmonary rehabilitation for those with COPD.

Conclusions: Breathlessness causes distress and impacts negatively on psychological wellbeing. Lack of routine identification and assessment mean chronic breathlessness is poorly identified and untreated, adversely impacting the older, frail population.

P 4.011 Care Problems of Older (80 Years and Older) Patients and Residents at their End of Life

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Background/aims: The end-of-life phase is accompanied by physical and psychosocial symptoms resulting in care dependency. The symptoms and care needs of old non-cancer patients are not specific for the end-of-life phase. This might be a problem in clinical practice since unspecific symptoms at the end of life lead to difficulties in identification. The recognition of the end-of-life phase on the other hand is of great importance for providing an adequate end-of-life care.

This data analysis aims to describe the level of care dependency, the prevalence of pressure ulcer, incontinence, malnutrition, falls, and pain of patients and residents aged 80 years and older at their end of life.

Methods: As a method, a secondary data analysis of cross-sectional studies was chosen. The data of the annually conducted nursing quality measurement of the years 2017, 2018, 2019, and 2021 were analyzed. The care dependency was measured with the Care Dependency Scale (CDS). The definition of end of life is based on the surprise question.

Results: 70% were female and half of the participants (N=457) lived in a long-term care facility. On average, they had 5 diagnoses, whereby 80% of them were affected by a disease of the cardio-circulatory system. Almost half of them (47,5%) were diagnosed with dementia and 18% had cancer. 64% were completely care dependent or to a great extend. 10% of the participants had a pressure ulcer, 73,5% had a urinary incontinence, 25% were malnourished, 42% fell in the last 12 months, and 32% experienced pain. Participants who were diagnosed with dementia are significantly more often affected by urinary incontinence (urinary 86%) and are significantly more care dependent.

Conclusions: The high care dependency and prevalence of incontinence, in particular of patients and residents diagnosed with dementia, implies a high care need. Furthermore, if care problems worsen, the entrance of older patients and residents into the end-of-life phase should be considered.

P 4.012 Anticipatory Prescribing Identifies Care Home Residents as Dying and Prevents Hospital Death – An Ethnographic and Interview Study

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Background/aims: Care home residents account for ~30% of deaths in England. Dying at age 80+ is extremely difficult to predict, with 22% of residents' deaths occurring in hospital. Inappropriate hospital admissions and deaths negatively affect end-of-life care quality, costs and hospital bed capacity. Policy streamlined the anticipatory prescribing of injectable controlled drugs (ICDs) to adults expected to be dying out of hospital. However, evidence that ICDs prevent residents' hospital death is scarce. This study identifies whether, how and why the anticipatory prescribing of ICDs affects care home residents' place of death.

Methods: Ethnography in five residential and nursing care homes in the South-West of England. Semi-structured interviews with 25 staff: five managers, ten carers, ten senior staff (six nurses and four senior carers).

Results: Senior staff want to avoid unexpected deaths on the care home's premises because these trigger a Coroner's investigation. If investigation reveals that staff exposed residents to avoidable risk of harm, the Care Quality Commission will prosecute the care home. To avoid a Coroner's investigation, senior staff anticipate residents' deaths and prompt GPs to prescribe anticipatory ICDs. Residents with available ICDs are not admitted to hospital when their health becomes critical or ICDs are insufficient to control symptoms.

Conclusions: The availability of prescribed ICDs on the care home's premises establishes the evidence base for GPs to certify death without triggering a Coroner's investigation. This enables senior care home staff not to pursue hospital admission when the resident's health becomes critical.

P 4.013 Using Normalisation Process Theory to Determine How (Does?) the Australian 'Palliative Care Needs Rounds' Model Work in the UK

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Background/aims: Implementing evidence and transferring evidence from one context to another is a recognised challenge. Normalisation Process Theory (NPT) offers a theoretical framework to interpret features of context and mechanisms which support or inhibit the use of such evidence to describe the use of NPT in a case example of using monthly 'Palliative Care Needs Rounds', developed in Australia, to the UK context where specialist palliative care nurses provide care home staff with practice-based support and learning.

Methods: This was a pragmatic implementation study using the iPARIHS (integrated-Promoting Action on Research Implementation) framework. We determined what worked, for whom, and in what circumstances for the UK version of the Australian Palliative Care Needs Rounds model. This paper reports 52 qualitative interviews with care home and hospice staff using the model in six sites across the UK. NPT supports iPARIHS by identifying factors which support/inhibit implementation; and hence was used to frame and interpret qualitative evidence collected during implementation, focusing on coherence, cognitive participation, collective action, and reflexive monitoring.

Results: There was a lack of coherence in the early implementation phase, with mixed understanding about how Needs Rounds would function, though this changed over time. Cognitive participation, the perception of value and buy-in to Needs Rounds, differed across the sites and was impacted by high staff turnover and Covid-19. Collective action, the steps taken to make Needs Rounds work, included modifying the protocol to suit local context. Through reflexive monitoring, a number of costs and benefits of Needs Rounds were identified.

Conclusions: Not all parts of Needs Rounds were successfully implemented across sites. Monthly discussions were valued, helping to build staff skills and confidence, and improved communication mechanisms with families and other professionals. However, contextual factors restricted the success of implementation.

P 4.014 Creating Spaces in Sweden for Children and Older Adults to Engage with End-of-Life Issues through Arts Activities — Studio DöBra

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Background/aims: Studio DöBra was a community-based participatory action research project in which arts activities were used to create spaces for intergenerational interaction and community end-of-life (EoL) engagement. The project was motivated by Sweden's age-segregated context and lack of community-engagement in EoL and palliative care. A public health palliative care approach was applied as theoretical framework. We investigated the processes and impacts of developing, facilitating, and participating in Studio DöBra.

Methods: Two iterations were held (2016, 2018) in different Swedish cities in a collaboration between academic and community partners (i.e., organizations for children, older adults, and artists). Each involved 8 children (9 y/o) and 8 older adults (most 80+) in a series of 5 arts workshops addressing EoL-issues. Ethnographic methods were used to generate qualitative data (interviews, participant observations, meeting documentation), which were analyzed using various qualitative methods.

Results: Partners were found to have power over and a sense of responsibility for the children and older adults, which could lead partners to deliberately or unwittingly facilitate or hinder participants' engagement with EoL-issues. Children's and older adults' personal EoL-experiences and perceived lack of intergenerational interactions informed their participation. Using both imagination and real-life experiences, they seemed to act with agency in bonding across generations and in creating spaces for EoL engagement in Studio DöBra and in their social networks. Based on findings, a conceptual model was developed that distinguishes three types of impact (impact on individual and group development, action-oriented impact, and strategy-oriented impact) and how these evolved from each other.

Conclusions: This research contributes to understanding ways in which arts initiatives can be developed and facilitated to stimulate community-engagement in EoL-issues and intergenerational interaction.

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P 4.015 Trends in Critical Care Admissions of People with Dementia in the Last Year of Life in a Large English Cohort Using a Novel Data Linkage

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Background/aims: Critical care admissions (CCAs) of people with dementia, need careful consideration as to whether benefits outweigh treatment burdens. CCA rates for people with dementia in the last year of life vary across countries but there is little information on this from England. We investigated trends in CCAs of people with dementia in the last year of life using a novel data linkage in a large English cohort.

Methods: Retrospective cohort study using mental healthcare data of decedents diagnosed with dementia in South London and Maudsley Hospital, UK (2007-2020), linked with national hospital use data to identify those who had ≥ 1 CCAs. We extracted sociodemographic, illness and admission-related data. Outcomes were number and age-sex standardised rates of CCAs in the last year of life and place of death. We described variables (median (Q1-Q3) & frequencies (%)), examining temporal trends using linear regression.

Results: Of 14,469 decedents with dementia, 612 (4.2%) people had ≥ 1 CCA, while 355 (2.5%) had a CCA in the last year of life. Median age at CCA was 81.5 (76-86.5), 50.7% (n=310) women and in 53.2% (n=325) dementia severity was mild. Almost a third (n=175, 28.6%) of the decedents died in the hospital following the CCA, including 46.3% (n=81) who died in the critical care unit after a median of 10 (3-19) days. 30.4% (n=186) were discharged and died in a later hospital admission, and 41.0% (n=251) died elsewhere. Over a 12-year period, despite a decrease in overall CCA use among people with dementia ($\beta = -0.05$; 95%CI -0.01, -0.0003; $p = 0.04$), CCA rates in the last year of life increased from 0.95% (2008) to 2.63% (2019) ($\beta = 0.11$, 95% CI 0.01 - 0.20, $p = 0.03$).

Conclusions: While only 2.5% of decedents with dementia experienced a CCA in the last year of life, an increase in CCAs in the last year of life was observed over the time period. Detailed, population-level data is required to be able to make better judgements about the nature of CCAs among people with dementia nearing the end of life.

P 4.016 Frailty, Anxiety, & Depression among Elderly Filipino Patients Diagnosed with Advanced Cancer

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Background/aims: Frailty is a condition of loss of homeostasis due to multiple systemic dysregulation yielding to lower biological reserve against different forms of stressors. ¹ Geriatric societies generally agree that biomedical frailty clinically manifests as diminished strength & endurance, and reduced physiologic function of several organ systems. ¹ As the population ages, the likelihood of cancer increases, with approximately 70% of cancer deaths and 60% of all new cancer cases occurring in adults aged 65 years and older. ² This study aimed to determine whether aging-related deficits, manifesting as frailty, were significantly associated with anxiety & depression among older Filipino patients with advanced cancer.

Methods: Single-center, cross-sectional, descriptive study done in the cancer institute of a tertiary hospital in the Philippines

Results: 105 patients were included in the study. Over-all, 86 patients (81.9%) were frail. Significant association was seen between patients' functional status (ECOG score) & frailty ($p = 0.001$). The likelihood of being frail increased by 30% per unit increase in the ECOG score (OR 3.685, CI 1.623 – 8.366). Strong association was seen between frailty, depression & anxiety ($p = 0.000$ & 0.001 , respectively). The likelihood of being anxious & depressed was 7-times as much for those who were frail (OR 7.000, CI 2.132 – 22.981; OR 7.150, CI 2.406 – 21.246, respectively).

Conclusions: Frailty had a strong association with both anxiety & depression among elderly Filipino patients with advanced cancer. Frailty had good predictive value for anxiety & depression. Patients' functional status (ECOG score) had a strong association & a good predictive value for frailty.

P 4.017 Less than One-quarter of Dutch Older People Has Knowledge of Timely Utilization of Palliative Care

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Background/aims: Lack of public knowledge of palliative care may be a barrier to timely use of palliative care and hinder engagement in advance care planning (ACP). International studies report varying levels of knowledge of palliative care, but little research has been conducted among older people in the Netherlands. This study aimed to determine knowledge of palliative care and explore factors that contribute to knowledge of palliative care among older people.

Methods: A cross-sectional study consisted of 1242 older persons (≥ 65 years) from a representative sample of the Dutch population (LISS panel). Older persons were asked four statements about palliative care (true/false/don't know). Descriptive statistics and logistic regression analyses were done using SPSS.

Results: Most older people knew that palliative care is not only for people with cancer (73.9%) and that palliative care is not only provided in a hospice facility (60.6%). A minority knew that palliative care can be provided alongside life-prolonging treatment (29.8%) and that palliative care is not only for people who have a few weeks left to live (23.5%). Higher education level (OR ranging from 1.34 to 4.67 for the four statements), personal experience with palliative care (ORs from 1.35 to 2.44), being female (ORs from 1.00 to 1.88), and higher income (ORs from 0.95 to 1.81) were positively associated with knowledge about palliative care, while increasing age (ORs from 0.51 to 0.68) was negatively associated.

Conclusions: Knowledge of palliative care is limited, stressing the need for population-wide interventions, such as information meetings. During such meetings, attention should especially be paid to timely utilization of palliative care. This might expedite engagement in ACP and raise public knowledge of (im)possibilities of palliative care.

P 4.018 Frequency of People with Diagnosed Dementia in Palliative Care - A Register Analysis

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Background/aims: Patients with advanced dementia - an incurable and life-limiting disease - are in risk of unmet needs and reduced quality of life at the end of life, and thus in need for specialized palliative care. There is a lack of empirical data on their occurrence in a specialist palliative care context. How frequent is the documentation of a dementia diagnosis among patients in specialist palliative care?

Methods: Retrospective analyses of documented diagnosis of dementia in the German National Hospice and Palliative Care Register since 2009 in the population of patients aged over 64. Descriptive statistics were performed with SPSS (version 28.0.0.0).

Results: The register included 69,116 data sets of patients aged over 64; 3.3% of them had documented dementia as main diagnosis (ICD-10 F00-F03; G30). In palliative care wards the frequency was 0.8% (148 out of 19,161), in inpatient palliative care services 2.2% (52 out of 2,380), and in specialist palliative home care 4.3% (2014 out of 46,803). Prevalence was low, compared to the general population where the dementia prevalence of 64+-year-olds is 8.6%. Patients with recorded dementia diagnoses deceased significantly more often in palliative care than patients with other diagnoses. The latter were significantly more often transferred to other (palliative) care settings or discharged to their living environment ($\chi^2 = 161.898$; $p < .001$) (significant also after Bonferroni-correction of the α -level).

Conclusions: The dementia prevalence according to the records of the German National Hospice and Palliative Care Register is lower than expected according to general population data. We would have expected higher rates of patients with dementia in specialist palliative home care. We cannot tell if the underrepresentation of diagnosed dementia is caused by a lack of coding of dementia diagnoses, by a lacking documentation of a once diagnosed dementia or by disabled access to palliative care services.

P 4.019 Attitudes of Healthcare Professionals towards Deprescribing in Older Patients Receiving Palliative Care in Hospice Settings

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Background/aims: Deprescribing is a potential solution for inappropriate prescribing in older patients with limited life expectancy (LLE) to evaluate HCPS' attitudes toward deprescribing for older patients with LLE receiving palliative care in hospice settings.

Methods: An online and paper-based questionnaire was administered through three UK hospice organisations in April - June 2021. Permission was sought to use the Attitudes Toward Deprescribing at the End of Life (ATD_EOL) questionnaire adapted to the UK context. The questionnaire collected data on participant demographics and extent of agreement with statements about deprescribing in six domains: *burden*,

appropriateness, concerns about stopping, involvement, organisational, educational. Two global questions measured perspectives of patients' and carers' willingness to deprescribe and satisfaction regarding medicines. Ethical approval was obtained from [Research Ethics Committee name]. Statistical analysis was performed using SPSS® V26. **Results:** 55 HCPs participated. Over half (56.4%) were aged ≥ 45 years, 92.7% were female, and 41.8% worked in the inpatient setting. Many (78.2%) were concerned that many patients were taking large numbers of medicines. Most (92.7%) agreed that some patients were receiving inappropriate medications, and 69.1% agreed that medicines were a burden to most patients. Most (96.4%) agreed that they would consider a patient's wishes and preferences in deprescribing. Beliefs about the positive impact of deprescribing on a patient's quality of life were significantly associated with concerns that many patients were taking large number of medicines and that these were burdensome ($P=0.000$) and that patients may be taking one or more medicine(s) they no longer needed ($P=0.001$).

Conclusions: Discussion/ conclusion: HCPs were willing to deprescribe inappropriate medicines and considered patients' EOL priorities when making deprescribing decisions. This may facilitate deprescribing in routine clinical practice.

P 4.020 Family Carers Experiences of Compassion When Caring for Older Ageing Adults Living with a Long-term Condition: A Systematic Review

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Background/aims: Carers UK estimate there are 13.6 million unpaid carers in the UK and save the economy £132 billion a year. As highlighted in a report by Marie Curie, this comes at a cost. Carers of older ageing adults experience burden, isolation, sadness and anxiety. Compassion (the ability to recognise and be motivated to reduce suffering in others and self) may be a possible target for intervention to improve wellbeing.

Aim: To explore barriers and facilitators to cultivating compassion and to identify the tools that have been used to assess compassion in carers of older ageing adults.

Methods: Five databases (i.e., CINAHL, EMBASE, PsycINFO) were searched from inception to February 2022. using search terms for compassion and carers. The Hawker appraisal tool assessed methodological quality of included studies. A narrative approach synthesised the evidence on experiences of compassion and the tools that have been used to measure compassion in this population.

Results: A total of 11,586 citations were identified, 10 studies were included. Where studies reported qualitative data ($n=5$), themes defining barriers to compassion included demands of the role and prioritising the needs of the older adult. Facilitators to compassion included emotional attachment and support from family and friends. Where studies reported quantitative data ($n=7$), six different tools were used to measure compassion (e.g., Compassionate Engagement and Action Scale; Self-Compassion Scale-Short Form; Caregiving Compassion Scale) and the types of compassion explored varied between studies (e.g., compassion for self, others and receiving compassion, compassion fatigue, compassionate love).

Conclusions: The paucity of evidence on carers experiences of compassion in the context of caring for an older ageing adult is evident. While a compassion-based intervention may have the potential to improve carer wellbeing, research is needed to explore carers understanding of compassion and how an intervention may be tailored for this group.

P 4.021 Tools and Guidelines Regarding the Appraisal of the Appropriateness of Medications and Deprescribing and its Applicability in Persons with Limited Life Expectancy: Umbrella Review

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Background/aims: Several tools and guidelines have been developed and reviewed to help clinicians avoid or to deprescribe potentially inappropriate medications (PIM). However, it is not clear if and to what extent these tools and/or guidelines are applicable to palliative care situations.

Methods: We conducted umbrella review to summarize tools and guidelines for the appraisal of the appropriateness of medications and deprescribing. We searched MEDLINE (Ovid), Embase, Cochrane CDSR, CINAHL, Web of Science, and five specialized guideline databases from data of inception to 07 July 2022. The link between explicit tools (i.e., tools comprise list of PIM) was described based on their genealogy. Tools were summarized and described in terms of different characteristics (e.g., development, validation, settings, target group, and the covered aspects of inappropriate prescription).

Results: We identified 15 systematic reviews reporting 81 tools (61 explicit, 9 mixed, 11 implicit), and 8 deprescribing guidelines developed based on the GRADE approach. Genealogically, 27(44%) of explicit tools were developed based on Beer's criteria. In the majority of the explicit tool, 53 (87 %) used the Delphi method to validate their criteria. Looking at the patient populations 63 (71%) of tools were developed for use in older adults. Eleven tools (8 to identify PIM and 3 to initiate deprescribing) were designed for use in frail patients with limited life expectancy or in palliative care settings (2 for cancer, 2 for diabetes mellitus, and 7 not disease-specific).

Conclusions: Existing tools and guidelines are available in a diversity of populations to appraise the appropriateness of medications and support deprescribing. However, the clarity of tools in terms of their methods of development and target group specifications for use in clinical setting are limited. Particularly the deprescribing tools and guidelines relevant for palliative care are based on a limited level of evidence and research to generate this evidence is highly needed.

P 4.022 Assessing the Quality of Life in Older Patients with End-stage Kidney Disease Receiving Palliative Care

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Background/aims: Patients with end-stage kidney disease (ESKD) are choosing not to start dialysis when it is recognised that dialysis can only provide little or no benefit. Clinicians will then be involved in end-of-life care of patients with ESKD. This study aimed to investigate the factors associated with the quality of life in patients with ESKD receiving palliative care.

Methods: A descriptive, cross-sectional study was undertaken in a palliative unit at a medical centre in Taiwan. Patients aged over 65 years, receiving kidney palliative care and not undergoing dialysis were included. Fred phenotype was used to assess the frailty status. Quality of

life was assessed by the SF-36 and KDQOL-SF. Descriptive statistics on SF-36 with 8 domains and KDQOL-SF with 11 domains were reported. Multiple linear regression was used to examine the factors associated with the quality of life.

Results: Data from 220 patients were analysed and 56.8% were male. The mean scores of SF-36 and KDQOL-SF were 54.8 (SD=19.4) and 58.5 (SD=18.5), respectively. The lowest score on KDQOL-SF was the sexual function (M=13.8, SD=11.9) domain. Gender was the only demographic factor associated with the quality of life. Females have a higher quality of life score in SF-36 ($p<0.001$) and KDQOL-SF ($p=0.007$) than males. In KDQOL-SF, no differences were observed in sexual function while all other domains were significantly associated with gender (female > male, all $p<0.05$). Patients identified as frail have significantly lower KDQOL-SF scores on cognitive function and social support than those who were identified as pre-frail and robust (all $p<0.05$).

Conclusions: Our study findings revealed the need for an evidence-based, gender-specific intervention to improve the quality of life in patients with ESKD receiving palliative care. Early detection and management of frailty are key to improving the quality of life in particular to cognitive function and social support aspects.

P 4.023 Shared Decision-making in Feeding Strategy for Late-stage Dementia Patients Living in Long-term Assisted-living Institutions for the Elderly (LT/AL): Integration of Early Palliative Care (PC)

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Background/aims: Dementia burdens the mental and physical health of patient and family, and the need for full-time care leads ever more patients into assisted living. The aim of this study was to assess the early PC approach integrated with shared decision-making on the choice of feeding strategy in late-stage dementia patients in LT/AL facilities.

Methods: Cross-sectional study on the approach taken by PC team about feeding strategies on a cohort of late-stage dementia patients admitted to an LT/AL facility located in Belo Horizonte, Brazil, between February and July 2022.

Results: The PC approach was proposed for 16 patients aged over 80. Upon admission, 12 patients' families met weekly with the staff on the pros and cons of alternative feeding methods and to plan for the care to be provided. Effective communication about the risks and benefits of artificial feeding led to a reduction in enteral and percutaneous endoscopic gastrostomy (PEG) tubes. In comparison to the four patients transferred from hospital with PEG, the lack of a concerted PC approach became clear: the families noticed no quality-of-life improvement nor reduction in food aspiration and pneumonia after the procedure.

Discussion: Dementia's progression is inexorable, and a reduction of food intake due to dysphagia very likely. Food is a strong social and psychological bond, and not feeding can be seen as giving up on the patient or hastening their clinical decay. Most scientific evidence denies lower mortality or improvements in function or quality of life in late-stage dementia patients due to artificial feeding. Patients with PEG still present high prevalence of pulmonary aspiration, pneumonia, pressure ulcers, sarcopenia and malnourishment.

Conclusions: Medical practice must not eschew scientific evidence, nor disobey informed consent. Early PC approach and shared decision-making has lessened family anxiety, shed light on the progression of the disease, and lowered the use of artificial feeding.

P 4.024 Advance Care Planning by Proxy in Residential Aged Care Facilities in Switzerland: Results of a Pilot Study

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Background/aims: Advance care planning (ACP) has been shown to promote care that is coherent with patient wishes, however retaining decision making capacity (DMC) is a precondition for traditional ACP models. Alternative models of ACP are needed for use with and on behalf of people lacking and who no longer have DMC. We have developed a model of ACP by proxy (ACPbp) specifically for use with residential aged care facility residents (RACF) who no longer have DMC. This study aimed to test the acceptability and feasibility of this ACPbp intervention through a pilot study, and to explore the impact on health professional (ACPbp facilitator) self-efficacy in providing care that is coherent with RACF resident wishes.

Methods: Data collection took place in four RACFs in French-speaking Switzerland. ACPbp facilitators participated in semi-structured interviews and completed a numerical self-efficacy scale (1: not at all confident, 10: very confident) before (n=14) and after (n=4) ACPbp completion. Interviews were transcribed verbatim and analysed thematically.

Results: Before the intervention, one-third of facilitators expressed low to moderate self-efficacy and practice uncertainty, predominantly feeling that they were providing care that was more consistent with their own values than the residents'. Two-thirds described high self-efficacy due to good knowledge of the residents. Post-intervention, self-efficacy increased- practice was modified according to residents' presumed wishes that were reconstructed through the ACPbp interventions. The low number of health professionals participating in semi-structured interviews reflected the significant turnover of personnel in RACFs and the number who did not find time to conduct the ACPbp discussions.

Conclusions: While RACF health professionals and their superiors were enthusiastic about ACPbp and its potential to improve patient centred care for people lacking DMC, ACPbp implementation is complex due to the RACF context and staff turnover.

P 4.025 Can Multidisciplinary Geriatric Intervention Preserve Quality of Life and Independence in Vulnerable Older Cancer Patients Receiving Oncologic Treatment? A Recruiting Randomized Interventional Trial

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Background/aims: Elderly cancer patients have different physical and psychosocial resources. Those whose resources are exhausted by treatment require more support. The application of a Comprehensive Geriatric Assessment (CGA) could be suitable for their identification. The purpose of this study is to offer proof of principle that a screening-based CGA followed by multidisciplinary intervention helps maintain QOL and independence in older cancer patients.

Methods: Patients (≥ 70 yrs) receiving outpatient systemic or radiotherapy and with a G8 screening score ≤ 14 will be informed of the study. A 1:1 randomization will be performed. The control group (CG) receives standard of care. The intervention group (IG) receives a CGA with corresponding multidisciplinary interventions. Primary outcomes are the independence (IADL) and Quality of Life (QoL) with treatment toxicity (CTCAE) and extent of palliative care planning as secondary outcomes. Assessment will be filled at baseline (T1) and after 3 months (T2). It is expected that the IG will be more independent and have a higher QoL at

time of T2 compared to CG. Primary endpoint is a significant effect detection in the primary criteria at time of T2. Power calculations reveal the need to enroll 350 patients. Regression models are used for the analysis of treatment effects.

Results: After 6 months of recruitment 72% of the screened patients were identified as vulnerable. Of the affected, 20% participated in the study to date (77 ± 5.5 yrs.). 20% of patients (>80% Stage IV tumor disease) had no advanced care planning at all. Global quality of life, fatigue, depression, and polypharmacy were notable.

Conclusions: Experience to date suggests that CGA is suitable to detect vulnerable patients and implicates a high need for support. If the intervention proves effective, it may improve care for the vulnerable target group maintaining their QoL and independence.

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P 4.026 Estimating the Palliative Care Need of Care Home Residents in England and Wales, 2010 to 2019

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Background/aims: Significant numbers of people over the age of 65 in England and Wales die in care homes. Many have complex underlying health conditions and are in the last year(s) of life but may not be receiving palliative care. With an ageing population and increasing pressure on social and health services it would be useful to estimate how many care home residents could benefit from it. The primary aim was to estimate the palliative care need of care homes residents over the age of 65 in England and Wales.

Methods: This was a retrospective descriptive observational study using data from the Office of National Statistics that explored deaths in care homes in England and Wales between 2010 and 2019 in those aged over 65. To aid analysis of the main causes of death and trends for specific disease groups, the five International Classification of Diseases groups that accounted for over 85% of all care home deaths and are associated with significant palliative care needs were chosen. For the analysis of specific palliative care need two groups of ONS data were analysed using previously established methodology.

Results: Over the ten years, 52% more men and 21% more women are now dying in care homes. Deaths from circulatory and respiratory diseases have decreased; those from cancer have seen a small increase. However, the number of care home residents dying from mental and behavioural disorders and diseases of the nervous system has increased rapidly, by 151.8% and 160.4% respectively. Of all people who are dying in care homes, between 80.6% and 81.9% are estimated to have had palliative care needs.

Conclusions: A large percentage of people dying in care homes would likely have benefited from the input of palliative care services. To make more detailed recommendations about the specific needs in care homes and about how this need can be met, more research needs to be conducted using a wider variety of data.

P 4.027 Analysis of the Mode of Palliative Care in Long-term Care Institutions-Characteristics of the Super-senior Veterans Who Died Well at Veterans' Homes in Taiwan

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Background/aims: The Veterans' Homes, the largest long-term care institution in Taiwan, are like second homes for many senior veterans. Taipei Veterans General Hospital Hospice Home Care Team provides regular visits by physicians and nurses and is dedicated to assisting

terminally ill residents to receive palliative care and to die with dignity at the Veterans Home. Our study aimed to better understand the characteristics of the residents who received hospice care and died at the Veterans' Home, so as to be able to intervene timely.

Methods: We retrospectively analyzed the residents who received hospice care and died peacefully from November 2018 to September 2022 at the Taipei Veterans' Home and Banqiao Veterans' Home. The analysis includes age, gender, unmarried status, cancer diagnosis, dementia diagnosis, advanced decision (AD), Body Mass Index (BMI), etc. We also discussed differences in the number of days from case acceptance to death, number of hospitalizations in the half-year before case acceptance, and number of hospitalizations after case acceptance under different conditions.

Results: The average age of the 90 veterans (96.7% of them male) who died at Veterans' Homes was 92.0 ± 5.3 . Among these veterans, 27.8% were unmarried, 28.9% had cancer diagnoses, 48.9% had dementia diagnoses, and 7.8% had signed an AD. The average number of days from hospice receipt to death was 144.9. Married and unmarried veterans showed no difference in days to death. Elderly people with a cancer diagnosis had fewer hospitalizations after hospice enrollment. Elderly people with a BMI of less than 18 had a significantly shorter time from admission to death and fewer hospitalizations after admission.

Conclusions: In addition to residents with cancer, long-term care institutions should be concerned about other terminally ill residents. Low BMI is a significant indicator of rapid disease progression. If necessary, early hospice intervention should be made to help residents of long-term care institutions to die in the local area.

P 4.028 Value Anamnesis': A Tool to Elucidate Patient Values in Geriatric Oncology

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Background/aims: Geriatric oncology care can be better adjusted to patient values order to improve appropriate, person-centered care. Yet, evidence-based tools that both elucidate patient values and warrant that they are taken along in (inter)professional communication throughout the patient journey are lacking. The aim is to improve appropriate, person-centered care in geriatric oncology by supporting care providers and patients in elucidating patient values and promoting the attention to these values in dialogues and decision-making throughout the patient journey.

Methods: A participatory development design is employed to develop and design the tool together with a 'Community of Practice' (n=15): representatives of patients, family members and care providers involved in the care for older patients with cancer at an academic hospital. The findings of a systematic review on existing tools provides input for the Community of Practice meetings. The tool is tested in two pilots (n=20) through researcher observations and interviews with patients, informal caregivers and health care providers, on the basis of which the tool is further refined by the Community of Practice in a cyclic iterative process.

Results: We will present the results of our systematic review, our observations, the interviews as well as the tool itself. The review included 6 studies that focus on the design or feasibility of value elucidation tools, however none of these studies were conducted in geriatric oncological patients. In the design of our tool to stimulate value elucidation in geriatric oncology we attempted to overcome obstacles identified in the review and sought ways to embed 'value anamnesis' throughout the patient journey as well as in electronic health records.

Conclusions: Developing a tool that elucidates patient values and wishes is important in aligning geriatric oncological care with the personal values of patients. Further research needs to assess and improve the feasibility and implementation of the tool in geriatric oncology.

P 5 - Education and Advocacy

P 5.002 The Impact of Applying Gagne's 9 Events of Instructional Learning in Designing a Virtual Palliative Care Course

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Background/aims: The authors' organisation offers regular palliative care courses in Singapore to meet the growing demand. Recently, 63 healthcare professionals enrolled in a virtual synchronous course on geriatric palliative care in advanced dementia. The aim of this study is to evaluate the impact of using Robert Gagne's 9 steps of instructional learning as a framework for designing and delivering a virtual palliative care course. Gagne, a pioneer in instructional design, is chosen as the

framework stands taller among other prominent curriculum designers for its efficacy in learners' engagement.

Methods: The 2-day course was developed and conducted as illustrated in the table below. Digital teaching tools were used for virtual engagement.

Results: Despite being online, qualitative comments appreciated the interactive roleplay on communications and case study group discussion.

All respondents would recommend the course.

Conclusions: Gagne's 9 instructional events were well-received by learners. Though not statistically significant, without a longitudinal study, the results will help PC educators in curating a systematic and robust online course. Virtual courses will continue with a gamut of digital tools available for use. By designing courses based on Gagne's framework, instructors will be able to select the most appropriate tool to scaffold their lesson plans.

Table. P5.001

	Gagne's 9 Events	Activities	Digital Tools	Outcome
1	Gain attention	Email a welcome note to learners and encourage learners to write learning objectives (LO)	Padlet	27 respondents listed their LO in Padlet
2	Inform learners of objectives	Frontload learning outcomes in each topic	Zoom	96% agreed LO was met, 24% strongly agreed.
3	Stimulate recall of prior learning	Trainer's narrative of real cases of patients with advanced dementia (PWAD) Learners recall experiences of challenges in caring for PWAD	Zoom	Learners responded in chatbox
4	Present stimulus	45-minute synchronous lectures with new content with videos, images, mnemonics	Zoom	76% agreed to illustrations, practical examples, and case studies were effective.
5	Provide learner guidance	Learners' opinions were polled, handouts given.	Zoom Poll Padlet	
6	Elicit performance	Case studies discussion and group presentation.	Zoom Breakout Room	70% of respondents liked the trainers' knowledge, case studies, peer learning, and role play.
7	Provide feedback	Trainers' responses to learners' questions and cases studies Peer feedback	Zoom	
8	Assess performance	Roleplay on communications. Mini quizzes throughout playback of instructional video on communications	EdPuzzle Wheels of Names	
9	Enhance retention and transfer	Learners are to list at least 1 specific action he/she to apply new contents Slides handout, prereading material and Padlet forum discussion up to a year post course	Google Form	Feedback received

P 5.003 Palliative Competence Tool (PalliComp): Construction and Validation of a Research Tool for Medical Education

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Background/aims: The European Association for Palliative Care described ten central competencies in Palliative care (PC) in 2013. This research aimed to develop and validate a Brazilian Portuguese research tool named Palliative Competence Tool (PalliComp) to measure competencies among medical students.

Methods: After ethical approval, the authors started the construction process of the questionnaire with the writing of 30 statements, totally correct or incorrect, that addressed the competencies of the EAPC, at the level of undergraduate medicine. The statements would be answered by future participating students using a 5-point Likert scale. The material was submitted to the evaluation by the specialists (inclusion criteria: specialists must be the same time doctors, professors, and Brazilian natives), through the steps of Delphi methodology. The evaluation criteria were previously established: writing quality, content adequacy to competence, general quality, and intention to keep the item. The approval of the items - by competency set - occurred when the grades exceeded 70%. For validation, the questionnaire was applied to a sample

of students enrolled in the 4th year of the Faculty of Medicine. The data were evaluated using Bartlett's sphericity, Kaiser-Meyer-Olkin (KMO), and Cronbach's alpha coefficient tests.

Results: Of the specialists, 24 agreed to participate in the content evaluation and approval took place in the fourth step of the Delphi methodology. The 30 statements initially developed were corrected and reformulated, leaving 24 items in the final version. 71 students answered the PalliComp and a validation statistical study showed that it was an identity matrix with adequate correlation (Bartlett test $p < 0.001$), relatively compact and little dispersed correlation patterns (KMO = 0.63), and internal consistency (Cronbach's alpha coefficient = 0.73).

Conclusions: It was possible to develop and validate the PalliComp instrument to assess the acquisition of PC competencies among medical students.

P 5.004 The Last Aid Course as Approach for Public Palliative Care Education (PPCE) – From Idea to Practice in 20 Countries Worldwide

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Background/aims: The idea to introduce Last Aid courses for the public has been first described in 2008. In 2015 Last Aid courses have been started in Norway, Germany and Denmark to teach the public about palliative care and to stimulate the public discussion about death and dying. At present the International Last Aid working group includes members from 20 countries including Brazil, Canada and Australia. The aim of this presentation is to provide an overview of the evolution of the Last Aid Movement and the existing scientific evaluation of the effects of Last Aid courses as model for an easy to scale approach to Public Palliative Care Education (PPCE).

Methods: Last Aid courses have already been established in 20 countries. Research has been an integral part of the implementation process since 2015. An overview of the existing literature on Last Aid courses is provided. In addition a summary of the experiences from the implementation process of Last Aid courses in different countries will be provided.

Results: Since the start of implementing Last Aid Courses in 2015 a number of scientific papers and studies on the effects and implementation of Last Aid courses have been published. The overall results show that Last Aid courses are feasible and well accepted by the participants in different countries. In Germany there are already 4000 Last Aid course instructors and 50000 citizens have participated in Last Aid courses. Both adults and children (from the age of 8) appreciate the possibility to talk about death and dying and to learn end-of-life care. The experiences from implementation in different countries have shown that the Last Aid course is transferable to different nations and cultures.

Conclusions: People from different countries appreciate Last Aid courses and like to talk about death and dying. Many people feel encouraged to talk about death and to participate in end-of-life care. This contributes to the aims suggested by the Lancet Commission on the value of death to bring death back into life.

Conflict of interest: G.B. is the leader of Last Aid International, holds a trademark for Last Aid, and receives financial compensation for Last Aid instructor courses. He is one of the chairs of the Last Aid Research Group International (LARGI).

P 5.005 Competencies Required from a Physician in Palliative Care - The View of Physicians

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Background/aims: The need to ensure proper competence of palliative care to physicians in undergraduate and specialist education is recognized. The aim of this study was to describe physician's palliative care competence areas in basic and specialized level in health care.

Methods: The data was collected with an electronic questionnaire containing open questions (n=20) from palliative care physicians (n=64). The physicians answered the question "What should physicians know about the following areas" in 10 different categories. The data was analyzed with inductive content analysis.

Results: The questions and results are presented in Table 1. The most important results were ethics, interaction and multiprofessionalism. Ethics consists of theoretical competence, human-oriented ethical activity and sensitive ethical competence. Interaction competence consists of theoretical competence in interactions, in addition to interaction and encountering with patient and their loved ones and working community. Multiprofessionalism consists of recognizing the need of multiprofessionalism, competence in teamwork and planning and organization of palliative care.

Table 1. Questions and categories.

Questions	Categories
Goals of care and advanced care planning	Theoretical competence of goals of care and advanced care planning Comprehensive competence of palliative care and end of life care
Pain management	Theoretical competence of pain management Comprehensive expertise in pain management
Treatment of the other symptoms	Theoretical competence of treatment of the other symptoms Comprehensive competence of symptom management
Psychosocial support	Comprehensive competence of psychosocial support
Existential aspects	Comprehensive competence of existential aspects
Interaction competence	Interaction skills Encounter skills Skills to interact in a working community Theoretical competence of interaction
Ethics	Theoretical competence of ethics Person-oriented ethical action Sensitivity as part of ethical competence
Multiprofessionalism	Multiprofessional competence in teamwork Competence of teamwork Planning and organization of palliative care
End-of-life care	Versatile expertise in pharmacological treatment in end-of-life care Expertise in person-oriented end of life care
Other questions at basic and specialized level	Development of palliative care Work well-being skills

Conclusions: The study provides guidance to improve students' curriculum. The results demonstrate the importance of multiprofessionalism, ethics and interaction competence in palliative medicine. Reaching excellence in palliative medicine needs evidence-based practice and strong leadership to implement palliative competences into integrated palliative care programs and services.

P 5.006 Palliative Care Goes to School – Results from a Project for Upper School Classes in Vorarlberg

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Background/aims: To find out about the attitude of young people towards Palliative Care and Euthanasia a survey was conducted among upper class pupils in Vorarlberg. The school visit of a multiprofessional palliative care team was evaluated through a questionnaire.

By arousing interest for palliative care work, pupils should experience that assisted suicide is not the only answer to severe illness. The insight into the daily work of a palliative care nurse or a physician might influence the perception about Palliative care.

Methods: A questionnaire was filled out a week before (T0) and a week after (T1) the school visit of a palliative care team. The evaluation of the survey (partly questions that allowed personal comments, partly those with a rating scale) was done by the University of applied sciences Vorarlberg.

Results: A total number of 460 T0 and 453 T1 sheets were completed. The age of the pupils ranged from 14 – 20 years. 63,5 % (292) had experienced death and severe illness in their private environment. (T0) The question „Everybody should have the right to commit assisted suicide“ was rated by 53% (190) students with „true“ und „very true“ in the T0 questionnaire. After the school visit this number reduced to 45 % (159) The main associations with Palliative Care work before the lecture were „death and dying“ (77%), symptom control (60,4 %), hope (38,5 %), very serious topic (37,4%) and anxiety (35,4%)

After the visit symptom control (74,8 %) and „death and dying“ were still the most frequent comments, but positive associations followed close to it: „hope“ (68,4%), „humor“ (48,6%) and fulfilling work“ (37,3%). The difference was statistically significant ($p < 0.001$).

Conclusions: An introduction into practical palliative care work showed a change in the attitude towards assisted suicide. The terms associated with Palliative Care modified after the visit: much more positive expressions like „hope“, „humor“ or „fulfilling life“ were mentioned.

P 5.007 The Care for People Who Are Ready to Die. What Competencies Do Nurses Need?

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Background/aims: A number of countries are in the process of legalising hastened death. The documents deal with the role of doctors; the role of nurses is mostly left out or inadequately regulated. The topic of hastened death is not addressed in nursing curricula. Nurses are therefore not prepared for this role either in training or in continuing education. This unpreparedness can confront nurses with ethical and moral challenges that they may find difficult to overcome. The aim of this study was to find out which competences nursing staff need in order to be able to professionally accompany people who are willing to die without getting into an ethical or moral dilemma themselves.

Methods: A qualitative systematic review was conducted. From July 2021 to April 2022 the literature search was conducted in five databases: CINAHL, LIVIVO, Medline via PubMed, OVID, Web of Science. Two researchers screened the hits for suitability and assessed the quality using the JBI Critical Appraisal Checklist for Qualitative Research. Data analysis was carried out using deductive content analysis. The results were classified into three predefined categories: professional competencies, social competencies, and personal competencies.

Results: The professional nursing competencies required range from understanding suffering to post-mortem activities. On the social level, nurses need to be able to create a communicative atmosphere and build a relationship with the person who is willing to die and their family. On the personal level, nurses must learn to respect the person's wishes and reflect on their own attitudes towards dying and death.

Conclusions: Nurses need high quality training in caring for people who are willing to die. The findings of this study can serve as a basis for the development of a module for the nursing curriculum. Due to the great importance of the interpersonal component, teaching methods such as research-based theatre appear to be purposeful.

P 5.008 Unintended Outcomes from Face-to-Face Palliative Care Education: Can We Justify Face-to-Face Learning in a Post-pandemic World?

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Background/aims: Face-to-face learning at the start of a Masters course in palliative care recommenced in 2022 after two years of virtual learning due to COVID-19. Previous evaluation demonstrated that 86.4% of learners had reported in 2021 that the use of technology and the virtual learning environment had no adverse impact on their learning. Recognising wider opportunities for exploring the justification of face-to-face learning, we explored the opinions of learners on their experiences of unintended outcomes (learning or experiences gained that were not intentionally delivered by the educator) from the reinstated face-to-face sessions in 2022.

Methods: Prospective qualitative evaluation with thematic analysis of the free text data collected.

Results: 23 sessions formed a 5 day programme delivered face-to-face in 2022. 100 evaluation responses were received (response rate 24%). Five themes were identified from the free text data that categorised the learners' opinions on unintended outcomes gained from the sessions: sharing knowledge between peers, personal reflection, skills, networking and support. Multiple impactful statements on the experience of face-to-face learning were identified from the evaluation: „Connection with others“; „invaluable experiences“; „it felt more natural“. The benefits of face-to-face teaching were expressed spontaneously 12 times. 1 comment suggesting the teaching may have worked virtually.

Conclusions: These findings confirm that the benefit of face-to-face learning extends beyond that of the content delivered by the educator. As palliative care is rebuilding post pandemic, the need for education remains a priority, but the need for peer learning and networking is also valuable. Whilst virtual learning is now a credible form of delivery, this finding supports the need for face-to-face palliative care education in a post-pandemic world.

P 5.009 Evaluation of a Palliative Care Program in Nursing Homes

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Background/aims: Studies have shown that nursing home (NH) residents have a high prevalence of end-of-life (EOL) symptoms & unmet palliative needs. Whilst services have been developed to improve palliative care delivery to NH residents, the quality of EOL care & quality of death have yet to be evaluated. A service in Singapore, GeriCare, provides both geriatric & palliative care to NH residents through educational & clinical partnership. This study aims to compare the quality of death of NH residents who died in NHs under the GeriCare program compared to those who died in acute hospitals.

Methods: A descriptive study to evaluate the quality of death in 217 residents from 6 NHs over 2 years from 2020-21, after the implementation of a comprehensive palliative care training program. All patients enrolled under the GeriCare service underwent a death quality audit as part of a mortality review. The quality of death was assessed based on 4 domains-symptom control, anticipatory prescribing of EOL drugs, family preparedness for patient's demise & advanced care plan (ACP) concordance.

Results: 62% of deaths occurred in NHs. Whilst symptoms of pain & dyspnea were well controlled in both groups, rates of anticipatory prescribing of EOL drugs were higher for residents who died in NHs (92% vs. 29% for opioids, 92% vs. 25% for anti-secretory drugs and 91% vs. 18% for anti-psychotic drugs). Family preparedness was higher in deaths that occurred in NHs compared to acute hospitals (98% vs 93%). With regards to ACP concordance, more residents who died in NHs had their preferences for place of care (100% vs. 87%) & place of death (100% vs. 20%) honoured compared to those who died in acute hospitals.

Conclusions: This study shows that whilst symptom control was equally good for residents who died in NHs compared to acute hospitals, families were better prepared & more patients' preferences were honoured for those who died in NHs. These results highlight the importance of supporting NHs with a comprehensive palliative care program.

P 5.010 Creation and Development of an International Research Network: The End of Life and Palliative Care in the ICU Research Network (EPCIN)

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Background/aims: Sharing ideas, lessons, and experimental approaches are integral to research. Co-ordination of research efforts maximises use of resources whilst minimising research waste. We therefore aimed to establish an 'End-of-Life and Palliative Care in the Intensive Care Unit' Research Network (EPCIN) to provide a forum for professionals working in intensive care or palliative and end-of-life care. EPCIN aims to encourage and organise networking events, develop a research repository, facilitate collaboration, share knowledge of best practice, and provide mentor/mentee/peer support.

Methods: The following methods were adopted: 1) scoping the need, 2) identifying pre-existing networks, 3) inviting co-chairs, 4) designing materials, and 5) establishing communication pathways 6) planning and executing a seminar programme.

Results: No existing similar network was found. Two co-chairs with ICU nursing and research expertise in the field were recruited. Communications were established using Canva to create branded EPCIN adverts shared on Twitter and word of mouth. For seminars, researchers in the field were approached to present their work online followed by audience discussion. Seminars have covered: an introduction to the network and aims, information for patients and families at end of life in the ICU, palliative care interventions on the ICU, and ethics surrounding palliative care in the ICU. Presenters have included doctors, nurses, and the patient charity ICU steps. The EPCIN has 323 international members and continues to grow. Attendees recognised the important role of networking and commented that the meetings were enjoyable, stimulating, and inspiring.

Conclusions: Creating a new research network was feasible with co-chair support, knowledge of using Canva and other software, and advertisements through Twitter. The EPCIN has been well received and is fulfilling its aims at this early stage. Information on joining is on the network Twitter page @EPCINetwork.

P 5.012 Co-design and Evaluation of a Postgraduate Taught Programme to Build an International Workforce of Palliative Care Leaders

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Background/aims: In 2015, nearly 25 million people died with serious health-related suffering, with 80% in low- and middle-income countries. Palliative care reduces suffering and is affordable, but access is poor to co-design and evaluate refinements to an MSc programme (hereafter Programme) to maximise its access and develop its content to build a future workforce of global palliative care leaders.

Methods: Phase 1: International online co-design workshops with educators, and past and present students (i.e. stakeholders); qualitative interviews with purposively sampled stakeholders. Phase 2: Student survey to determine learning objectives and preferences, career plans, and confidence to study. Educator surveys to determine confidence in distance learning and international teaching. Data were analysed thematically and using descriptive statistics. Findings informed refinements to Programme, and its evaluation.

Results: Two workshops with 30 and 15 participants respectively, 5 semi-structured interviews, and online surveys with students (n=9) and educators (n=33). Workshop and interview themes were: (1) international

networks including collaborations with peers, alumni and leaders, (2) leadership skills to advocate for policy change and develop services, (3) international lecturers, (4) flexible models of learning. Survey results supported these findings with reasons for enrolling including progressing the field of palliative care (89%), developing and leading services (78%), and developing leadership skills (67%). 67% of students preferred the flexibility of both online and classroom learning.

Conclusions: Changes to the Programme include transition to hybrid delivery to accommodate learning requirements and professional commitments; a change of Programme timings to improve access to training opportunities; annual student seminar to provide networking and project dissemination opportunities, and development of guidance on teaching content, assessment, and delivery.

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P 5.013 Can a Short Video-intervention Increase Knowledge and Readiness for Advance Care Planning? An Experimental Study with Cancer Patients

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Background/aims: Advance Care Planning (ACP) can improve the autonomy and quality of life at the end of life. Engaging in ACP-activities is particularly relevant in populations with severe illnesses such as cancer. Still, ACP is not widely used in Germany. One hindering factor is the lack of knowledge about ACP and its possible benefits. The aim of this study is to investigate the effect of a short educational video intervention on knowledge about ACP and readiness to engage in ACP-related activities in a cancer affected population.

Methods: In an experimental online design 103 cancer patients (male 57.3%, mean age 65.5 years) were randomly assigned to the intervention group (video about ACP) or an active control group (video about chronic back pain). Central outcomes were knowledge about ACP and readiness for ACP. These were assessed pre- and post-intervention via patient reported outcomes and an additional behavioural measure for readiness (download-option for an ACP guideline). Furthermore, the ACP-video was evaluated regarding comprehensibility and perceived utility.

Results: Preliminary results show that there was a greater increase in ACP-knowledge in the intervention group than in the control group ($F[1, 101]=10.92$, $p=.001$, partial $\eta^2=.098$) as well as in readiness ($F[2, 100]=3.51$, $p=.034$, partial $\eta^2 = .066$). This could also be seen in the behavioural outcome, where 82% of the participants in the intervention group were interested in obtaining the ACP-guidelines ($\chi^2(1)=17.75$, $p<.001$, $\phi=.42$). The educational video was rated as helpful and easy to understand.

Conclusions: Short video-based interventions can enhance the knowledge about ACP and increase the readiness for it and seem to be well received by cancer patients. It seems promising to implement educational videos about ACP in clinical structures to help patients getting informed in order to reach a decision whether they want to communicate their future health care decisions and if so, which steps to take. The study was funded by the German Cancer Aid.

P 5.014 Going Digital – Informing the Creation of a Novel, Online, Scalable, Evidence-informed Serious Illness Communication Teaching Tool to Standardize Teaching and Consolidate Learning

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Background/aims: Goals of Care (GOC) and Advance Care Planning (ACP) conversations are essential to meet the needs of seriously ill people, but most clinicians receive little or no training on these skills and no global standard exists to teach them. We explored the current GOC/ACP teaching in Canada's largest Family Medicine (FM) training program to assess resident and faculty experiences with teaching and feedback methods in order to inform curriculum reform.

Methods: An online survey was emailed to all graduating FM residents between May 1 and May 30, 2020. Resident and faculty focus groups (FG) and one-on-one interviews were conducted using purposeful sampling. Descriptive thematic analysis was used to gain a deeper understanding of preferences and needs for teaching and learning.

Results: Survey completion rate was 60% (93/155) with 100% (14/14) of training sites participating. Most residents preferred using a structured approach to learn how to lead GOC/ACP conversations and preferred direct observation and feedback to develop skills. However, most were not taught using this approach. Thematic analysis from four FGs and four 1:1 interviews with faculty and residents highlighted a preference for: structured, time-efficient, evidence-based training and teaching approaches; opportunities to consolidate and teach skills longitudinally; different approaches for teaching core versus advanced skills, and a need for psychological safety to inform teaching methods.

Conclusions: Residents and faculty value using a standardized, evidence-informed, and longitudinal approach to teach and practice GOC/ACP conversation skills. These data will be used to create and evaluate an asynchronous online learning module that could be part of any institution's core curriculum. It will introduce foundational skills that may better prepare trainees to deliberately practice and consolidate needed communication skills, and offer clinician teachers an approach to assessing high-yield skills.

P 5.015 Help your Patient Out of the Closet before the Coffin!

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Background/aims: The situation for lgbtqi people is still far from equal and in some parts of the world it gets worse. Many have negative experiences from both non-accepting family and previous caregivers. Minority stress is high, and many avoid getting help as long as they can. Don't expect everyone you care for to be like the majority. This presentation will give advice to caring personnel.

Methods: The presentation is built on extensive review of literature, associations work and participating observations.

Results: Include LGBTQI-persons into a caring palliative setting through conscious choices of words and by understanding the special circumstance in their situation. Pro-active symbols, like the pride flag next to your nametag signals your knowledge about minority issues. A nametag has a status and by showing you are an ally; it will help both the patient and their close ones. Inclusive language and choice of words that don't exclude partners and chosen family members will open up for varied and a close caring setting around the patient. Use words like partner, parent, they/them and have more than just two genders as a choice. What norms are you upholding? Is the care setting heteronormative? Are all bodies, genders and sexualities welcome and represented in the art, brochures and informative posters? Are transgender people or same-sex relationships welcome? Do you have to ask for the sex in your research or pamphlets? Could you include more genders even if the law doesn't recognize more than two? "Other" and non-binary are examples of more inclusive genders.

Conclusions: Create a safe space where the patient and chosen family can be themselves and process their past negative experiences. The

pride symbol can open up conversations about relatives who are LGBTQI and no longer part of the patient's family. A caring conversation can lessen feelings of guilt and shame. Help your patient with flying (pride) colours.

P 5.016 Online Learning about Death, Dying and Grief: OpenLearn Resources and Free Education

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Background/aims: The Death Awareness Movement and Death Education promote the notion of raising awareness about death, dying and grief amongst the general public. At The Open University (OU), modules on death and dying have been consistently popular with students for over two decades, although enrolment has been impacted by UK increases in tuition fees. The Open University has a commitment to providing free educational resources drawing on its expertise via OpenLearn. Open Thanatology at the OU curate a collection of free death-related materials on this platform to enable public education about palliative care, death, dying and grief.

Methods: On the OpenLearn platform, we create and provide free open educational resources informed by learning design based on Open University research and curriculum. These include short articles, animations, videos, interactives, and short courses. The latter are often developed from our university-level modules on death, dying and bereavement. Items are curated on the Open Thanatology Hub to enable people to search by topic and type of learning. Videos and animations are also shared via YouTube and social media. Items have creative commons licences and can be re-used.

Results: As a platform, OpenLearn has over 16 million visits annually. The introductory course on death, dying and bereavement had over 16,000 unique visits in 2021-2022 with over 4,000 completing the course; 20% of visitors clicked to learn more about studying at university level (click-through rate). Animations and interactives received between 300-1000 visitors during that year (click-through rates between 13-20%). Three core interactives attracted over 10,000 learners between 2018-2021.

Conclusions: It is possible to create free educational resources about death that can reach wide adult audiences and can attract them to study these topics at university level. Typical website data metrics currently does not provide enough information about how learning about death impact thoughts and behaviours.

P 5.020 The O2PZ Programme: Optimizing Palliative Care Education in the Netherlands

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Background/aims: Palliative care is not yet adequately addressed in education and training for healthcare professionals in the Netherlands. This pertains to all levels of education. Over the last five years, the O2PZ programme, a consortium of educators, healthcare practitioners and researchers, has accomplished substantial improvements by means of a series of interconnected projects focused on developing, implementing and consolidating frameworks and tools for good palliative care education nationwide.

Aim: To improve palliative care education in the Netherlands in such a way that every healthcare provider has the right competencies to provide high-quality palliative care.

Results & output O2PZ 2018-2022	Description
Palliative Care Education Framework	Describes competencies of both PC generalists and specialists on all professional/educational levels. The framework is (being) implemented in the curricula of 17 applied universities, 8 universities, 35 vocational education institutions.
Palliative Care Education Hubs	Network of 7 regional PC Education Hubs and 1 national Hub, 1 Hub on pediatric palliative care. Covers the entire Netherlands. Led by 22 ambassadors. The hubs implement innovations, developments and activities in PC education provision in their region.
Education platform, presenting 1-4	Online platform to disseminate materials to improve PC education.
Interprofessional collaboration model	Describes how professionals can collaborate in good PC provision
Toolbox educational materials	
Catalogue of continuing education & training	
Competency scan	Self-assessment for professionals
Screening committee	Screens education materials for quality control. Consists of 8 experts that represent all educational levels.
Vocational training – elective courses PC	Scope: for all vocational training institutions. Courses cover 10 themes corresponding with 10 domains of Quality Framework for PC (Boddaert, 2022).

Methods: Several interconnected projects and studies were conducted: (1) knowledge synthesis on palliative care education in the Netherlands, (2) participatory development of (a) an education framework (incl. scoping review, surveys, modified Delphi study), (b) an online education platform including education materials and tools and (c) education hubs (3) participatory implementation of PC education within vocational training, applied universities, and medicine curricula in all regions of the Netherlands.

Conclusions: Discussion: Challenges, lessons learned and recommendations will be discussed with regard to optimizing PC education nationwide, which may be useful to others who seek to improve palliative care education. The O2PZ programme receives governmental funding by ZonMw.

P 5.021 Postgraduate Nursing Students' Experiences with Simulation-based Learning in Palliative Care Education

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Background/aims: Palliative care requires advanced nursing competence, but educational variations exist, and clinical placement opportunities are limited. Students can develop clinical skills, increase their knowledge, critical thinking, and confidence through participating in simulation-based learning (SBL). However, postgraduate nursing students may have other learning needs regarding SBL than undergraduate students. No studies have explored postgraduate nursing students' experiences with SBL in palliative care education. The aim of this study was to explore postgraduate nursing students' experiences with SBL in postgraduate palliative care education.

Methods: An exploratory and descriptive design using qualitative method. The study participants attended two palliative care SBL sessions. Further they participated in three focus group interviews (FG1, n=3; FG2, n=3; FG3, n=5) and reflective notes from participants were reported (n=8). The data was analysed using systematic text condensation.

Results: The postgraduate nursing students had limited previous experiences with SBL which affected them in the SBL. The preliminary themes consist of three different tensions; between the desire to feel confident in the SBL-setting and the need to be challenged; between relying on existing professional experience and being open to the possibilities of acquiring new knowledge; and between expectations regarding the SBL and what they experienced in reality.

Conclusions: Preliminary themes and results from the analyses in progress indicate that postgraduate nursing students need clear information about preparations and what is required ahead of the SBL in palliative care education. A learning environment characterized by feeling safe and mutual learning is of great importance for this group of adult students. Participants see opportunities for SBL as a recurring learning activity throughout the palliative care education.

P 5.022 "Morphine? Respiratory Depression. Morphine Addiction." It's Like a Brick Wall.' Views and Experiences of Opioid Access amongst Clinicians and Public Representatives in Two States in India

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Background/aims: Increasing equity of access to opioids for cancer-related pain is a key challenge for the achievement of universal health coverage globally. We aimed to explore views and experiences of palliative care providers and public-involvement representatives about opioid analgesia access in two South Indian States with differing service availability.

Methods: Virtual qualitative interviews with a purposive sample of palliative care providers and public-involvement representatives from Kerala and Karnataka. Transcribed audio-recordings were subjected to thematic analysis.

Results: Twenty interviews were conducted (doctors (10), nurses (4), pharmacists (2), service managers (2) and public representatives (2)). Three themes were identified. 1) Attitudes and awareness: opioids treatments are perceived as end-of-life (last days/weeks) interventions; fears of addiction and misunderstanding of goals of pain management limit access. 2) Expected and unexpected inequities: patients/carers from lower socioeconomic strata accept doctor recommendations if opioids are affordable; more educated patients/families have reservations about taking opioids, delay access and perceive expensive medicines as better. Non-palliative care specialist doctors have negative entrenched views of opioids and require specialist training. 3) Experiential learning – exposure to benefits of opioid analgesia can positively alter attitudes, but may reinforce perceptions of opioid treatment as end-of-life care. Kerala participants report improved attitudes, awareness and understanding of opioid treatments, influenced by exposure and community awareness.

Conclusions: Attitudes to opioids influence access to analgesia. Negative views are entrenched and are reinforced by negative experiences, positive experiences improve attitudes. To promote appropriate exposure and positive experiences, opioid prescribing must be needs-based and not linked to prognosis.

P 5.023 Invasive Measures at End of Life: Why Don't I Want them for myself but Would Recommend them to my Patients?

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Background/aims: Palliative care becomes more important as the disease evolves, and is a necessity at the moment when there is no longer any perspective of a cure. The difficulty of health professionals in using a humanized approach in patients with incurable chronic diseases has caused the prolongation of suffering and death. Thus, the use of invasive measures, unnecessarily, in patients with conditions that have no possibility of cure or that are a threat to the continuity of life, prevents the guarantee of quality, comfort, and dignity in the dying process.

Methods: A cross-sectional and descriptive study was conducted to compare the use of futile invasive measures in patients at the end of life and the preference of healthcare professionals for these measures. The knowledge of medical specialists about palliative care was evaluated in an anonymous questionnaire with two clinical cases of hypothetical patients addressing palliative care assistance. In parallel, the same professionals received a new hypothetical clinical case through Google Forms in which they were the patients in the dying process.

Results: The physicians indicated intensive care unit (ICU) and cardiopulmonary resuscitation as the highest rate of indication for invasive measures (48.4%), followed by nutrition (45.2%) and venous access (32.3%). Regarding personal preferences for their active dying process, 80% would not want artificial feeding, 93.3% would not want cardiopulmonary resuscitation, and would not want to be admitted to an ICU. It is important to emphasize that the interviewees preferred non-invasive procedures for their end-of-life, but indicated these measures for their patients.

Conclusions: The gaps in the academic training of medical professionals and issues related to defensive medicine, such as the fear of lawsuits, may be responsible for the physician indicating unnecessary invasive measures. Thus, further studies should be conducted to understand the reasons for this situation.

P 5.024 Palliative Competencies among Medical Students in Brazil

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Background/aims: Teaching Palliative Care (PC) is important to future doctors to acquire the competence to offer the PC approach to patients. This study is based on the Palliative Competence Tool (PalliComp), a Portuguese-validated tool, developed from the competencies proposed by the European Association for Palliative Care. This study aimed to evaluate the medical student's competencies in PC at four medical universities in a Brazilian city.

Methods: After ethical approval, all medical students were invited to participate in the research. Each participant answered an electronic form containing demographic data and the PalliComp. Performance was then transformed into scores (between 0-100), which were grouped according to academic cycles (basic, clinical, and internship). Mean scores per cycle were studied by analysis of variance (ANOVA) and the Tukey test. A statistical significance level of 0.05 was adopted.

Results: 435 students participated, with a mean age of 23.6 ± 3.5 years, 63.0% women and 37.0% men, of those, 29.2% attended the basic cycle, 51.3% to the clinical, and 19.5% to the internship. Were enrolled in university A 61.1% of the students, in B 22.8%, in C 8.5%, and in D 7.6%. The

average PalliComp scores of students in the basic cycle were 32.9 ± 8.9 , in clinical 28.2 ± 8.6 , and in internship 24.5 ± 9.8 ($p < 0.001$). In universities A and B, which consisted of 83.9% of the sample, there was a decrease in the average scores according to the cycle progression (A: $32,3 \pm 9,2$; $28,4 \pm 7,9$; $25,1 \pm 10,9$. B: $34,2 \pm 8,5$; $27,1 \pm 10,7$; $23,0 \pm 7,2$. $P < 0.001$ for both).

Conclusions: Acquiring competencies is more than attending courses or internships. It is about adequate knowledge, training abilities, and attitudes expected of future physicians. Surprisingly, the students showed a decrease in the PalliComp scores according to the cycle progression. It is probable that inadequate concepts of PC were passed by during the course, which, unfortunately, is observed in Brazil.

P 5.025 Advance Care Planning Training for Generalist Health Care Staff: Developing and Evaluating a Novel Online Resource

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Background/aims: Through advance care planning (ACP) health care staff can discuss end-of-life care with people to help them plan and share preferences. However, many health care staff do not feel confident having these discussions, and there is little online training in ACP for general health care and ambulance staff to improve their skills and confidence. To develop online ACP training for health care and ambulance staff.

Methods: Stakeholder workshops (health care and ambulance staff and members of the public with an interest in end-of-life care) explored which factors would be useful in ACP training. Recommendations enabled adaptation and co-production of an online ACP training package for healthcare staff. The training was evaluated with a short questionnaire.

Results: Five workshops were held with 22 participants in 2021. ACP training was needed that addressed timing of ACP discussions; skills and confidence for having these discussions; cultural and family sensitivity in ACP and managing end-of-life care preferences in emergency situations. The training has been completed by staff from community (33%), hospital, and ambulance services (38%), 43% nurses, 48% allied health professionals, with only 9% previously regularly conducting ACP discussions. 95% agreed it covered all key areas of ACP, and 91% that it gave them useful information on talking to patients about ACP, and 86% intending to use it in their future practice. Comments included; 'An excellent resource that I will go back to time and time again to support my practice', and 'refreshing to have the person in the centre throughout with a desire to find out what matters most to them, rather than a health care management plan/hospital avoidance plan which is often badged under ACP'.

Conclusions: Working together with health care and public stakeholders enabled the development of easily accessible online ACP training which addresses the issues and topics considered central to successful ACP by health care staff and members of the public.

P 5.026 Evaluating the Usefulness of the Graphic Novel Vivian, about Gender and Palliative Care, from the Perceptions of Swedish, English and Aotearoa New Zealand Student Nurses

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Background/aims: The World Health Organisation has identified that with ageing populations on the rise improving palliative care through education is a global priority. One means for achieving this is through the use of the creative arts to promote new discussions about the social determinants of end of life care. The graphic novel *Vivian* was created to raise awareness of gender and palliative care. The aim of this project is to explore undergraduate student nurses' views regarding the usefulness of *Vivian* as a teaching tool about gender and palliative care in undergraduate nursing curricula in Aotearoa New Zealand, England, and Sweden.

Methods: Focus groups (either in-person or online) were held with 2nd and 3rd year nursing students in the three countries. Data were jointly analysed by the cross-national project team, using thematic analysis.

Results: Student nurses in the three different cultural contexts felt that *Vivian*, and other graphic novels, could be useful additions to the undergraduate nursing curriculum. The combination of images and text were seen as more engaging than text-based instruction alone. The images also prompted a critical, empathetic reflection on the content. They humanised the story, thereby aiding comprehension and recall about the issues related to gender and palliative care. More attention to the storyline in future graphic novels could help with reader engagement.

Conclusions: Arguments for using the arts to represent research include their ability to foster a deep engagement with audiences as well as their potential for conveying alternative forms of knowledge beyond information transfer. In this sense, *Vivian* speaks to the potential of graphic novels to provide a means for engaging with undergraduate nursing students about topics of importance to the palliative and end of life care curriculum. They offer an alternative to heavily text-driven resources. The project was funded by the U21 Health Sciences Research Fund.

P 5.027 Palliative Care in Sparsely Populated Rural Areas - Collaboration between District Nurses and Doctors

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Background/aims: Palliative care requires major nursing interventions as well as medical interventions, thus the district nurse and the doctor are both central to the palliative team. Sparsely populated rural areas are characterized by large geographic distances and can mean that the different professionals are located a long way from each other, which can pose a challenge to collaboration. The aim of this study was to describe district nurses' experiences of collaborating with the doctor in charge during palliative home care in sparsely populated rural areas.

Methods: Semi-structured interviews were carried out with ten district nurses. The material was analyzed using inductive content analysis.

Results: The experiences of the district nurses are described under the overarching theme of *Experiences of acting as the patient advocate*, which is divided into two categories. The category *Positive experiences of collaboration* generated the sub-categories *Pride, Confidence, Support and Mutuality*. The category *Negative experiences of collaboration* generated the sub-categories *Inadequacy, Frustration and Shortage of time*. Consensus and coherence, or lack thereof, between district nurses and doctors affects how collaboration is experienced. When the doctor shares the district nurse's holistic approach this generates positive experiences, while collaboration is experienced as negative when the doctor does not make decisions in accordance with what the nurse judges to be beneficial to the patient.

Conclusions: These experiences are probably not unique to this situation and can possibly explain the interprofessional collaboration in other contexts involving interaction between the nursing and the medical professions. An understanding of how collaboration is

experienced is necessary to bring about enhanced collaboration, thus an equivalent analysis of doctors' experiences is therefore suggested for future research.

P 5.028 Palliative Emergency: A Questionnaire to Measure Palliative Attitude and Palliative Knowledge of Emergency Physicians

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Background/aims: Emergency services often are involved in end-of-life care at home. Here, appropriate medical and psychosocial care is called for. In this context the hypothetical construct "palliative attitude" is commonly used although there is no definition offered. The aim was to develop a questionnaire to measure emergency physician's palliative attitude and knowledge in a quantifiable way of measurement.

Methods: A standardised questionnaire was developed based on a literature review and 3 questionnaires, reviewed by a panel of experts and piloted on a group of experienced emergency and palliative care physicians. The questionnaire was presented to physicians at an emergency medical training course after an intervention designed as a teaching lesson in Palliative Care. The survey was performed in a post-then design. The data were analysed using SPSS and R. The significance level was set to 0.05.

Results: A 37-item questionnaire was developed to measure palliative attitude and knowledge in emergency physicians. The questionnaire uses a 6-point Likert scale. A survey was performed on 549 emergency physicians in training with a response rate of 72% (n = 397). An exploratory factor analysis (EFA) showed 4 underlying factors that contribute to palliative attitude: dealing with death and dying, (self-) reflection, cooperation and patient-centred decision making. Cronbach's alpha for the factor subscales range from 0.31 to 0.67. t-Tests showed a significant improvement of self-assessed attitude during the teaching lesson.

Conclusions: We developed a standardised questionnaire to measure palliative attitude and knowledge in emergency physicians. Extensive discussions of the expert panel ensured that all relevant topics have been included. The results of the EFA show construct validity and identified 4 factors contributing to palliative attitude. Criterion validity is shown by the significant improvement during the teaching intervention. The questionnaire may be useful for course evaluation in Palliative Care.

P 5.029 Palliative Care Competencies Required of Undergraduate Nurses – An International Nominal Group Technique Study

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Background/aims: The ageing population and the increasing amount of people with non-communicable diseases increases the need for palliative care. The need for nurses to have appropriate skills in palliative care is of great importance. Prior to the development of training programmes,

the palliative care core competencies for European undergraduate nursing training need to be defined based on research. The aim of the study was to define the most important palliative care core competencies that European nurses need to provide quality palliative care.

Methods: Nominal Group Online Inquiries (NGT) were organised in 4 European countries. The research question asked was: What are the most important palliative care core competencies in undergraduate nursing bachelor's degree programmes? The entire qualitative data and top ten lists obtained in the NGT survey of different countries were analysed through a thematic analysis.

Results: A targeted group (n=35) of professionals attended the NGT sessions. In order to ensure the highest possible degree of comparability for the nominal group surveys, the participants in all NGTs had similar contextual and professional backgrounds. Thematic analysis of the top ten lists of NGT groups identified 10 common themes. All groups contributed holistic symptom management skills and communication skills in palliative care. Most issues were raised by at least two different countries. Based on the overall qualitative data, 11 analytical themes and 41 sub-themes emerged based on the data. The palliative care competence required of graduates is a combination of themes as symptom management, cultural sensitivity, empathy and knowledge of ethical and legal aspects.

Conclusions: Undergraduate nurses require a variety of different competencies to ensure quality palliative care for patients. The core competencies can be used in the development of the nursing curriculum and various teaching methods.

P 5.030 Fast-tracking Strategic Advocacy for the Inclusion of Palliative Care in Universal Health Coverage to Ensure Equity in Uganda

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Background/aims: Universal health coverage (UHC) means that all people have access to the health services they need, when and where they need them, without financial hardship. Palliative care in Uganda is offered at private facilities and at only 4.8% of the public hospitals in the country (Health Sector Development Plan 2015/16 – 2019/20)

The Lancet Commission 2018 states that only 11% of those who need pain control and palliative care access it in Uganda. Palliative care has been left out in UHC processes the project aimed at advocating inclusion of palliative care in UHC processes in Uganda by increasing number of actors integrating palliative care work in their programming.

Methods: Palliative Care Association of Uganda (PCAU) developed an investment case, and aligned it with the Essential palliative care package. This was done through sharing compelling stories. A stake holder analysis done, Ministry of Health engaged to map out allies and key players involved in UHC work in Uganda. PCAU identified, mobilized and engaged partners, patients and care givers at workshops held to educate them on the UHC package and equip them with skills in advocacy.

Results: Launch of the Essential palliative care package for UHC in Uganda derived from the African package. It has 4 components; essential palliative care medicines, essential equipment, patient supportive devices, technologies and supplies, Human resources and psychosocial interventions. Continuous engagement with media to build evidence for palliative care through collecting stories from direct beneficiaries. Empowered direct stakeholders (palliative care patients, service providers and care givers) to lead advocacy for palliative care services. Developed a database of key players and partners for continuous engagement.

Conclusions: Patients and caregivers are key in advocacy for palliative care as witnessed from one of the beneficiaries. Universal Health Coverage can't be achieved without equitable palliative care, and its inclusion has to be part of a national effort.

P 5.031 Handling the Wish to Hasten Death – An Elective Course for Medical Students

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Background/aims: The prevalence of the wish to hasten death among palliative patients (WHD) is between 8 and 22 %. Understanding the complex background containing reasons, functions and meanings that can lead to a WHD can help future physicians to deal with affected patients and their relatives. Therefore, medical students were offered an elective course to enhance their knowledge and skills and to reflect on their own attitudes. The aim was to evaluate an elective course for medical students in relation to didactics, personal attitudes and learning gains.

Methods: Online evaluation of the course and questions on attitudes were collected using a five-point Likert scale. Learning gain was calculated using the Comparative Self-Assessment (CSA) Gain.

Results: Participant (n=13, response rate=86.7%) satisfaction with the course was 100%. The increase in knowledge and skills training, e.g. through simulated conversations, gave participants confidence (100%) in dealing with patients. 76.92% indicated a change in their own attitudes as a result of the elective course. In terms of learning gains, the highest was found in knowledge (CSA Gain 81.0%), followed by skills (CSA Gain 71.2%) and dealing with one's own attitudes (CSA Gain 53.5%). Thus, the skill of intentionally addressing a WHD increases by 82.15% while awareness of one's attitude increases by 9.12%. The burden of a WHD expressed by patients could only slightly be reduced with the course (CSA Gain 13.02%).

Conclusions: An elective course can support medical students in dealing with patients who experience a WHD and their relatives. Simulated conversation with simulating patients can train practical skills and prepare for real-life situations. However, the attitude plane is more difficult to achieve, as has been identified frequently. Real patient contact may be necessary for this. In addition, further support of the future physicians in real life situations is needed to reduce burdens.

P 5.032 Professionals' Self-Efficacy in Advanced and Shared Care Planning in Argentina: Cultural Validation of the ACP-SEs Scale

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Background/aims: Advance Care Planning is a reflective, deliberative and structured process shared between the sick person and their healthcare providers. Perceived self-efficacy is one of the main predictors of success in learning strategies and promoting the acquisition of new behaviours. We aimed 1) To cross-culturally adapt the ACP Self-Efficacy Spanish (ACP-SEs) scale in Argentina); 2) To explore its reliability and validity, and 3) to assess Argentinian professionals' Self-Efficacy pre and after a training course.

Methods: Comprehension tests and psychometric validation were carried out by multidisciplinary healthcare providers who assist advanced chronic patients. Structured cognitive interviews using the think-aloud method were applied to at least eight professionals until saturation. The reliability and validity of the scale were analysed to assess psychometric properties. The Argentine-Spanish version was sent as an online survey to professional association members. Sociodemographic variables, background experience and ACP-SEs Scale: 19 Likert-type items were analysed.

Results: From 243 respondents (2019-2022): 76.3% were females, 56.1% doctors, 13.3% psychologists, 12.7% nurses and 16.8% others; 80.8% had experience caring for chronic patients; 51.7% had specific training in ACP; 52.7% did perform an ACP, 89% reported not having a personal Advance Directive Document. The validation of the ACP-SEs and the national situation diagnosis helped design a training program as an online/face-to-face moderate-intensity course. The theoretical-practical program based on Kolb's experiential learning was divided into five modules (3 hours each), including audiovisual material, group discussions, case reviews, role-playing, and interactive electronic simulation activities. The Kirkpatrick model assessed the training program's impact at five levels: Reaction, Learning, Behavior and Results.

Conclusions: ACP process is underskilled. We seek to improve chronically sick people's care by improving professionals' skills.

P 5.033 Cultural Adaptation of the ENABLE (Educate, Nurture, Advise, Before Life Ends) Programme for Heart Failure Patients and Caregivers in Singapore: Preliminary Findings

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Background/aims: ENABLE is a nurse-led supportive care intervention that seeks to empower patients to live well with their serious illnesses and to support their caregivers that has undergone testing in the U.S. While certain elements of ENABLE are universally applicable, some might be culturally sensitive. Hence, this study aimed to culturally adapt ENABLE for HF patients and their caregivers in Singapore.

Methods: Formative evaluation study consisting of patients with NYHA Class II-IV heart failure, their family caregivers, and healthcare staff. Semi-structured interviews on cultural acceptability of ENABLE were conducted and analysed using thematic analysis.

Results: Seven patients, five caregivers, and seventeen healthcare staff participated. Whilst participants saw potential benefits in participating in ENABLE, potential barriers included: health coaching as a new concept, the culture of "familial harmony" and "non-confrontation" around communication and decision-making, the culture of "practicality" – wanting the coach to solve their problems instead of gaining self-empowerment – and lastly, concerns around discussing topics such as sexuality, due to conservative beliefs that sexuality is a private matter. To mitigate these cultural barriers, participants suggested pacing conversations, and normalizing traditionally taboo or sensitive topics.

Most participants preferred having flexibility around the choice and sequence of coaching topics and had mixed views of sessions being conducted as individuals or dyads. Participants shared that the characteristics of their ideal coach were adaptability and adequate life and healthcare experience.

Conclusions: While easily overlooked, the adaptation of an intervention should consider the contextual and cultural elements of the setting it will be implemented in, as it would affect an intervention's acceptability, feasibility and effectiveness locally. These themes presented would be used to make modifications to ENABLE in Singapore, which will be tested in the future.

P 5.034 DNAR Order Forms in Patients Referred for End-of-Life Care: An Audit

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Background/aims: DNAR (Do not attempt resuscitation) orders are an important part of patient care when approaching end of life. If it is likely that a cardiorespiratory arrest would be the terminal event in a patient's

disease trajectory, it is advisable to have a DNAR in place to prevent avoidable harm and suffering. DNAR orders should also specify a treatment plan in lieu of cardiorespiratory resuscitation. The aim of this audit was to assess completion of DNAR order forms for 28 patients referred for end-of-life care to our service between August and September 2022 and their associated specified treatment plan.

Methods: The presence and content of DNAR forms of 28 patients referred to palliative medicine services for end-of-life care were assessed.

Results: All patients had been documented as "not for resuscitation" and 27 of the 28 referred patients had a completed DNAR form in keeping with hospital practice.

In the specified treatment plan, fifteen patients (53.3%) were documented as being for "ward-based care". Only eight DNAR forms (28.5%) referenced whether a patient would be suitable for non-invasive ventilation or not while only one form specified patient's suitability for dialysis.

No patient had a DNAR order form with a treatment plan specifying the patient should not receive IV antibiotics, IV fluids or phlebotomy despite this ceiling of care commonly being in practice at time of review. It is unclear whether the discrepancy between treatment plans documented in a patient's DNAR order and what was enacted in their care resulted in unnecessary intervention.

Conclusions: It is important to have a DNAR form completed for patients approaching end of life. Where there is a specified treatment plan, this should contain clear, unambiguous language that accurately reflects patients' current treatment plan. This audit highlights the need for clinician education regarding this, with an opportunity for subsequent re-audit of DNAR forms for patients referred for end-of-life care.

P 5.035 The Development of an Online Medical Undergraduate Palliative Care Course in Response to COVID-19 Pandemic: A Hospice Experience

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Background/aims:

- Before COVID-19 pandemic, undergraduate (3rd/4th year) medical students from 3 universities attended 1-day palliative care teaching, 1-day home visit and ½ day post-mortem as part of their palliative care education and training in a hospice organization, located in an urban area, Kuala Lumpur, Malaysia.
- In response to COVID-19 pandemic, an online undergraduate palliative care course was developed to bridge the gap.

Methods:

- We adapted Kern's six-step approach to develop our online undergraduate palliative care course
- Duration: April 2020 – October 2022 (on-going)

Kern Step 1. Problem identification and general needs assessment

- As a hospice organization that places great emphasis on palliative care education, we needed to be innovative and adapt to changes brought on by COVID-19 pandemic.
- Teaching palliative care to medical students is an important component of medical education. Hence, it was necessary to provide ongoing education despite disruption caused by COVID-19 pandemic.
- The challenge was to create a course that reflected the unique learning which medical students gained from seeing patients in their own environment.

Kern Step 2. Targeted needs assessment

- A prompt shift to online teaching was needed.
- We searched for a learning management system that was user-friendly, cost-effective, and supported a variety of different content types.

- Medical students should be able to access it at their convenience, from anywhere, at any time (taking into consideration access to broadband and computers may be challenging for some).

Kern Step 3. Goals and objectives

- Medical students should be able to use a patient-centred approach in assessing a patient diagnosed with life-limiting illness upon completion of the course.
- We wanted learning to be fun, interactive and used videos made by our clinical team to demonstrate skills.

Kern Step 4. Educational strategies

- Our curriculum is composed of the following educational components: - a) 9 learning modules covering common topics in palliative care with a focus on assessment skills b) Virtual class (Live Question and Answer session) 1 month after completing online course
- Content was reviewed by 2 doctors.
- Quizzes in various forms were included in each module.
- Video recordings made by our clinical team included palliative care assessment with demonstration on how to use Edmonton Symptom Assessment System (ESAS), goals of care discussion, discussion on spirituality, breaking bad news and psychological exploration.
- We received input from the lecturers (of the 3 universities), our clinical team and an independent expert review on the development of our e-learning course.

Kern Step 5. Implementation

- Internal funding from hospice council members was needed to subscribe to a learning management system.
- 1 doctor to create content and to be an administrator (with a backup from another doctor).
- A timeline of 3 months was set for content creation.
- Pilot testing of the e-learning course will be done with our clinical team before implementation of the e-learning course

Kern Step 6. Evaluation and Feedback

- A survey with our clinical team was conducted to evaluate the course.
- Feedback was received during virtual session with medical students and from the lecturers of the 3 universities.
- E-learning course will be reviewed on a yearly basis.

Results: Our e-learning course was launched in September 2020. We migrated to a different learning management system beginning of the year 2021 because the first learning management system had limits on the number of students who could access the e-learning course at any one time. Our organizational budget could not cover for the upgrading of package.

A total of 413 medical students and 388 medical students accessed the e-learning course in the year 2021 and 2022 respectively. Feedback suggested the e-learning course was seen as valuable by both medical students and their lecturers. Medical students suggested improving the sound quality of the recorded videos. In June 2022, we secured funding to engage a software company to host the learning management system. The contents and the instructional design of the e-learning course are currently being reviewed.

Conclusions: E-learning has proved useful in minimizing the disruption to undergraduate teaching caused by COVID-19 pandemic. Moving forward, e-learning will be used as part of a flipped classroom approach to free up actual class time for more effective learner-centred activities.

P 5.037 Post-graduate Course in Palliative Medicine: Experiences from a eLearning-based Pilot Program, a Mixed Methods Study

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Background/aims: The use of eLearning has increased dramatically during the COVID-19 pandemic. eLearning methods may provide new possibilities also in the context of palliative medicine training. The aim of this study was to study whether eLearning methods are feasible in the post-graduate education of palliative medicine.

Methods: A national pilot eLearning based post-graduate course in palliative medicine was conducted with 24 participants. Evaluations from different aspect of the a course were analysed numerically. Answers to open-ended questions about eLearning was analysed with inductive content analysis.

Results: Overall evaluations of different aspects of the course were good. For example, issues of pain and symptom control, lectures, exams and group discussions were deemed suitable for eLearning. Benefits of eLearning included efficacy, better accessibility, and possibility to go back to the material. Reduced networking and face-to-face interactions remain the challenges of eLearning.

Conclusions: eLearning is feasible in the post-graduate education of palliative medicine and can be 'surprisingly rewarding', offering many benefits compared to contact learning, with also some challenges. Further studies are needed to assess the increase in competence by different learning methods.

P 5.038 Narrative Medicine: A Strategy to Address Suffering in Medical Education

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Background/aims: To describe the experience of using Narrative Medicine, as a pedagogical-training model, during the activities of an extension project in palliative care (PC) with medical students in Brazil.

Methods: Face-to-face meetings were held to provide training on PC, then 15 students visited palliative care patients in a teaching hospital and were subsequently encouraged to write about their emotional experiences during these activities.

Results: Medical education usually prioritizes disease and treatments, so students are taught to write medical records from a clinical perspective. The emotions and suffering observed in the learning process are needed to develop empathy and compassion for future doctors. The students brought up the theme of pity for those who die, frustration with medicine that does not cure, impotence with death, the need to learn how to manage symptoms, communication, spirituality, and human needs. The group of students was encouraged by the professor to validate suffering, with discussions on how to include medical care and self-care actions. At the end of the activities, all students appreciated the approach, felt more encouraged for new visits, wanted to learn more about PCs, and indicated the need for spaces like this in training.

Conclusions: Narrative Medicine emerged as a strategy to alleviate the sufferings of the educational process of physicians, which provides the opportunity to address different faces of illness.

P 5.039 Palliative Care Education in Radiation Oncology: Current Knowledge, Skills and Attitudes

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Background/aims: In 2021 Entrustable Professional Activities for Palliative Care (PC) were formulated nationally to improve knowledge, skills and attitudes for all future medical specialists in the Netherlands. We assessed to what extent current residents in radiation oncology comply with these PC EPAs and how to improve their education on PC.

Methods: In September 2021, all residents of the eight academic teaching hospitals received an electronic survey including five existing questionnaires about their knowledge, skills and attitudes on PC and on their current education on specific PC topics. In a focus group, six residents discussed how to improve their PC education.

Results: Of the 85 residents, 57 responded (67%); 64% was female, 35% had not received special PC education. Residents were mostly taught on physical dimension (59%) and working interdisciplinary (41%). They were least taught on spiritual or ethical dimensions (both 9%) and care options outside the hospital (25%). Most residents were satisfied with their communication skills (81%) and knowledge of working interdisciplinary (93%). They had least knowledge on care for the family (23%), bereavement (15%) and existential aspects (25%). Although only 9% had had any education about end-of-life-care issues, 69% felt comfortable communicating about such topics with patients. In the focus group, residents mentioned that end-of-life-care was rarely part of the daily work as radiation oncologist. They suggested education to be more in line with daily problems by discussing case-studies and ethical issues. An internship within a hospital's Palliative Care Consultation Team might also contribute.

Conclusions: The current palliative care education for residents in radiation oncology in the Netherlands lacks psychosocial, spiritual, and ethical topics. In addition, more case studies should be discussed. Hospitals Palliative Care Consultation Teams could provide internships to enlarge the knowledge and skills of residents with focus on 'training on the job'.

P 5.040 Enhancing Palliative Care Related Empathy and Communications Skills of Medical Students and Health Professionals by Means of Virtual Reality

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Background/aims: Communication skills and empathy have become equally essential competencies for a doctor as well as their medical knowledge and skills let alone in Palliative Care (PC). Virtual Reality (VR) could offer an adjunct teaching method to all undergraduate (and/or postgraduate students and hospital residents) and health professionals regardless of location, time or environmental parameters. COVID-19 and its implications for education and live attendance made it clear that alternative and innovative educational approaches are and will be of high priority. Therefore, this study aims to explore the implementation of VR-based interventions as an educative method in teaching empathy to medical students (and health professionals) and the usefulness and usability of this educative approach.

Methods: This study explores the feasibility, usability, and usefulness of VR technologies in medical students and health professionals. A case study is being implemented at the School of Medicine of Aristotle University in Thessaloniki, Greece, where 10 students and 10 health professionals are invited to use VR tools and applications and evaluate them. Questionnaires, interviews, and observations are used to collect data.

Results: The VR applications have been rated as an experience beyond interesting and insightful supporting teaching on how to act in an

empathic way, how to relate with their patients, and the way they can fit into this relationship all the emotional components each patient carries while dealing with a disease and PC. They also mentioned that the notion of empathy became clearer, and the scenarios helped them to clarify this.

Conclusions: VR can be used as an adjunct teaching method to support medical students in an immersive and entertaining way of learning, repeatable and in any location, adding to the usefulness and value of this innovative tool.

P 5.041 Palliative Care Integration, Mentorship, Support Supervision and Communication to End Inequities in a Rural Hospital

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Background/aims: To improve access to palliative care in a rural faith-based hospital by building and strengthening the capacity of health professionals within the hospital departments.

Methods: Financial support was secured and provided in 2014 to train health professionals (HPs) in a phased manner to ensure a multidisciplinary team was in place. Doctors and nurses were trained and they acquired certificates, diplomas, and degrees at an accredited institution. This process has been ongoing with onsite mentorship, communication, and support supervision visits as well as refresher training.

Results: 9 years later, the hospital now has 18 Health Professionals (HPs) fully trained in palliative care and other 7 HPs in 2 nearby health facilities, which has shown a huge impact within the district. The hospital currently has a fully-fledged Palliative Care program that manages patients in the hospital wards and the community within 14 villages. The Palliative care team secured two motorbikes for home-based care as well as use of hospital vehicles. The team can provide the required essential medicines especially Oral Liquid Morphine and other basic needs for needy patients. A Whats App group was created for case discussions with mentors for experiential learning purposes and care provision improvement. The Palliative care team has continued to showcase their improved knowledge and skills through teaching refresher courses and offering support to two nearby health facilities.

Conclusions: Support supervision visits, effective communication, and mentorship play a big role in ensuring the Palliative care team is capable of providing quality services to patients and families experiencing serious health-related suffering. Hospital management support is key in ensuring a smooth process of palliative care education, integration, and ownership

P 5.042 Increasing Competency in Research for Palliative Care Professionals - Experiences from an International Training

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Background/aims: To assess participants' experience and their acquisitions of competencies during a 5 days basic research training, as part of "Research for Palliative Care Clinicians" (RESPACC) project.

Methods: Using the RESPACC Framework, a 5 days course was designed for the domain Scientific thinking with 13 sessions. Each session was 90 minutes-30 minutes pre-recorded videos followed by facilitated discussions, practical exercises and small group work, designed to develop/refine own research project. Feedback after the course was asked using an anonymized evaluation via an online survey. For competence acquisition, a pre and post-tests with 26 questions each was based on session objectives, scored with 5 points each. Each participant had assigned a code to be able to compare results between the tests. Results were analyzed descriptively.

Results: Out of 37 participants from 5 countries attending the course, 20 persons completed pre and post-tests (RR=54%). There was an average increase in score of 12 points (mean pre 79, mean post 91) in post test scores, with a variation of -5 to +35 points. Lowest score (50) and highest score (110) in pre and post test showed an improvement in competency. Due to small sample, no analytic statistics were performed. The open evaluation, showed as positive aspects, participants interest in the topic and training format, trainers expertise, good time management, networking opportunity, concrete work on projects during working groups, with improve required in: length of the videos, to pause the video for interaction with the audience and fewer topics in more depth.

Conclusions: The training aimed to increase clinicians' basic competencies in research and evaluations have shown that the aim was achieved. Interactivity, work on own projects and interaction with other delegates were highly appreciated. More in-depth training on certain topics is needed.

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P 5.043 Customised Communication Skills Training for Hospice Staff

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Background/aims: Palliative care patients and their families often go through challenging times. To provide optimal care and comfort, it is essential for palliative care practitioners to possess effective communication skills. However, many clinicians are neither well-trained nor confident in this area. An internal learning needs analysis identified communication skills as one of the top training needs. A 10-hour customised curriculum, consisting 3 modules, was hence developed to meet the needs.

Methods: Modules 1 and 2, 2 hours each, provided foundational training for all patient-facing staff. The key contents included concepts and strategies on self-awareness, self-reflection, micro-communication and attending skills. Module 3, an advanced-level training for clinicians who often face challenging conversations, comprising three 2-hour parts, focused on managing 1) misalignment of expectations, 2) desire for hastened death, and 3) anger, abusive and aggressive behaviors.

To ensure training effectiveness, the following strategies were employed: 1) Extensive literature review on end-of-life communication and its training framework; 2) Pre-workshop reading, including self-explanatory slides and self-made video on positive demonstration of communication skills; 3) Small group teachings with 1 facilitator to no more than 7 participants; 4) Active role plays with standardised patients, based on authentic discipline-specific case scenarios; 5) Debriefing and processing after each role play; and 6) Pre- and post-workshop quiz and reflection.

Results: 148 staff attended the training. Post-workshop evaluation revealed positive outcomes including a vast improvement in self-rated confidence across disciplines. Feedback from supervisors showed that

staff felt empowered and had been employing the skills and strategies learned from the workshop into practice.

Conclusions: Staff benefitted from the training. Further work includes longitudinal workplace-based assessment and extending the training to palliative care community.

P 5.044 "When your Patient Is Dying" - Evaluating the Impact of a Palliative Care Education Workshop for Interns on Self-reported Competence in Generalist Palliative Care

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Background/aims: Palliative care provision is a core role of all health-care providers. Junior physicians frequently indicate a lack of confidence and competence in delivering palliative care and can find it distressing. Aims were as follows: To assess the impact of a structured education programme on intern's perceived preparedness in providing palliative care. To explore intern's baseline competence in palliative care using a competence based educational framework. To seek specific education and support needs for junior doctors as palliative care providers.

Methods: Ethical approval was obtained for this survey. Our cohort self-selected as all interns working in a large regional hospital. We utilized the Palliative Care Competence Framework Questionnaire to assess baseline competence in palliative care prior to receiving five education sessions over a three week period. The questionnaire was adapted to an online format and was entirely voluntary and anonymised. Upon completion of the five sessions we repeated the survey to evaluate the impact of the workshops.

Results: At baseline, interns recognised that palliative care was part of their role and the importance of this. However self-reported competence and knowledge was low, indicating a lack of confidence and competence in providing end of life care. Less than 10% of cohort had undergraduate clinical exposure to palliative care. Responses following educational intervention indicated improved competence and knowledge, and also identified specific areas of focus for future education and supports.

Conclusions: Interns did not feel prepared to provide basic palliative care. Most did not have undergraduate clinical exposure to palliative care. They recognized palliative care as an essential part of their role but did not report being competent in its provision. More emphasis should be placed on undergraduate and post graduate development of primary palliative care competence for junior doctors.

P 5.045 Integrating Palliative Care: Medical Teaching and Protection

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Background/aims: "Sometimes healing, but always giving relief and protection". Palliative care focuses on the complexity of the human being, and on its physical, social, psychological, and spiritual aspects, and it aims on protecting from the suffering of progressive, incurable illness. Educating future physicians on Palliative Care is crucial in giving patients their due care. This study presents the Palliative Care discipline in medical school and highlight its importance in a well-rounded physician's education.

Methods: Experience report from a School of Medicine in Brazil.

Results: Since 2019, in the 4th graduation-year, students were invited to debate, gaining insights into palliative care. They learned concepts and principles of palliative care and its role in progressive, incurable chronic disease, regarding the “whole symptom” concept. About patient—and family—suffering, they focused on organ failure, neoplasia, the negative events, and the need to protect the patient. They have debated on the bio-techno-scientific paradigm, on the harsh finality of life, and patient needs; on the ethics of thorny cases: clinical facts, conflicting values, duties and responsibilities. They role-played and saw videos on breaking bad news to families and bedside manners. The main reflection was: having medical students learn palliative care is crucial for compassionate care. It helps students deal with the anguish, frustration, fear and suffering of patient and family, as well as being spread too thin. They learned that knowing chronic illnesses helps on identifying their progression to provide proper care for the patient as a *person*, and how to integrate early palliative care into the overall care.

Conclusions: Medical school must teach Palliative Care in a holistic approach to physical, psycho-social, and spiritual aspects, especially with an aging population and rising chronic illness. Students can improve themselves, shifting focus away from disease and towards the *person*, improving quality of life up to their final days.

P 5.046 Palliative Care Education in a Pandemic

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Background/aims: The COVID-19 pandemic and increased home deaths has highlighted the need for rapid, scaleable and cost-effective education on palliative and end of life care for health and social care staff in community settings.

Methods: During COVID academics and clinicians running a university MSc in palliative medicine rapidly developed and delivered webinars on end-of-life care aimed at staff managing patients dying at home or in nursing and residential care from COVID, frailty and other conditions. They were delivered through the Zoom digital platform and made interactive by the Q&A facility, chat function and polls. Sessions were free to attendees as part of the university's ‘Civic Mission.’ All sessions were recorded and uploaded to a university YouTube channel without time restrictions. A second series of webinars with expanded content was funded by a local integrated health provider for their staff and delivered by local clinicians. Electronic feedback was collected via Likert scales on content, delivery and organisation.

Results: On evaluation, more than 90% of respondents gave scores of ‘very good, or ‘excellent’ for all domains.

Data taken 2-4 weeks after the end of series 1 and the more locally targeted series 2 showed means of 182.6 and 89.4 registrations respectively per session, 49.4 and 33.2 live attendees and 126.6 and 38.6 YouTube viewings. However, re-analysis of YouTube data 22 months after completion of series 1 and 7 months after completion of series 2 showed viewings continuing to rise with more than 180 and 100 viewings respectively for the most popular sessions.

Conclusions: Valuable and interactive education can be produced and delivered efficiently via virtual platforms and at minimal cost. Good quality digital recording of sessions provides an ongoing and sustainable resource that continues to be accessed regularly approaching 2 years after some live events.

P 5.047 Virtual or Face-to-Face Learning in Palliative Care: Perception of the Impact of Technology versus the Self-reported Reality

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Background/aims: This research set out to explore if learning was impacted by mode of learning (virtual or face-to-face). A face-to-face teaching block at the start of a Masters course in palliative care was run virtually in 2021 (due to Covid-19 pandemic) and returned face-to-face in 2022. Evaluations were undertaken in 2021 to establish student perception of whether learning had been impacted by the virtual learning environment. 86.4% of learners reported in 2021 that the use of technology/ virtual learning environment had no adverse impact on their learning. The same group of learners were asked in 2021 and in 2022 to rate their understanding of the concepts taught in the sessions. We present 2 years of evaluation data.

Methods: Prospective online evaluation using a likert scale. Data was analysed from a cohort of students who experienced the teaching virtually in their first year and face-to-face in their second year.

Results: 12 sessions ran virtually in 2021 for Masters students in their first year over 3 days and 13 sessions ran face-to-face in 2022 for these students at the start of their second year. The cohort gave 87 responses in 2021 and 67 responses in 2022. In 2021 (virtual) 39.1% selected the top two levels of understanding, compared with 46.3% in 2022 (face-to-face).

Conclusions: Students rated their understanding of concepts taught in the session higher when taught face-to-face compared with virtually, despite having previously reported that they did not feel the virtual learning environment had negatively impacted on their learning. There appears to be an additional effect on learning from face-to-face teaching which merits further exploration to be able to determine the most effective mode of delivery.

	2021 virtual	2022 virtual
Some significant CONFUSIONS AND/OR BLIND SPOTS	1.1%	1.5%
BASIC FAMILIARITY with the concepts	10.3%	14.9%
SOLID UNDERSTANDING of the concepts	49.4%	37.3%
COMPREHENSIVE UNDERSTANDING of the concepts	39.1%	44.8%
EXPERT-LEVEL UNDERSTANDING of the concepts	0.0%	1.5%

P 5.050 Palliative Care Goes to School – How Did Pupils

Experience the Visit of a Multiprofessional Palliative Care Team?

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Background/aims: Palliative Care goes to School – how did pupils experience the visit of a multiprofessional palliative care team?

To find out, if a 2 hours lesson with interactive components about Palliative Care can reach the interest of pupils between 14 and 19 years.

Methods: A questionnaire was distributed 1 week after the school visit of a multiprofessional Palliative Care team. 453 sheets were completed. Some questions allowed multiple choice answers concerning the presentation, others rated the total impression on a numerous scale from 1 (very good) - 5 (unacceptable). Personal comments could be mentioned.

Results: The lesson was assessed informative 85,9% (389), exciting 61,6% (279), touching emotionally 59,8% (271), boring 9,3% (42), too depressive 1,3% (6).

The performance of the palliative care team was judged with 1 (Very good): 55.4% (228) and 2 (good): 36,2% (149).

The question „Do you think it is important for pupils to hear about palliative care“ was answered with 1 (very important) 44,8% (189) 2 (important) 38,7% (163) and 3 (a little important) 12,1 % (51). Only 4 % found it less important (13) or not important (5)

Personal comments expressed the need for further information about this topic: „Parents do not talk about this“, „Definitely more broadening among the population“, „Keep going, I have learned a lot of new things“.

Conclusions: Upper class pupils find it important to get information about palliative care. An interactive lecture can reach children even with serious topics. The discussion about palliative care should be part of general education.

P 5.051 Association between Palliative Care Knowledge and Professional Quality of Life of Nurses Caring for Greek patients at a Dialysis Unit

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Background/aims: The increased burden and complicated care needs of patients with End-Stage Kidney Failure requires the integration of comprehensive Palliative Care (PC). Investigate the association of knowledge towards PC of Greek nurses, caring for patients in Dialysis Unit (DU), with the quality of their professional life.

Methods: This cross-sectional study's convenience sample was 92 (RR: 73.0%) registered nurses working >6 months in the DU of a private agency (December 2020 - February 2021). The translated in Greek Palliative Care Quiz for Nurses (PCQN) and the Greek version of Professional Quality of Life Measure (ProQOL5) were used. PCQN: 20-item true, false and 'I don't know' test of knowledge. An overall score $\geq 15/20$ indicates sufficient knowledge. ProQOL5: 30 items, 5-point scale, comprising 3 subscales: Compassion Satisfaction (CS), Secondary Traumatic Stress (STS) and Burnout (B). Higher values indicate higher outcomes. The level of statistical significance was set at p -value < 0.05 .

Results: Nurses' mean age was 31 years old and the DU's experience 5 years. The mean Overall PCQN score (11.0 ± 2.8) was low. Moreover, nurses had mean moderate CS (33.7 ± 4.9), B (30.7 ± 3.7) and STS (24.8 ± 4.4) scores. The Overall PCQN score was negatively statistically significant correlated with CS and positively with STS ($p < 0.050$). According to multiple linear regression analysis results the CS ($R^2 = 10.8\%$, $F=6.77$, $p=0.046$) and STS scores ($R^2=11.2\%$, $F=10.97$, $p=0.016$) were related with the Overall PCQN score. The nurses with higher Overall PCQN score had a lower CS and a higher STS score. Almost none of the other nurses' demographic and professional characteristics was associated with quality of professional life scores.

Conclusions: Despite study's limitations, these results reveal the low knowledge of Greek DU's nurses on PC, but also its impact on their quality of professional life. Future research is needed in order to further investigate this impact.

P 5.052 Words Can Heal Too: Facilitating Reflective Writing for Health Care Workers

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Background/aims: Burnout negatively impacts the wellbeing of health-care workers and the quality of patient care. It is essential to develop reliable tools to promote resilience in this group. Evidence suggests that creative pursuits may reduce burnout among health care workers by providing an effective space to process emotions and experiences. This ongoing project aims to examine the feasibility and acceptability of an innovative, cross-disciplinary pilot program using facilitated poetry

writing and discussion to mitigate burnout for health care providers in Palliative and Emergency Medicine.

Methods: A writing facilitator with experience across multiple disciplines and settings led a series of six virtual writing workshops. Participants were presented with a model poem, then encouraged to write and share their own poetry via discussion and posting to an interactive online platform. We collected data on recruitment, retention, satisfaction, intent to participate in future programming, and factors affecting participation.

Results: Of the 19 participants consented (13 Palliative; 6 Emergency), 16 attended at least one session. Of those who participated in at least one workshop, the median attendance was three sessions. Participant satisfaction, likelihood to recommend, and likelihood to engage in similar programming were measured using a 5-point Likert scale. Most respondents reported being at least "somewhat satisfied" with individual sessions (39/42; 92.8%) and the program overall (8/9; 88.9%). The majority reported being at least "somewhat likely" to recommend the program (47/51; 92.2%) and engage in similar programming (38/51; 74.5%). Barriers included clinical duties, conflicting meetings, and competing time commitments.

Conclusions: While participant retention was lower than expected, individuals who engaged with the programming reported overall satisfaction with the sessions and program as a whole, indicating feasibility and acceptability of this type of program.

P 6 - Ethics, Policy and Law

P 6.001 Lack of Ethical Guidance in an Ethically Controversial Area: A Systematic Review of Clinical Practice Guidelines on Palliative Sedation

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Background/aims: The decision-making process for palliative sedation is often challenging, especially for continuous deep sedation until death, and should include thorough ethical reflection. Numerous clinical practice guidelines (CPGs) have been published to support this process. Reviews of documents so far have focused on the clinical aspects of this therapy, but little is known of how ethical reflection should be conducted. To evaluate the ethical content of CPGs on palliative sedation and thereby also identify the ethical implications of each form of this therapy.

Methods: A systematic review of CPGs on the palliative sedation of adults was performed, using bibliographic databases, guideline depository websites, Google and Google Scholar, websites of associations for palliative care, citation tracking, and contact with palliative care experts across the world. Textual and thematic analysis of the CPGs focused on the ethical dimension of these texts and the ethical issues of each form of palliative sedation.

Results: In total, 36 CPGs from four continents (America, Asia, Australia and Europe), published in English, French, German or Italian, were included in the analysis. An ethical component was poorly presented or even absent from the CPGs. Only five texts contained a section explicitly related to ethics, two of which limited this to a few sentences. In these sections, 'ethical issues' were named, conceptualized and presented in various ways. The material was insufficient to identify the specific ethical issues of each form of palliative sedation. Only one third of the CPGs were developed with ethics expertise but this did not always correlate with the ethical dimension of the text.

Conclusions: These findings highlight the need for the integration of an explicit ethical orientation in GCPs on palliative sedation. Interdisciplinary collaboration between palliative care specialists and ethicists should be supported.

P 6.002 Facing a Request for Assisted Death - Views of Finnish Physicians

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Background/aims: Discussions about the ethical justification of hastened death due to unbearable suffering are ongoing and there are debates about the legalization of euthanasia in many countries, including Finland. Ambivalence toward assisted death among Finnish physicians has decreased in recent decades. However, it is not well known what lies beneath these attitudes and how the physicians actually face requests for assisted death. The aims of this study are to assess and describe physicians' views on assisted death and to describe physicians' actions when facing a request for assisted death and their views of the ethical aspect regarding the request.

Methods: A questionnaire survey, including also open questions about assisted death, was conducted with all Finnish physicians (n= 26740) belonging to the Finnish Medical Association in 2020.

Results: 6889 answers were received, giving a response rate of 26%. 1068 (16%) of the responders had faced a request for assisted death. 897 (13%) fully agreed and 3027 (44%) fully disagreed with a statement that they could assist a patient in a suicide. Youngest physicians (<35 years old) were most willing to assist in a suicide (42%), while 55-64 years olds were the least willing (26%) and the oldest (>65years olds) were again more willing (32%), p<0.001. 19% of responders fully agree that accepting euthanasia would harm the doctor-patient relationship and 9% fully agree that it would benefit the doctor-patient relationship. Qualitative analysis from 3033 answers to open questions is currently under review.

Conclusions: Only few responders had actually faced a request for assisted death and a minority of Finnish physicians are willing to perform a physician-assisted death. More in-depth analysis on the reactions and views on assisted death will be ready by the time of the EAPC congress.

No specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors was received.

P 6.003 Attitudes towards Euthanasia among Medical Students, Resident Doctors and Polish Philology Students

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Background/aims: The aim of the study was the analysis of attitudes towards euthanasia practice and legislation and exploring attitudes towards palliative care and factors affecting these attitudes among medical students, resident doctors and Polish philology students.

Methods: A 23-question questionnaire was sent by email to 670 medical students, resident doctors and Polish philology students in order to evaluate their understanding of the introduced concepts, acceptance of

euthanasia and assisted suicide, attitudes towards current legislation, readiness of participants to take part in these practices, personal experience of serious illness and assisting in disease and death among participants and their attitudes towards palliative care, euthanasia and assisted suicide.

Results: Questionnaire results were collected from 313 participants (response rate 46.72%). In total 215 participants (68.69%) supported legalizing euthanasia, 112 (35.8%) support legalizing assisted suicide. 25 (23.1%) medical students (years I-IV), 61 (62.2%) medical students (years V and VI) and resident doctors and 72 (67.3%) Polish philology students perceive current regulations banning euthanasia as too restrictive (p < 0.001). Medical students of higher years (year V and VI) and resident doctors were more likely to declare readiness to perform euthanasia - 49 participants (50.08%), compared to medical students of lower years (year I-IV) - 41 participants (38%) (p = 0.034). Religious beliefs, place of permanent residence and past personal experience of serious disease were the most important factors affecting participants' attitudes toward assisted suicide and euthanasia.

Conclusions: In the context of the ongoing worldwide debate concerning euthanasia, it is important to explore the attitudes of medical and other students and young doctors. It is also essential to look into how education in palliative care and promotion of hospice care can advance an ethical approach to seriously ill patients in medicine and society.

P 6.004 Teaching Ethics within Palliative Care: Identifying Priority Topics and Preferred Learning Styles

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Background/aims: There are multiple approaches to teaching clinical ethics in palliative care. What is not clear are the preferences of specialist palliative care providers (SPCPs) regarding priority ethics topics and teaching methods. Understanding these is crucial in ensuring training programmes are focused, effective, and relevant to time-pressed professionals to explore SPCPs' priorities for ethics training topics and preferred methods of teaching delivery

Methods: As part of a larger project exploring ethical challenges facing SPCPs in Uganda, we conducted semi-structured interviews with staff in Uganda, exploring their views about priority ethics topics for teaching and preferred teaching methods.

Results: 36 participants (17 nurses, 8 physicians, 5 clinical officers, 6 social workers) were interviewed across 7 clinical sites. 11 knowledge areas were prioritised: autonomy, goals of care, confidentiality, nature of ethics and ethical theories, justice, beneficence, truth telling and collusion, non-maleficence, philosophy of palliative care, professional ethics, and euthanasia. Participants also described five priority skills: communication skills; how to approach and manage ethical challenges; self-care for moral distress; understanding one own's ethical biases; and advocacy skills. Five preferred teaching methods, in order, were: real-life case group discussion, simulated case group discussion, roleplay, lectures, and clinical placement with an ethical focus.

Conclusions: The topics prioritised by SPCPs in Uganda covered a broader range of ethical challenges than are usually included in current training materials. Participants wanted both ethical knowledge-based training, and training in the skills for using that knowledge in practice, including self-care for moral distress around difficult ethical

decision-making. Participants preferred learning via case discussions to lectures or clinical placements
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P 6.005 Telemedicine Applied to Palliative Care: Ethical Implications and Benefits

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Background/aims: The palliative care environment offers many new opportunities to improve communication and support patients and their families at the end of life. However, there are ethical concerns in the end-of-life context, mainly associated with the risks of neglecting patient privacy and confidentiality and issues related to the humanization / dehumanization of care. To identify the benefits and ethical implications of telemedicine applied to end-of-life care.

Methods: Systematic review with narrative synthesis. All study designs were included, except grey literature. Systematic reviews were only selected to identify relevant and significant articles for inclusion in the review.

Results: Included 22 studies of 321 found. Qualitative studies were in the majority, there was a significant variation in sample sizes. Home care was the most common application of telemedicine, and tele-consultation forms constituted the majority of interventions. The main benefits were the improvement in quality of life, associated with a better management of symptoms (pain and psychological well-being). It was also recognized the improvement of access to specialized palliative care, with a more centered approach. Another benefit was the more active role and empowerment of patients and families. Ethical issues and concerns were also identified, associated with privacy and confidentiality of patient's data. Ethical implications were recognized regarding justice and equality of access to technology and digital devices and knowledge, amplifying the already existing problems in vulnerable populations.

Conclusions: Telemedicine interventions were identified with great potential to improve the quality of care. Some articles raise questions about the humanization of care. They are superficially addressed and do not correlate with patient/caregiver satisfaction and quality of life. The most considerable ethical implications is relate to the privacy and security risks of the technology, recognized by both patients and healthcare professionals.

P 6.006 Effects of CURA on Care Provider Moral Resilience and Moral Competences

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Background/aims: Palliative care providers are known to experience diverse moral challenges in daily practice. Dealing well with these challenges is important for both caregiver well-being and good patient care. CURA is a clinical ethics support instrument tailored to the needs of nurses in palliative care that aims to foster their Moral Resilience (MR), i.e. the capacity to deal well with moral distress, and Moral Competences (MC), i.e. the skills necessary to navigate moral challenges in (palliative) care practice. CURA provides guidance by methodically structuring (joint) reflection on moral challenges experienced by care providers. This study aims to investigate the effects of CURA on care provider MR and MC.

Methods: Ten healthcare organizations (hospitals, hospices, home care and nursing homes) in the Netherlands participated. 'CURA-ambassadors' (n=72) were trained in initiating and facilitating CURA

sessions with colleagues. Data were collected among CURA-ambassadors using two questionnaires: the Euro-MCD and the Rushton Moral Resilience Scale at baseline and follow-up. Analysis was done using descriptive statistics and Wilcoxon signed rank test.

Results: 47 participants filled out questionnaires at baseline and follow-up. At baseline, the median Moral Resilience score was 2.9 on a 4-point Likert scale. At follow up, the score was 3.1 ($P < .001$). The subscales of the Euro-MCD (Moral Competences, Moral Teamwork and Moral Action) all increased significantly as well. Frequent use of CURA (>5) did not significantly result in higher scores on most subscales. There was no difference between novice and experienced care providers.

Conclusions: Respondents scored significantly higher on all (sub)scales. Specifically, teamwork, moral competences and response to moral distress improved. Based on these findings, CURA seems a promising intervention to improve palliative care for patients as well as caregiver well-being.

P 6.007 Attitudes of German Physicians and Medical Students towards Assisted Dying

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Background/aims: With its 2015 decision German parliament banned assisted suicide intended to be repeated in Germany. In 2020 this decision was overruled by the German federal constitutional court, who declared assisted suicide as a human right, surprisingly not only for patients with life-threatening illnesses. After this verdict the German Medical Association deleted the paragraph, that physicians may not provide assistance in suicide, in its model professional code of conduct. However, it is stated, that „assisted suicide is not a physician's task“. The aim was to evaluate the attitude of medical students and physicians towards assisted dying.

Methods: In educational courses, the willingness to support physician-assisted suicide, voluntary stop eating and drinking (VSED) and death on request (prohibited in Germany) was evaluated.

Results: Of the physicians in further training in intensive and emergency medicine (n=285, rr=73.6%), 72.3% considered VSED to be conceivable and 34.4% for physician-assisted suicide. Death on request was rejected by 69.1%.

Of the medical students (n=37, rr=66.1%) who participated in compulsory courses on palliative medicine, 81.1% were in support of possible accompaniment during VSED and 67.6% were in favour of physician-assisted suicide. Death on request was rejected by 46.0%.

In an elective palliative course for medical students (n= 13, response rate rr=86.7%) 61.5% could imagine supporting patients in VSED and 52.8% in physician-assisted suicide. Death on request was rejected by 53.9%.

Conclusions: Open exchange and detailed information can help to develop an attitude towards this complex topic. Differences may exist due to the medical students' lack of practical work experience. They can also arise from the fact, that in the group of the intensive care and emergency trainees the question was asked without prior discussion. In order to approach the topic further, a more detailed survey is planned.

P 6.008 The Role of Relatives in the Decision-making Process for Euthanasia or Physician-assisted Suicide According to Dutch Physicians: A Mixed Methods Study

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Background/aims: Relatives do not have a formal position in the practice of euthanasia and physician-assisted suicide (EAS) according to Dutch legislation. However, it is known that patients involve relatives in their EAS decision-making. Little is known about the impact of relatives' opinions on EAS decision making by physicians. We aim to investigate how Dutch physicians view the role of close relatives in a request for EAS and how they deal with the opinion of these relatives.

Methods: A mixed methods study was conducted among a random sample of 2255 general practitioners, clinical specialists and elderly care physicians between April and October 2022 (N=746, response 33%). They completed a questionnaire that included the statements:

- 1) I want to know close relatives' opinions about an EAS request, and
- 2) close relatives' opinions play a role in my decision about an EAS request.

In subsequent qualitative interviews (N=15) we explored why physicians do (not) want to know relatives' opinions and why it does (not) play a role in their decision. Descriptive statistics were used to analyse statements and thematic analysis for the interviews.

Results: Of all physicians, 79% agreed that they want to know close relatives' opinions on an EAS request, and 29% agreed that their opinion plays a role in making a decision. Interviewed physicians explained that they want to know relatives' opinions in order to possibly mediate in case of opposing views because they feel it is important that relatives are at peace with the way in which their loved one dies. Relatives do not have a formal position in EAS practice where the patient is expected to have an autonomous voluntary request, which is why according to physicians relatives' opinion is not considered to impact the final decision.

Conclusions: Although physicians know that relatives have no formal role in EAS decision-making, they consider it good practice to ask for relatives' opinions. Yet, this is to support relatives and not to influence a physician's decision.

P 6.009 Shaping Palliative Care Policy Using a Human Rights-based Approach

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Background/aims: COVID-19 public health restrictions and interventions in nursing homes had a clear human rights dimension as they engaged rights such as: right to private and family life, right to life, and the right to be free from inhuman or degrading treatment.

In Ireland the regulatory landscape changed rapidly and visiting restrictions were implemented in March 2020 that included: limited visiting, identification of two named visitors, visits of limited duration, and/ or remote contact visits. To examine rights-holder experiences of palliative care, people living in nursing homes, family carers and nursing home staff and whether existing policies are sufficiently robust to protect and promote human rights during pandemics.

Methods: An initial legal analysis of existing palliative care policy within nursing homes to inform the development of a survey that was completed by rights holders. Followed by analysis of the information from the survey to identify potential needs and/or gaps in palliative care policy based on a human rights approach.

Results:

- Policy analysis of COVID-19 restrictions identified 27 policy/guidance documents related to nursing home, 6 to palliative care and 5 ethical frameworks.

- 82.2% of survey respondents, 25 residents, 42 family carers and 51 staff, reported a COVID-19 case had occurred, 50.9% reported feeling safe and 70.3% feeling lonely
- Human rights were seen to be upheld from survey results, but individuals commented on residents' right to self-determination and decision-making about needs/safety being limited.

Conclusions: Respect for human rights should inform and shape the development of national public health guidance and policy. National public health advisory groups should include persons with expertise in human rights and equality. The experience of nursing home residents, their families, and staff must inform the development of future pandemic planning.

P 6.010 Shared Care Planning with Amiotrophic Lateral Sclerosis (ALS) Patients. Planela Study

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Background/aims: Shared Care Planning (SCP) is a deliberative process that facilitates the reflection and understanding of the disease experience, promoting the shared decision making. SCP helps Amyotrophic Lateral Sclerosis (ALS) patients and their families to face the difficulties, not only in relation to the physical symptoms but also to the emotional and social impact. The aims of the study are to identify the different ways in which people affected by ALS and their families feel the experience of the disease to identify their main areas of concern and to establish a SCP process suited to their needs.

Methods: By using a qualitative approach through depth interviews, focus groups and life stories, points of view of patients and relatives were collected and audio-recorded. At least three independent investigators did a systematic themes analysis that were discussed later by the investigation team.

Results: From January to June 2020 ten interviews (10 patients and 9 relatives), three focus groups (10 patients and 11 caregivers) and four life stories (3 patientes, 1 caregiver) were collected. Most important issue for patients is keeping the control of the information and their participation in decision-making. They feel the lost of physical capacity but they don't want to loose their autonomy and their right to make decisions. Because of that, SCP is considered a great opportunity to express their values and preferences. Patients are worried about symptoms related to dying, not about death. Relatives or caregivers are more reluctant to think about the future, they are focused on practical issues about daily care. They are worried about death and grief.

Conclusions: ALS patients consider SCP as a good opportunity to express their concerns and preferences in order to keep their autonomy. Health and social workers should include SCP in the attention of ALS patients and their families.

PLANELA study was funded by CASER Foundation.

P 6.011 Treating Healthcare Professional - Patients - Clinical Issues Faced by a Palliative Care Team

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Background/aims: Many palliative (PC) teams care for colleagues. No practice guidelines address the dying healthcare professional-patient (HCP). Studies on longitudinal care supplied to this group are

scarce and focused on the physician-patient to describe types of support provided, obstacles and pitfalls in this special PC – HCP relationship.

Methods: All HCP admitted to a hospital PC program, who died during Jan20 to Oct22, were included. Administrative data and medical records were reviewed to collect demographic and clinical characteristics, interventions (symptoms, drugs, psychosocial wellbeing, end-of-life discussions) and aggressiveness of care during the last month of life (LML). Descriptive statistics and nonparametric tests were employed as appropriate.

Results: Seven doctors (3 psychiatrists) and 5 nurses – 9 of whom female participated. Median age was 68.5y (range 42-78) and survival after PC 83days (IQR 73). All except one had cancer (the second for 3), mainly pancreatic / biliary tree (n=5). Prior to diagnosis 75% worked full-time. Three were early referrals, 5 by Oncology, 4 by a different doctor and 7 ongoing disease-modifying treatment. Most (n=8) had a spouse caregiver or a career that is also HC (n=5). Ascites (n=4) was the main reason for referral. All patients experienced symptoms but 7 out 10 denied it. Mean MEDD was 36.4mg (\pm 16.3). Hypnotics were largely accepted. Self-prescription or therapeutic changes are the rule for doctors. In contrast, domiciliary care services (7 out 10), psychological (10 out 11) and spiritual interventions (10 out 12) were refused. End-of-life was discussed with other specialists (n=11) and patient/family (n=10). Non-adherence to PC follow-up (n=5) was more likely in those who didn't accept disease progression (p=0.012) but it didn't affect the aggressiveness of care during LML.

Conclusions: Our HCP testimony the complexity, challenges, and emotional demand faced by PC providers. Their lived experience with PC programs must be explored in future studies.

P 6.012 Desire for Self-determination in Palliative Care Patients Asking for Assisted Suicide – A Qualitative Interview Study

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Background/aims: In February 2020, the German Federal Constitutional Court justified the provision of assisted suicide (AS) as part of the general right to a self-determined death which is not restricted to people with a terminal illness. Concrete legal regulations have yet to be adopted. Within this framework, the concept of autonomy and self-determination is of central importance - more than in other jurisdictions that demand an incurable disease or unbearable suffering as prerequisites for AS. Critics of this ruling questioned whether autonomous decisions in the context of severe illnesses are possible at all. We investigated whether and how palliative care patients who asked for AS expressed their desire for self-determination in this context.

Methods: Ten patients who had spontaneously expressed a desire for AS were recruited in the palliative care department of a German university hospital. Semi-structured interviews were conducted and analysed with qualitative content analysis.

Results: Thoughtful and reflective narratives were given that made references to the patients' life stories and fundamental values. The desire for self-determination was central and could be categorized into two main themes with several subthemes:

- 1) *Maintain autonomy while living*
prevent suffering
preserve dignity
avoid dependence on others
- 2) *Gain control over dying*
decide on the "right moment"
avoid an agonizing death
retain a sense of security

Conclusions: In our study, the desire for self-determination was an essential aspect for patients who expressed a desire for AS and was often deeply rooted in their general concept of life. In anticipation, some patients had sought information about PAS even before they had fallen ill. Narratives from patients explicitly requesting AS may focus more on this aspect compared to patients expressing a less specific wish to die.

P 6.013 Humanity in the Maltese Context of Palliative Care Nursing

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Background/aims: Little attention has been given to the concept of 'humanity' in the field of palliative care nursing and in Malta. Numerous definitions of humanity exist in the literature (Maltese: l-umanità) that are often used interchangeably. This research is aimed at exploring how nurses working in a palliative care unit in Malta experience, narrate, and enact if at all, humanity during practice.

Methods: This ethnographic study focused on the daily routines of nurses working in an inpatient palliative care unit in Malta. Participant observation, sixteen semi-structured interviews, and two focus groups were conducted with nurses and the multidisciplinary team between June and August 2022. The interviews and focus groups were audio-recorded and transcribed verbatim.

Results: Nurses often struggled with the term humanity in relation to their palliative care work. They frequently reverted to describing humanity by sharing personal experiences to portray their understanding of concept. Humanity was often described as core to palliative nursing and associated with support, respect, dignity, compassion, and being human. In practice, humanity was experienced when relatives thanked them for their work. Everyday practices that were often deemed as little things, such as shaving a beard or offering a cup of coffee, were highly valued by patients and relatives. Dealing with death and the nature of the work challenged professional boundaries and evoked nurses' humanity in terms of limitations, emotions and blurring the boundary between the professional and personal self. For example, when being used as a 'punching bag' by relatives. Nurses also acknowledged practicing humanity by being compassionate, advocating for patients, and going the extra mile.

Conclusions: This study can provide an opportunity to explore further the intersection of the multiple understandings of the concept of humanity in palliative nursing in Malta to understand how humanity is enacted in practice despite difficulties in defining the concept.

P 7 - Diversity and Disparities

P 7.002 A Theoretical Framework for Understanding Equitable Access to Palliative Care: What Is Known and What Is Missing?

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Background/aims: The need to improve equity of access is a priority issue within palliative and end-of-life care, with a growing number of research studies and initiatives in this area. Crucial to the success of this goal is an understanding of how and why inequitable access occurs, highlighting the value of theory to this practice. However, discussions of equitable palliative care access often neglect theory. This review aims to

identify and explore the conceptual and theoretical landscape relevant to equitable access to palliative care.

Methods: This is a critical literature review of key theories and models of access, considered in relation to palliative and end-of-life care. Relevant theories and models of access were identified through searches of health and social science databases using terms related to access, equity, theory, and health.

Results: Widely used models of access include Aday-Andersen's behavioural model, Levesque et al.'s interface model and Dixon-Wood et al.'s candidacy model. Aspects of all models were applicable to palliative care, although level of engagement with equity issues or theory varied. There is a landscape of established and developing social theory, including that on justice and capabilities, relevant to understanding equitable access to palliative care.

Conclusions: This is the first known exploration of different models and theories for understanding equitable access to palliative care. Palliative care researchers and practitioners may benefit from drawing from multiple models and theories in their work, aligning practical initiatives with an understanding of how socio-political structures, relationships, and individuals can influence access.

P 7.005 Population-based Analysis of Area-based Deprivation and Out-of-Hours Emergency Department Visits in the Last 12 Months of Life in England

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Background/aims: The quality of care provided outside of normal working hours is a priority for patients and families living with terminal illness. Living in a more deprived area is a risk factor for several indicators of poorer quality of care towards the end of life. The relationship between deprivation and out-of-hours Emergency Department (ED) visits in the last months of life has not been described. To describe the rate of out-of-hours ED visits in the last 12 months of life, by age, sex and level of area-based deprivation.

Methods: Retrospective cohort study using individual level population-based mortality data for all deaths in England in 2020, linked to emergency department data for the 12 months preceding death.

We describe the crude rate of out-of-hours ED visits, per death and per 1000 deaths, over the last 12 months of life, by month before death, and by age, sex and level of deprivation. Out-of-hours was defined as after 6pm and before 8am.

Results: 570,416 deaths were recorded in 2020, with 647,320 out-of-hours ED visits in the last 12 months of life. Out-of-hours visits increased rapidly in the months before death; per 1000 deaths the rate of out-of-hours ED visits increased from 84.25 at month 4 before death to 336.05 during the last 30 days of life. The rate of out-of-hours ED visits was higher for people living in the most deprived areas (1.28 per death during the last 12 months of life) than for people living in the least deprived areas (1.02). A clear social gradient was observed: for each increase in deprivation the rate of out-of-hours ED visits increased, this was consistent across age and sex categories.

Conclusions: Living in a deprived area is a risk factor for having more out-of-hours ED visits in the last 12 months of life. It is important to monitor this inequality going forward and to identify the reasons for this inequality and how best to address it.

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P 7.006 Palliative Care and Homelessness: Developing Tools to Gather Feedback on the Experiences of Health and Social Care Support at the End of Life, from People Experiencing Homelessness and their Carers

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Background/aims: Our previous research demonstrates that people experiencing homelessness (PEH) have extremely limited access to palliative and end of life care (PEOLC) despite high levels of need and that improvements to care should be informed by those with lived experience. Understanding the experiences of care and support received at the end of life will facilitate the planning, commissioning, and delivery of services for this underserved population. This project aimed to create and pilot surveys to gather feedback about the PEOLC experiences of PEH and those supporting them to help commissioners identify local PEOLC need and plan service improvements accordingly.

Methods: Focus groups and interviews with homelessness hostel staff, people with lived experience of homelessness and a palliative care coordinator were conducted in a number of hostels in London. They explored the types of questions that would best gather feedback around experiences of PEOLC. From these, surveys were co-produced for use by people with advanced ill health and for carers (such as hostel staff) and peers, following a death.

Results: Participants identified accessibility and flexibility, communication, patient choice and multi-disciplinary working as quality indicators of a supportive PEOLC service. Capturing the extent to which PEOLC services were able to incorporate the unique needs of PEH, including addiction support, in their holistic assessment and facilitate dying in a hostel were also felt to be vital to understanding the patient experience and gaps in current practice. Hostel staff felt that this survey had an additional therapeutic benefit of providing the opportunity to debrief and gather closure when completed following a client's death.

Conclusions: If implemented in collaboration with palliative care providers, these surveys have the potential of real time improvement in care whilst strengthening relationships between health and social care providers.

P 7.007 Investigating the Main Causes of Suffering Associated with Euthanasia & Assisted Suicide of 39 People with an Intellectual Disability and/or Autism Spectrum Disorder in the Netherlands (2012-2021)

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Background/aims: EAS is legally possible in the Netherlands, provided that statutory due care criteria are met, including 'unbearable suffering without prospect of improvement'. There is post-euthanasia scrutiny of all cases and annual reporting by the Euthanasia Review Committee (RTE). To investigate the main causes of suffering and the factors associated with the experience of unbearable suffering which led to the EAS requests granted to patients with an intellectual disability (ID) and/or autism spectrum disorder ASD.

Methods: All 927 case summaries publicly available on the RTE website (2012-2021) were searched for patients who had ID only (n=15), ASD only (n=20) or both ID and ASD (n=4) (total n=39). Inductive thematic analysis was used on these case summaries.

Results: These were highly complex cases. Characteristics directly associated with ID or ASD were the only cause of suffering described in 8 cases (21%). In 8 cases (21%) suffering stemmed from the fact that ASD or ID made it difficult to cope with non-life threatening somatic symptoms or physical decline. In a further 8 cases, characteristics associated with ASD or ID were a significant (but not the only) cause of suffering. In 15 cases (38%) the suffering was caused by psychiatric and/or somatic conditions not substantially related to their ASD or ID. The most frequently described specific causes of suffering were loneliness (77%), physical symptoms (69%), dependence (62%), lack of coping ability (56%), poor quality of life (49%), loss of hope (46%) and lack of flexibility (44%). 18 patients (46%) were younger than 50 years when they died.

Conclusions: For two thirds of patients in this study, the suffering leading to EAS stemmed from the characteristics ASD or ID rather than an acquired medical condition. There is an important national and international discussion to be had around the implications of EAS for conditions that are an inherent and life-long part of the person.

P 7.008 Palliative Care Should Be Offered to More Liver Disease Patients Earlier as Parallel Planning as their Risk of Death in Each Admission Is Very High

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Background/aims: Liver disease (LD) deaths and hospital admissions in England continue to rise. Hospital admissions are associated with high risk of mortality in the admission and within the following two months, yet few liver disease patients have palliative care input. To describe, using national mortality and hospital admissions data the special features of people dying of liver disease heightening their need for early palliative care input.

Methods: People who died from liver diseases as underlying causes were identified from a linked Office for National Statistics (ONS) national mortality and hospital episode statistics (ONS-HES) dataset. Descriptive statistics of patient socio-demographics, place of death and aspects of their emergency admissions in the last year of life (EALYoL) were generated.

Results: 1 in 6.7 people who died from Alcohol related liver disease (ArLD) in 2020 were aged <44 years, 1 in 2.3 < 55. 61% of deaths were in males. There was 4.7 fold higher age standardised <75 mortality from ArLD in the most deprived decile compared to the least, 4.6 and 9.3 fold differences for Hepatitis B and C related deaths. Substance misuse (alcohol and/or drug) was associated with these deprivation differences. 71% of ArLD patients died in hospital. 13% had no EALYoL, 29% just one EALYoL (and in this 24.8% died < 3 days) and 21% only 2 EALYoL. In contrast, 22% had >5 EALYoL, many for paracentesis. Acute decompensation, septicaemia and bleeds were among the commonest presentations. 25% all liver causes died in a final admission of <3 days and 33.2 % patients admitted to ITU during last admission.

Conclusions: LD patients die young and are more likely to come from more deprived and marginalised groups with complex, alcohol +/- drug dependence +/- psychosocial problems. All emergency admissions are serious, often life-threatening with a quarter of patients dying with the first 3 days. Some patients ~ 30% die in their first and only EALYoL. All patients admitted with decompensated liver disease should be seen within 48 hours by a Palliative Care Specialist as this

and each subsequent admission could be their last. The approach should be of parallel planning, hoping for the best (applying life saving interventions e.g. in haematemesis) while planning for the worst (considering advance care planning and palliative management of symptoms including ascites. This applies to patients suitable for liver transplant and especially not deemed suitable unless they decide for only palliative care.

P 7.009 What Impact Does Socioeconomic Status Have on Older Adults' Views of Weight Loss?

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Background/aims: Unintentional weight loss in older adults is common, with 15-20% of those >65 having clinically significant and unplanned weight loss, which is associated with increased mortality and morbidity. Older adults with a higher socioeconomic status have a more favourable Body Mass Index (BMI) and weight circumference profile. More disadvantaged people are more likely to be overweight but also to become frailer in older age. We aimed to explore if socioeconomic status has an impact on patient experience of unplanned weight loss.

Methods: Qualitative secondary analysis of semi-structured interviews with older adults from two prior studies i), those at risk of frailty i) those with cancer. Reflexive thematic analysis was conducted, using the lens of the Nutrition Equity Framework, on anonymised transcripts with formation of themes and subthemes, with relationships between themes investigated. Postcode was used to indicate socioeconomic status.

Results: Transcripts from 23 older adults (mean age 73, range 65 to 87 ; 34% men, Index of Multiple Deprivation (IMD) 1-6 higher deprivation: n= 17; IMD 7-10 lower deprivation: n= 6) were analysed. Three major themes were identified. 1. 'Personal Factors'; that influence a patient's view of weight loss and the likelihood of weight loss prompting help-seeking behaviour. 2. 'Healthcare Systems'; interactions with either public health or individual healthcare systems influence patient experiences of weight loss. 3. 'Can I Change?'; is patients' perspectives of their ability to implement change. Factors in each of the themes were understood through motivating (reinforcing) and demotivating (balancing) factors. The interactions between these themes shape how patients navigate unintentional weight loss and how they experience and interact with the healthcare system.

Conclusions: Patient views of weight loss exist in a complex matrix of personal and systemic factors including socioeconomic status. These may provide barriers to implementing change in these patient groups.

P 7.010 Promoting Culturally Safe Palliative Care: Lessons from Aotearoa, New Zealand

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Background/aims: Internationally, there is recognition of the need to address the difficulties Indigenous and ethnically minoritised people experience in accessing symptom relief, information and emotional support at the end-of-life. Cultural safety has been proposed as a framework to ensure aspirations around equitable palliative care provision are met. To use a cultural safety framework to explore the views of Indigenous

Māori health practitioners and whānau (family) caregivers regarding barriers and enablers to culturally safe palliative and end-of-life care in Aotearoa, New Zealand.

Methods: Design: A qualitative study using a Kaupapa Māori Research approach.

Setting/participants: Interviews were conducted with 103 participants from 4 areas of the North Island of Aotearoa New Zealand. Participants comprised bereaved whānau (family) of Māori with a life limiting illness and Māori health professionals, tohunga (spiritual practitioners) and rongoa (traditional medicine) practitioners.

Results: Māori health practitioners work hard to promote culturally safe palliative and end-of-life care for Māori patients. Such work is, for most, unpaid and unrecognised. Non-Māori staff can support this work by becoming culturally competent ie. familiarising themselves with te reo Māori (Māori language) and respecting cultural care customs. However, to achieve culturally safe palliative care will require fundamental structural change and power redistribution to address the ongoing effects of racism and colonialism.

Conclusions: This research contributes to current efforts within palliative care to promote equity by demonstrating the value of a cultural safety approach. We recognise that what is important for Māori will not be the same for other Indigenous and ethnically minoritised groups. However, the broader principles of acknowledging and enabling the work Māori do, as Māori, for Māori, and with Māori, could be translated into other cultural, geographical, and professional contexts.

P 7.011 Equitable Care for All Ethnicities (ECAE) Audit: A National Clinical Audit of the Validity and Consistency of Recorded Ethnicity within UK Palliative Care Records

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Background/aims: The COVID-19 pandemic demonstrated the importance of ethnicity data in monitoring racial and ethnic inequalities. Good quality ethnicity data is consistent, complete and the recorded ethnic group should be self-determined by the patient. Valid and consistent data can be used to demonstrate the extent, nature and impact of ethnic inequalities in society and improve services. The Equitable Care for All Ethnicities (ECAE) audit examined ethnicity data in palliative care records across the UK. The aim was to investigate the validity and consistency of recorded ethnicity groups across palliative care relevant UK healthcare databases using patient self-definition.

Methods: Nationwide clinical audit led by King's College Hospital (approved 4/4/22). Audit sites recruited from UK palliative care centres (hospitals, hospices, and community services). A one-day 'snapshot' of data was collected to determine 'validity' (a patient's self-defined ethnic group matched their healthcare record), and 'consistency' (recorded ethnic group was consistent across databases). Descriptive analysis was conducted using SPSS.

Results: Sites (N=51) returned data, representing England, Wales, Scotland and Northern Ireland. Data was audited from N=1179 patients. Around 3/4 of audited patients had a valid ethnic group. Many patients were too unwell, lacked capacity or could not participate for another reason. Rates of validity, consistency and missing data by ethnicity will be presented.

Conclusions: The implications of identified patterns in consistency and validity by ethnic group will be discussed, including the impact of poor quality data that can inhibit rigorous research and the monitoring of equitable access and delivery of services. We will make recommendations on ways these may be improved.

P 7.012 Palliative Care in Early Dementia: A Scoping Review

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Background/aims: Early palliative care is recommended for all people with life-limiting illnesses, especially those with dementia. However, neither effective palliative care elements nor palliative care needs are well-defined for early dementia.

Methods: We searched PubMed, CINAHL, EMBASE, Cochrane, PsycINFO, WoS (up to Febr 2021) for studies with different designs and reviews in English over the last decade that focused on palliative care in early stages of dementia. We included papers targeting at least one of the 4 palliative care outcome domains and ACP. Evaluation of abstracts, full-texts, and study quality (using Joanna Briggs Institute tools), was independently screened by two authors.

Results: Sixty-nine studies and 38 reviews were included. Very few papers were explicitly aimed at early dementia. "Early" is still not well defined, but supportive care needs begin with (or before) diagnosis and continue throughout the disease trajectory. Unique opportunities for support arise at 'tipping points' (ie when symptoms, functional status, or caregiving needs change). Early care needs: assurance of future advocacy for enough (rather than too much) care, reassurance against threat of abandonment by caretakers, planning for future scenarios (practical, individual, and relational needs), establishing long-term relationships with providers who could be trusted for future care. Effective early palliative care elements: dementia-specific ACP/goals of care discussions, building a support network, resources for family, individualized care and knowledge of the person, and well-prepared providers.

Conclusions: Findings contribute to the existing literature in two ways: it summarizes palliative needs in early dementia as described by multiple stakeholders: patients, family, professionals; and when considered together, studies inform how dementia-specific early palliative care, including ACP, could be deployed to meet the needs for this population. Funded by King Baudouin Foundation (J1811240-219820); Atlantic Fellowship.

P 7.013 Experiences and Perceptions of People in Prison about Palliative Care and Dying during Incarceration

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Background/aims: The growing population of older people in global prisons is placing increased pressure on correctional healthcare services to provide palliative and end of life care. International human rights policy requires that people in prison should receive care equivalent to care available in the community. Yet little is known about the delivery of palliative care in prisons or people in prisons experiences of this type of care. The aim of this work is to explore the perceptions and experiences of people in prison about palliative care and dying in prison.

Methods: A systematic review and meta-synthesis of qualitative studies identified in PubMed, Medline, ProQuest, CINAHL, Web of Science and CINCH databases was undertaken to identify peer-reviewed articles published in English, from high-income countries, that included raw qualitative data about people's perceptions and experiences of palliative care in prison.

Results: Of the 2193 screened articles, 12 were included. Two analytical themes emerged: 1) the discordance between the expectations and the experiences of people in prison about palliative care, and 2) the pervasive impact of the prison environment on care delivery. People in prison expected to receive equitable end of life care to people in the community. However, many reported experiencing care that did not meet their needs. Lack of agency to advocate for themselves caused feelings of fear, helplessness and isolation. Organisational, structural and provider-level barriers of the carceral system often made palliative care inadequate or inaccessible, such that patients felt that dying in prison became an additional, unwarranted punishment.

Conclusions: Understanding the barriers related to better palliative care provision in prison is critical to developing strategies to ensure that access to best evidence based palliative care is available to those that need it.

P 7.014 Prison-based Palliative Care Indicators: An Essential Step in Quality Assurance

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Background/aims: The increasing demand for palliative care in prisons globally, driven by the rapidly ageing prison population, is a recognised issue. However, understanding of the health of older people in prison, their unique palliative care needs, and the nature and quality of current palliative care is poor. This work aims to review available measures that could inform the development of prison-based palliative care quality indicators.

Methods: A mapping of palliative care and prison health care indicators. This work is based on a Deeble Institute for Health and Policy Research policy issues brief. Systematic reviews of community-based palliative care quality indicators were identified by Medline search. As no palliative care quality indicator sets were found, general health quality indicators were used. Information on the scope, issues, limitations, and future directions of community palliative care and general prison healthcare quality indicators were synthesised to explore similar and divergent issues in quality indicator use across settings, and how these could inform future prison palliative care quality indicator development.

Results: There are limited indicators for any aspect of prison healthcare (n=222) compared to community palliative care indicators (n=390). Both disproportionately measured processes of care (care activities) rather

than health system structure (resources and organisation), or patient outcomes (results of care). Indicators in both settings could lack explicit measures and collect data inconsistently, while lack of clinical guidelines and profound differences between community and prison settings impeded development of prison-specific health indicators.

Conclusions: Developing palliative care quality indicators for prisons will be complex and rely on expert consensus until evidence-based guidelines are developed. Improving collection of standardised data about palliative care need and quality in prisons will help services to identify gaps in care and priorities for service improvement.

P 7.015 Using Peer Research to Explore the Experiences of British Muslims with Palliative Care Needs during the COVID-19 Pandemic

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Background/aims: Background: Everyone deserves the best possible end of life experience. The Covid-19 pandemic exacerbated pre-existing health inequalities and disproportionately impacted the health of people from minority ethnic groups. Understanding the complex intersectionality of religion, ethnicity, national identity and family living situation is vital to understanding these health inequalities.

Aim: To use peer research methodologies to explore the experiences of British Muslims with palliative care needs and those close to them during the pandemic and provide recommendations for improving support.

Methods: A collaborative peer research interview study. Peer researchers were recruited via a Muslim Faith Group and received training and support around qualitative methodologies. Three peer researchers used a coproduced topic guide to conduct telephone interviews between August and September 2021. Thematic coding of transcripts was undertaken and themes and recommendations were coproduced with peer researchers.

Results: 11 people were interviewed by peer researchers, 5 British Muslims with palliative care needs, and 7 family carers. Themes identified included negative impacts of COVID-19 on physical and mental well-being, challenges and barriers to accessing health care, the important role of family carers, experiences of social support and exclusion, and range of information sources and needs. Recommendations relate to culturally and faith appropriate services that meet local need, supporting informal carers, promoting person and family centred care, tackling health inequalities through early involvement and raising awareness of palliative care supports within different communities.

Conclusions: The importance of involving diverse voices in the design and delivery of research, public health policy and messaging and the design and delivery of digital inclusion activities is of paramount importance.

P 7.016 Ethnic Differences in Cancer Deaths at Home before and during Pandemic

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Background/aims: Place of death is a metric used for planning and monitoring palliative care (PC). The COVID-19 pandemic has seen a significant increase in cancer deaths at home. Aim: To determine whether

pandemic increases in the percentage of cancer deaths at home differ by ethnic group.

Methods/Data source: death registrations in England, 2018 to 2021 with underlying cause of death cancer (ICD-10 C00-C97). Ethnicity derived from linked hospital data. Analysis focussed on the largest ethnic groups: White, Asian/Asian British (Asian), and Black/African/Caribbean/Black British (Black). Percentage deaths at home (SDH) was standardised by age to reflect different patterns in place of death across age groups and ethnicities. Risk ratios (RR) comparing the probability of dying at home (DH) versus 'other places' in these ethnic groups in 2020-21 (COVID-19 Pandemic) versus 2018-19 (baseline) are presented, stratified by age (under 75 years, 75 – 84, 85+).

Results: For each ethnic group the SDH significantly increased ($P < 0.05$) from 2018-19 to 2020-21

Asian: 33.9%, 48.1%

Black: 27.1%, 39.2%

White: 30.7%, 41.2%

Largest increases in DH (2020-21 vs 2018-19) were found in Asians (RR 1.48) and Blacks (RR 1.56) under 75 years. These were both higher ($P < 0.05$) than Whites (RR 1.34).

Conclusions: Cancer deaths at home increased by > 10 percentage points during the pandemic for Asians, Blacks and Whites. Pre-pandemic ethnic differentials in these groups persisted in 2020-21, with Asians more likely than Whites, and Blacks less likely than Whites to die at home. The largest increase was for Asians. Differences in the size of the increase were driven largely by people under 75, with higher increases in DH for both Asians and Blacks compared to Whites. These ethnic differences merit investigation regarding: cultural preferences, impact of COVID-19 fears for hospital admission, family/community experiences of access to and quality of PC. Community-based PC needs to ensure appropriate multicultural support at home for more people.

P 7.017 Opioid-related Health Harms and End-of-Life Care: A Population-based Cohort Study

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Background/aims: The COVID-19 pandemic is increasing the prevalence of opioid-related health harms (OHH). Besides opioid poisoning deaths, people with OHH are at high risk of prematurely dying from all major diseases and can benefit from palliative care. This study's aim was to describe and compare healthcare utilization of people with and without OHH in the last 90 days of life.

Methods: This population-based cohort study (2015 to 2020) used linked ICES health administrative databases to identify decedents with OHH in Ontario, Canada. OHH was defined as opioid-related emergency department (ED) visit or hospitalization or opioid use disorder treated with opioid-agonist therapy within three years prior to death. The primary outcome was receipt of palliative care overall and stratified by setting. Secondary outcomes included acute care use (e.g., ED visits). Analysis included descriptive statistics and log-Poisson regression, adjusting for age, sex, socioeconomic position, comorbidities and substance use.

Results: Of 558,535 decedents, 5,903 had OHH. Compared to decedents without OHH, those with OHH were younger and more likely to reside in a low-income neighborhood. Relative risk of receiving palliative care

across all settings was similar among decedents with and without OHH (RR 1.02, 95% CI 0.996-1.03). When analyzed according to setting, those with OHH were less likely to receive palliative care in outpatient, home, long-term care and complex continuing care settings, and more likely to receive palliative care in inpatient settings. Decedents with OHH were more likely to have ED visits (RR 1.095, 95% CI 1.08-1.11), hospitalizations (RR 1.09, 95% CI 1.07-1.11) and ICU admissions (RR 1.36, 95% CI 1.31-1.42) in the last 90 days of life.

Conclusions: Compared to the general population, people with OHH are less likely to receive palliative care in community settings and more likely to receive aggressive care at the end of their lives.

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P 7.019 Specialist Palliative Care Provision to People with Intellectual Disability - Progress Yet Challenges Persist

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Background/aims: The Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing (IDS-TILDA) is a population-based longitudinal study of ageing in adults with intellectual disability (ID) aged ≥ 40 years. Data collection began in 2010. Follow-up at Wave 2 found that 107 of the original 753 participants had died. The aim of this study is to describe specialist palliative care (SPC) provided to decedents.

Methods: A convergent parallel mixed methods study utilising survey and interview techniques to collect data from bereaved caregivers. Quantitative data was analysed using descriptive statistics; qualitative data was analysed using thematic analysis.

Results: In total, 71 bereaved carers participated. The majority (57.7%) of decedents were female; 83.1% had moderate or severe disability; 73% lived in residential care. Reported duration of illness varied- sudden deaths occurred in 4.2%; 26.8% were unwell for ≤ 1 month, while 40.8% were unwell for ≥ 6 months. The most common place of death was the ID organisation (50.7%). Hospital was the next most common place of death (38%); followed by hospice (7%), nursing home (2.8%) and family home (1.4%). Community palliative care (CPC) and/or hospice was provided to 40.8% of decedents. CPC involvement was associated with achievement of home as place of death ($\chi^2(1, N=69) = 11.1, p = 0.001$). Bereaved carers generally spoke highly of SPC. However, SPC teams were often involved only at the end of life. Ongoing challenges to practice were noted. These included a lack of clarity around roles and responsibilities, unequal participation in decision-making, and some evidence of 'elite practice'.

Conclusions: In contrast to previous work, this study has demonstrated relatively high levels of access to SPC. There is evidence that a coordinated palliative care model has developed over time. Study findings point to areas where further improvements in care should be directed.

P 7.020 Achieving Sustainable Improvement of Palliative Care for People with Intellectual Disabilities: A Participatory Action Research Approach

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Background/aims: Sustainable improvement of palliative care for people with intellectual disability (ID) requires a tailor-made and context-sensitive approach with involvement of all stakeholders and integration into strategic policy. The current three-year participatory action research study aims to improve palliative care in ten ID care services in the Netherlands.

Methods: An action research group was formed in each ID care service. This group started with a self-assessment of their palliative care policies and practices based on nine core elements of palliative care described in the Dutch Quality Framework for Palliative Care. The self-assessment included a medical file review of a total of 100 people with ID who died non-suddenly. In addition, a total of 424 professionals returned a digital questionnaire on palliative care competencies and training needs.

Results: The self-assessments showed that individual care plans were recorded and multidisciplinary teams provided physical, psychological, social and spiritual care. Other core elements of palliative care, such as expertise in palliative care, were less present. The questionnaire showed that almost 10% of the professionals reported that they were not at all competent in providing palliative care, and 74% felt that they needed training in palliative care. Reported areas for improvement in the provision of palliative care were increasing the quality of palliative care, improving the expertise of professionals and identifying palliative care needs earlier. Based on the results and the context, in each ID care service goals has been set and tools chosen to improve palliative care. These tools are implemented by the action research groups following a cyclical approach (Plan, Do, Check, Act).

Conclusions: This participatory action research approach shows what is needed for sustainable improvement of palliative care in ID care services. To improve palliative care changes are required both in competencies of professionals, and organisational policies and practices.

P 7.021 End of Life for Socially Marginalised Greenlanders in Denmark - An Intersectional Approach to Total Pain

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Background/aims: Greenlanders share Greenlandic ethnicity but are Danish citizens with the same rights as all Danes. However, Greenlanders in Denmark are overrepresented amongst the poorest and the homeless. Socially marginalised Greenlanders' contact with health and social care is primarily under acute circumstances and few have contact with a medical practitioner and have a disproportionately high risk of ending their lives without palliative care adapted to their experienced pain. The study aims to shed light on the intersecting factors of total pain at the end of life for these Greenlanders in Denmark.

Methods: We conducted an ethnographic study of the everyday life environments where socially marginalised Greenlanders with life threatening conditions can be found. In addition, 10 interviews have been conducted with Greenlandic participants and 10 interviews with 'Greenlandic' and 'Danish' practitioners working in the field. Intersectionality is a theoretical framework used for analysing how identity characteristics such as ethnicity, culture and class impact the experience of total pain.

Results: The socially marginalised Greenlanders face intersecting forms of 'othering'. Characteristics such as language and ethnic appearance; cultural approach to illness and death, social networks, housing conditions, are the 'othered' qualities that affect the experience of physical, psychic, social and spiritual pain at the end of life.

Conclusions: A complex of intersecting ethnic, cultural and class related issues are of importance for the experience of total pain but the findings also illustrate various ways of interpreting and navigating within these indicators. Understanding Greenlanders' everyday life through an intersectional approach is important for understanding their experience of total pain.

P 7.023 Palliative Care for Cancer Patients during the COVID-19 Pandemic: Challenges and Strategies: An Integrative Review

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Background/aims: The COVID-19 pandemic has significant impacts on cancer patients' access to palliative care due to traffic lockdown, social isolation, clinics and hospitals closure, and the restricted visiting policy. The purpose of this integrative literature review was to describe the challenges of cancer patients when seeking for palliative care and to synthesize the strategies implemented by health care systems to cope with these challenges.

Methods: Six databases were searched including Medline, CINAHL, Embase, Web of Science, PubMed, and PsycINFO. The searching terms included cancer, COVID-19, and palliative care. Twenty-six articles that examined cancer patients' challenges or strategies implemented by health care systems, published between January 1, 2020 and July 31, 2022, and written in English were reviewed. These studies were appraised and analyzed using the inductive approach of content analysis.

Results: During the COVID-19 pandemic, cancer patients had five main challenges when seeking for palliative care: insufficient opioids; psychological, social, emotional, and spiritual problems; insufficient palliative care; barriers of communication; and economic hardship. The main strategies of coping with these challenges implemented by health care systems include: providing telehealth; improving the access to opioids; providing psychosocial and physical support; providing home based care; developing advanced care planning; triaging patients; promoting interdisciplinary collaboration; and developing guidelines of palliative care.

Conclusions: During the pandemic, cancer patients had challenges of managing both their physical and psychosocial health. Patients from different countries had different challenges of accessing to palliative care. Health care systems had implemented various strategies to cope with these challenges. Actions are needed to develop a universal guideline and standard of providing palliative care for cancer patients, especially during a pandemic disaster.

P 7.024 Researching Minoritised Communities in Palliative Care: An Agenda for Change

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Background/aims: Palliative care access, experiences and outcomes of care disadvantage those from ethnically diverse, Indigenous, First nation and First people communities. Research into this field of inquiry

raises unique theoretical, methodological, and moral issues. Without the critical reflection of methods of study and reporting of findings, researchers may inadvertently compromise their contribution to reducing injustices and perpetuating racism. To examine key evidence of the place of minoritised communities in palliative care research to devise recommendations that improve the precision and rigour of research and reporting of findings.

Methods: Narrative review of articles identified from PubMed, CINAHL and Google Scholar for a 10-year period augmented with supplementary searches.

Results: We identified and appraised 109 relevant articles. Four main themes were identified

- (i) Lack of precision when working with difference;
- (ii) 'black box epidemiology' and its presence in palliative care research;
- (iii) the inclusion of minoritised communities in palliative care research; and
- (iv) the potential to cause harm. All stymie opportunities to 'level up' health gain across the palliative care spectrum.

Conclusions: Based on the findings of this review palliative care research must reflect on and justify the classification of minoritised communities, explore and understand intersectionality, optimise data quality, decolonise research teams and methods, and focus on reducing inequities to level up end-of-life care experiences and outcomes. Palliative care research must be forthright in explicitly naming structural and systemic racism, describing its operation and engaging in non-judgmental debate on changes required.

P 7.025 Professional Uncertainty about Discussing Sexual Orientation and Gender Identity with Patients and their Significant Others: An In-depth Qualitative Interview Study

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Background/aims: Sexual orientation and gender identity (SOGI) are central aspects of identities. Inclusion of SOGI in discussions between practitioners and patients can inform person-centred care provision. However, comprehensive, evidence-based training for health and social care professionals on how to discuss SOGI is not consistently provided in curricula or by organisations, which may lead to uncertainty. To explore the presence of uncertainty within health and social care professionals' experiences of discussing sexual orientation and gender identity with patients with serious illness and their significant others.

Methods: Semi-structured, qualitative interview study conducted within a critical realist paradigm. Audio recordings were transcribed verbatim and analysed in NVivo using reflexive thematic analysis. Coding was conducted inductively and deductively to a multi-level, holistic model of uncertainty in health care.

Results: 27 health and social care professionals from across England were interviewed. Participants described uncertainties at macro-level,

regarding the relevance of SOGI to healthcare; and the preparedness of services and systems to store and utilise SOGI data for person-centred care. There were interactional-level uncertainties: lacking confidence in leading professional-patient interactions about SOGI; and how and if SOGI information should be shared with other members of the care team. Personal-level uncertainties, informed by individual SOGI experiences, fears, knowledge and beliefs, impacted professional choices about if and how to engage in SOGI discussions.

Conclusions: Professional uncertainty about SOGI discussions exists at multiple levels. Clear guidance and structures can alleviate ambiguity for health and social care professionals, which subsequently supports more consistent approaches to person-centred care and stronger professional-patient relationships.

Funding: National Institute for Health Research (NIHR) Research for Patient Benefit programme (PB-PG-0816-20001).

P 7.027 How Does Ethnicity Affect Presence of Advance Care Planning for Individuals with Advanced Disease? A Systematic Review

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Background/aims: Advance care planning (ACP) enables individuals to make informed decisions about their future healthcare. Some evidence indicates ethnic disparities in ACP. This review aims to examine disparities in the documented presence of ACP by ethnic group, and to identify clinician and patient factors affecting this.

Methods: Mixed-methods systematic review following PRISMA 2020 guidelines. Six electronic databases and four manual journals were searched for eligible papers from 2000–2022. Two independent reviewers searched titles, abstracts, and full texts; 35 papers were included and critically appraised using the JBI tool and Gough's Weight of Evidence. Two PPI contributors guided interpretation.

Results: The primary outcome measure was statistical significance differences in the documented presence of ACP by ethnicity or race. Fifteen papers were included; 12/15 reported White patients had statistically significant higher rates of formally documented ACP compared to people from other ethnic groups. There were no significant differences in the presence of informal ACP.

The secondary outcome measure was patient-based and clinician-based factors affecting ACP presence. Nineteen papers were included in the thematic analysis and narrative synthesis. Patient-based factors were discussed in 13/19 papers, three key themes: poor awareness and understanding of ACP; faith and religion; and family involvement. Clinician-based factors were discussed in 8/19 papers with three key themes: poor clinician confidence around cultural values and ideals; exacerbation of institutional constraints; and pre-conceived ideas of patients' wishes.

Conclusions: This review found differences across ethnic groups in the rates of formally documented ACP despite similar presence of informal ACP, and highlighted potential factors affecting this. Interpretation is limited by over-representation of papers from the US.

P 7.029 The Multicultural Experience of Bereavement during COVID-19

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Background/aims: Australians faced some of the strictest COVID-19 public health measures globally. With international borders closed, the experience of culturally and linguistically diverse (CALD) people living in Australia bereaved during the COVID-19 pandemic may be unique from others. To understand the experience of bereaved people from CALD communities living in Australia during the COVID-19 pandemic.

Methods: Multicultural health workers who provided psychosocial support to bereaved people from CALD backgrounds during COVID-19 participated in semi-structured interviews as community members as well as conduits between health services and their communities. Topics included visiting restrictions, funerals, social supports, mental health supports and the impact of restrictions on cultural practices. Interviews were conducted in English, audio-recorded, transcribed, and analysed using thematic analysis.

Results: Eleven interviews were conducted with workers supporting a range of community groups including: African, Lebanese, Afghan, Syrian, Vietnamese, Chinese and Spanish. People from CALD communities faced specific challenges. Data revealed perceived discrimination and blame for the spread of COVID-19 by mass media, expired Visas during lockdowns, and interactions involving police and government scrutiny that triggered traumatic histories, hypervigilance, and fear. Language barriers compounded confusion about restrictions. Being unable to gather with family, engage in religious or cultural rituals, brought on feelings of guilt and shame. Participants worked overtime to support and advocate for their communities and developed initiatives linking people with each other and their places of worship virtually.

Conclusions: The pandemic amplified the inequities of multicultural communities living in Australia. Lessons can be learnt from multicultural health workers who work to keep communities together and strong.

Funding: Medical Research Future Fund (MRFF).

P 7.031 'We Don't Know What to Do' - Finding a Model of Palliative Care for People Who Use Drugs and/or Alcohol

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Background/aims: End-of-life care for individuals who use alcohol and/or drugs poses multi-faceted challenges, considering complex clinical, social, and mental health issues. With little experience with this group of people, a literature review seemed the best starting point. The aim of the review was to identify the palliative care needs and models of care for people who use drugs and/or alcohol.

Methods: A mixed-methods systematic review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis and the JBI Manual for Evidence Synthesis; six databases were used to identify studies. Full-text reviews were completed independently by two reviewers and a third resolved differences. Qualitative and quantitative data were tabulated using narrative synthesis and categorised, with similar and divergent findings reported accordingly.

Results: Thirteen studies, a mix of qualitative and quantitative papers, were included. A range of data collection methods, across a variety of settings were identified. Three themes emerged which may underpin a model of care: interpersonal/organisational relationships; holistic care; and interactions with other services, including training.

Conclusions: The difficulties for individuals who use alcohol and/or drugs as well as their formal and informal carers, in relation to end-of-life care were highlighted, revealing issues to do with access, care, and skills; and which may form the basis for exploring improved care models. Despite the end-of-life needs of this group seeming no different to others, the challenges of creating a model of care include developing inclusive policies; sensitising staff to distinctive individual needs; and enabling staff training exchanges between both drug and alcohol services and palliative care services.

P 7.032 Advance Care Planning among Older Adults of Moroccan Origin: An Interview-based Study

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Background/aims: Advance care planning (ACP) is rare among elder migrants for social, cultural, and religious reasons. This study aimed to explore ACP-related knowledge, experience, views, facilitators, and barriers among older adults of Moroccan origin in Belgium.

Methods: Semi-structured interviews were conducted in Darija (Moroccan Arabic). General practitioners in Brussels and Mechelen recruited participants. Data were analyzed qualitatively using the constant comparative method.

Results: The 25 interviewees (average age, 74 years) lacked advance care planning knowledge and had not discussed it with healthcare professionals. They had discussed burial and residential care wishes with relatives. After a brief explanation, most interviewees did not find advance care planning useful or meaningful, mainly for religious reasons. After more extensive explanation with specific examples, they were more willing to have discussions with their general practitioners and/or relatives. The most frequently mentioned facilitator was general practitioners' provision of information; children's involvement in advanced care planning discussions and the desire to not be dependent on children were also mentioned. Barriers were a lack of knowledge, procrastination or good health, trust in one's children to take over care and make decisions, fear of worrying one's children, the possibility of returning to Morocco, and low education levels.

Conclusions: Despite an initial lack of knowledge about advance care planning, many older Moroccan migrants were willing to talk about it and some began it after receiving information in their native language. Care providers should facilitate advance care planning discussions for these patients, paying attention to individual needs and preferences.

P 7.034 Advance Care Planning among Older People with a Turkish Background and Palliative Care Needs: A Qualitative Interview Study

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Background/aims: Advance care planning is rare among older adults with a migration background for social, cultural, and religious reasons. To explore advance care planning-related knowledge and perspectives among older people with a Turkish background and palliative care needs in Belgium.

Methods: Semi-structured interviews were conducted in Turkish. Data were analyzed qualitatively using the constant comparative method.

Results: This study reveals that many older Turkish-origin patients with palliative care needs in Belgium lack awareness and detailed information about ACP. While some of our respondents had discussed their end-of-life preferences with family members, most did not feel the need to discuss future care preferences because their trust in God and family. One expressed reluctance to discuss ACP due to discomfort with the subject of death. However, some of our respondents viewed discussions as

beneficial, relieving the burden on families and answering “what if” questions ahead of time. This urges us to consider the importance of approaching ACP conversations in a personalized manner, as not all patients and families have the same views and needs. The self-identified barriers to ACP were fear of making the wrong decision and a “live in the moment” attitude. The most mentioned facilitator was obtaining sufficient information about ACP. Recent illness or a death in the family also triggered thinking about and discussing ACP issues.

Conclusions: Health care providers in Belgium should provide tailored information about ACP to Turkish-origin adults with palliative care needs. ACP discussions should also explore the individual’s health-related knowledge and personal values, paying attention to social and religious cues. ACP discussions should start well before patients become very old or palliative care needs arise.

P 7.035 Death as a Social Justice Issue: The Impact of Deprivation in Accessing Health Services in the Last Year of Life

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Background/aims: Research has found that people living in deprivation have reduced access to palliative care services known to improve satisfaction with end-of-life care. It has been suggested that the disparity might relate to specialist palliative care services’ availability, affordability, acceptability, and geographical accessibility. It has also been suggested that the ‘inverse care’ law might mean that *people in deprived areas not only receive less support from specialist palliative services but are also less likely to receive ‘primary’ or ‘generalist palliative care’ from their usual care providers*. To investigate end-of-life service access and utilisation for people living in areas of deprivation in two regions of Aotearoa, New Zealand.

Methods: The national unique identifier of people who died over a 6-year period was linked to service data from hospices, hospitals and primary care.

Results: Statistically significant associations were found between deprivation and health service use. People living in deprivation related to the distance they had to travel for essential services were less likely to experience a hospital admission ($p < 0.001$). Furthermore, people living in moderately remote areas with high deprivation were less likely to access their general practitioner ($p < 0.020$). An association between deprivation and contact with hospice services was identified with people living in areas of high deprivation, less likely to access a hospice admission in the last year of life ($p < 0.013$). However, people living in areas of deprivation in moderately remote areas were more likely to receive community hospice contacts, however this was not statistically significant ($p < 0.070$).

Conclusions: Evidence of inequities in access to and utilisation of health services in the last year of life for people living in deprivation is evident. Further research is needed to explore the strengths of a community experiencing deprivation which may help to explain how people use healthcare services in the last year of life.

P 7.037 Social Deprivation and End-of-Life Care Use among Adults with Cancer

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Background/aims: The role of social determinants of health in end-of-life (EOL) care inequities is poorly understood. Socioeconomic disadvantage, as measured by the social deprivation index (SDI), has been associated with poorer health outcomes, but its relationship to EOL outcomes has not been fully explored. We examined the relationship between SDI and EOL outcomes among adults with cancer.

Methods: This retrospective study used electronic medical records from an academic health system in Atlanta, Georgia, USA to identify adults who died with cancer between 2013 and 2018. We derived SDI from patient postal codes. EOL outcomes were palliative care consultation (PCC); hospice order; chemotherapy, radiation, or surgery (disease-directed treatment), intensive care unit (ICU) stay, and emergency department (ED) visit in the last month of life. We used multivariate logistic regression to evaluate the association between SDI and EOL outcomes, including an interaction between SDI and race.

Results: We included 26,655 decedents. Individuals residing in the most deprived neighborhoods had lower odds of receiving a PCC (aOR = 0.71; 99%CI = 0.57-0.90), hospice order (aOR = 0.86; CI = 0.72-1.02), disease-directed treatment (aOR = 0.72; CI = 0.55-0.93), and ED visit (aOR = 0.29; CI = .16-0.52). Relative to whites in the least deprived neighborhoods, Black people in the most deprived neighborhoods had 61% greater odds of receiving a PCC (aOR = 1.61; CI = 1.09-2.39), 37% greater odds of receiving a hospice order (aOR = 1.37; CI = 1.02-1.86), 51% greater odds of disease-directed treatment (aOR = 1.51; CI = 0.93-2.45), and more than a 400% increase in the odds of an ED visit (aOR = 4.43; CI = 1.92-10.2).

Conclusions: Further study is needed as to why Black people in more deprived neighborhoods receive more referrals for hospice and palliative care yet receive more disease-directed and emergency care at the EOL. Efforts to improve EOL equity should consider the role of neighborhood deprivation in care use and outcomes.

P 7.039 Access to Palliative Care among Muslim Immigrants and their Direct Descendants in Germany: Opportunities, Obstacles, Reservations

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Background/aims: Palliative care (PC), as well as hospice care (HC), does not reach all patient groups in Germany to a similar extent; in particular, people with a migration biography are conspicuous for low utilization. This especially applies to the group of Muslim immigrants and their direct descendants (MID), which comprises more than four million people. However, the current state of research is still limited and not yet able to portray the heterogeneity of diverse migration subgroups nor to elaborate frameworks to provide equal access to PC for these vulnerable communities. The aim of this study is to elucidate the underlying

reasons that impede utilization and to identify the conditions under which PC would indeed provide necessary aid, thus enabling lower-threshold and more targeted access to PC for MID.

Methods: This is a prospective multicenter four-arm grounded theory study using Kaufmann's "understanding interview". Consent forms and interviews were translated by interpreters as needed. An in-depth literature review, including grey literature, was conducted prior to recruitment.

Results: At present, three arms have reached theoretical saturation. So far, we involved 28 patients and relatives via two university hospitals along with a culturally sensitive HC service, two outpatient PC services, and a primary care urban hospital. Participants ranged between 24 and 78 years, originated from seven nations, and encompassed five branches of Islam. Currently, about 20 experts with various professional backgrounds are being interviewed in the fourth arm until December 2022.

Conclusions: To our knowledge, this is the first specific and one of the world's largest studies yet to examine PC among MID, with a decisive focus on access requirements. The data collection and analysis will be completed by the 18th World Congress in 2023, so we are looking forward to presenting our final results there for the first time.

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P 7.040 Spaces of Hope at the End of Life for Socially Marginalised People in Denmark

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Background/aims: Within the field of palliative care it is recognized that 'hope' is an essential phenomenon with potential to improve quality of life, to influence meaning and to help coping with pain. Socially marginalised people have limited access to palliative care and risk receiving a poorer quality of care leading to a death characterised by pain, loneliness and stigmatization. The aim of this study is from a palliative care perspective to gain insight into the forms of hope that need to be considered in order to achieve quality of end of life for socially marginalised people in Denmark.

Methods: An ethnographic study of the everyday places where socially marginalized people with life-threatening illness can be found. This was combined with photo-elicitation to gain an insight into the narratives of everyday life, and to capture symbolic representations of the target group's end of life hopes.

Results: The study finds various 'spaces of hope':

1. *Spaces of belonging* - everyday places such as homes, drop-in-centres- or pubs that can give recognition to people who are otherwise marginalised from 'the other side' of society
2. *Aesthetic spaces* - where nature, art or artefacts evoke an emotion of being connected to life.
3. *Spaces of legacy and grief* - memorialisation ceremonies which recognise and celebrate the value of life irrespective of how it was lived.

Giving back the 'photos of hope' to participants seems to encourage positive self-recognition in contrast to self-declared identities such as 'junkie' or 'fucking alcoholic'.

Conclusions: In caring for socially marginalized people with life-threatening illness, it is important to pay attention to which spaces of hope are accessible, to those that can be adapted to a life with deteriorating illness or whether new spaces can be opened up. Further research is needed to explore the potential for using photos in 'hope-work' at the end of life.

P 7.041 Exploring Attitudes to Death and Dying among Lesbian, Gay, Bisexual and Heterosexual People

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Background/aims: Background: Discrimination against LGBTQ+ people is common in many settings, including health care. Experiences of discrimination in health care settings may lead to delays in accessing care or avoiding care and can ultimately impact the quality of care that people identifying as LGBTQ+ receive at the end of their lives. To describe the priorities of LGBTQ+ people at the end of their lives, explore their experiences of bereavement, and their views on how society discusses death.

Methods: Questions were presented in an online survey designed to explore attitudes to death and dying among the UK public. It was distributed by a large health and beauty corporation to members of their rewards program. Data was subject to exploratory qualitative and quantitative analysis.

Results: 2,261 people responded to the survey, with LGB people having the strongest representation from the LGBTQ+ community. Participants from all sexual orientations felt that discussing death was important but not done enough in society. Similar barriers and facilitators to discussing death were common among all groups. LGB people were more likely to prioritize being around friends and having their cultural needs met than heterosexual people and were more likely to report creating openness among friends as a main benefit of discussing their own end of life. Following a bereavement, some LGB groups were less likely to have family, friend or counsellor support.

Conclusions: Health and social care professionals should recognise that people from the LGB community may have specific needs and desires about the people they want around them for support, and this may or may not include their biological family. Cultural needs may be particularly important for LGB people, which highlights a need for professionals to be trained to recognise and support cultural needs during caring activities and end of life planning. Bereaved LGB people may lack access to support and may benefit from targeted support programs.

Conflict of interest: No conflict on interest to declare.

P 7.042 Evidence on Sexual and Gender Minority Parents' Experiences from Paediatric Health Services and Healthcare Professionals' Attitudes

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Background/aims: Modern families' structure awareness and their unique culture are critical in providing high quality and comprehensive paediatric palliative care (PPC). Although, most studies focus is on a heterosexual and cisgender context, an increasing interest on sexual and gender minority (SGM) parents' experiences is observed. The aim was to assess and synthesise current evidence with regard to healthcare professionals' (HCP) attitudes, knowledge and beliefs, and SGM parents' experiences of accessing health services for their children with a focus on chronic conditions / complex needs.

Methods: A wide range of free text terms was used to conduct a systematic search in four electronic databases according to the PRISMA Statement guidelines. Predefined selection criteria were applied to retrieve research studies, with no time limit on publication. Findings were integrated in a narrative synthesis.

Results: Of 2,283 initial references retrieved, 17 articles met the criteria. The majority of the studies explored SGM parents' experiences with paediatric health services. Parents had positive and negative

interactions with HCP, with a wide spectrum of challenges reported that included the bureaucratic systems, homophobia, feelings of vulnerability, and the impact of disclosure tension on their children care. Only two studies found to report parents' experiences when children had complex or long-term medical needs, where overall discrimination affected the care they received for their children. HCP knowledge was poor, and their attitudes / beliefs were significantly associated with their professional, social, religious and political background.

Conclusions: SGM parents deal with many challenges when accessing healthcare for their children, especially in managing chronic disorders / continuing care. HCP should improve their awareness and have adequate training on how to care and advocate for those families. The review did not identify any studies on PPC setting which suggests that research on this context is required.

P 7.043 The Quality of Palliative Care for People with Intellectual and Developmental Disabilities in the Netherlands

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Background/aims: People with intellectual and developmental disabilities (IDD) in The Netherlands are rapidly getting older and their palliative care needs are increasing. However, we do not know the quality of palliative care for people with IDD. With this study we want to gain insight into the quality of palliative care for people with IDD in the Netherlands and its facilitators and barriers.

Methods: A team of researchers developed an online survey based on 13 consensus norms described in the European Association of Palliative Care White Paper on Palliative Care for People with IDD (2015), covering key areas of palliative care delivery for this population. For each consensus norm respondents were asked whether the norm has been implemented. Answers could be given following a 5-point Likert scale ranging from "never" to "always". There was room for comments. We analyzed these data using descriptive statistics in SPSS and thematic analyses in Atlas-ti.

Results: 328 respondents completed the survey. Most of them work in the direct care of people with IDD (73%).

High scoring norms include "support of physical needs" and "involvement of carers in end-of-life decisions". Lower scoring norms are "involvement of people with IDD in end-of-life decisions and telling them they are terminally ill", "training and support of professionals", "bereavement support of carers" and "cooperation between services".

The comments made by the respondents show professionals face various challenges in all the areas of the consensus norms. Additional, effective but also challenging elements are "expertise and skills", "collaboration and communication" and "organizational conditions".

Conclusions: Palliative care for people with IDD is complex and challenging. This study shows there is a great need for improvement in different areas and provides advice for the direction of needed improvements.

P 7.044 How Prevalent Are Palliative Care Related Symptoms and Needs among People with Dementia in the Community? A Cross-sectional Analysis of the Integrated Palliative Care Outcome Scale Dementia (IPOS-Dem)

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Background/aims: The IPOS-Dem is a holistic, person-centred outcome measure for monitoring palliative care symptoms and needs in people with different stages of dementia. Person-centred palliative care symptoms and needs in district nurse-/community care settings have not yet been described. The aim is to assess the palliative care symptoms and needs of people with dementia cared for by district nurse- and community services, and to contrast palliative care needs with quality of life (QoL).

Methods: Cross-sectional descriptive analysis of baseline data from a validation study of the Swiss IPOS-Dem. A convenience sample of people with dementia cared for by district- and community care services in Switzerland was recruited. IPOS-Dem and QUALIDEM (for QoL) were measured by both nurses and relatives at baseline. Data were analysed using descriptive statistics for individual items and scale scores.

Results: In this interim analysis, sample (n = 45, median age 84 years, 29% male), 19% had early-, 62% moderate-, and 8% severe stages of dementia. The Australian Karnofsky Performance Status median 60% (range: 40%-80%) showed moderate functional status. IPOS-Dem demonstrated major palliative care related symptoms and needs, with severe or very severe problems present in at least 25% of the sample for the items *Pain, Fatigue, Drowsiness, Poor Mobility, Skin problems, Communication problem, Patient anxiety, Family anxiety, Depression, and Aggressive behaviour*. Family anxiety was prevalent in 49% of the sample; *Fatigue, Drowsiness, and Skin problems* in 31%. Overall QoL was very good, with high median values of QUALIDEM; more than 70% in each area except for subscale *I: Having something to do* (median 67%).

Conclusions: Despite the overall high QoL measured in people with dementia living in their own home, hidden physical symptoms together with emotional and palliative care related needs may be highly prevalent even in earlier stages of dementia.

P 7.045 Experiencing Total Pain in Burn Intensive Care Units: A Meta-ethnographic Review

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Background/aims: Critically burned patients and their families experience unbearable pain and suffering. Working in burn intensive care units (Burn ICUs) is also a major cause of emotional distress for healthcare professionals. Although burn-related pain is part of the acute care provided to burned patients, little is known on how to optimally provide suffering relief. To understand patients, families, and healthcare professionals' experiences with total pain and its relief in Burn ICUs.

Methods: Meta-ethnography of qualitative evidence following PRISMA. Studies were retrieved from 3 databases (PubMed, ISI and EBSCO host searching CINAHL Complete, MEDLINE Complete, and MediciLatina), combining 3 sets of terms (suffering AND burns AND qualitative). Original qualitative studies exploring experiences of critically burned patients, their families and healthcare teams in Burn ICUs were included from inception to October 2022.

Results: 305 articles retrieved; 10 selected for analysis and synthesis, with 263 participants. 11 themes emerged from the analysis: Patients' suffering (changed self, mental anguish, physical pain and

its management from onset until discharge when it happened, and divergent opinions about sedation); Families' suffering (navigating through the experience, managing uncertainty about survival, vicarious suffering, and isolation in their "bubble of trauma"); and Nurses' suffering (stress, compassion fatigue, and burnout).

Conclusions: This meta-ethnographic review shows that critically burned patients and their families experience total pain. Nurses caring for these patients and their families express signs of physical and emotional suffering. Timely and targeted palliative care could have a positive impact on these patients, families, and professionals, improving care outcomes. Further research is needed to determine how healthcare systems can best optimise palliative care provision to critically burned patients and their families to address their experience of total pain.

P 7.046 Building CBPC Services for Marginalized Populations

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Background/aims: The existing palliative care services are not well equipped or designed for patients who are vulnerably housed, stigmatized, or isolated populations. In low-middle-income countries, most people have never received any palliative care resulting in a prolonged struggle with serious health-related suffering. Aim is to bring more insight into developing community-based palliative care services for marginalized communities.

Methods: Design, methods and approach taken: Multiple conversations with stakeholders, health care professionals, project officers, and representatives of marginalized communities experienced in community-based palliative care initiatives.

Results: Here is the revised step-by-step approach for establishing palliative care in a marginalized community.

Planning phase:

- 1 Define the target population
- 2 Setting protocols on patient recruitment, eligibility, basic services/ care and patient referral
- 3 Team Preparation/ Recruitment and training of staff
- 4 Planning the interventions with community heads
- 5 Site assessment

Implementation phase:

- 1 Community outreach activities
- 2 Selecting Volunteers from the community
- 3 Forming collaborations/ Linkages with other services
- 4 Train Volunteers
- 5 Identification of patients in the community
- 6 Facilitating Home visits
- 7 Social support Program
- 8 Doctors Home Visits
- 9 Initiating regular outpatient services
- 10 Scaling up services

Evaluation phase: Evaluation should include reporting on the structural characteristics and operations of delivering services to marginalized communities. Patient-reported outcome and experience measures could be used for socially disadvantaged people.

Conclusions: Ongoing efforts should be taken to improve awareness of palliative care. Engaging with the community for planning, implementing and evaluating services improved community ownership of the program.

P 7.047 Systematic Review of End-of Life Care Provision for People from Minority Ethnic Communities in the UK

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Background/aims: People from minority ethnic groups make up an increasing proportion of the UK population. Palliative care therefore needs to ensure the availability and accessibility of care that meets the diverse needs of people of all ethnicities. Summarising and understanding the current knowledge in this field is important for informing practice and policy, recognising and addressing the needs of people from minority ethnic communities, and indicating gaps in knowledge where more research would be valuable. Building from a previous review (Evans et al, 2012), we are systematically reviewing the evidence on end-of-life care (EoLC) for people from diverse ethnic backgrounds.

Methods: We initially searched three databases: MedLine, Embase, and CINAHL from inception to 2022. Two authors independently screened citations, agreed full-text papers for retrieval, assessed texts for inclusion, discussed differences, and agreed a final set. The review is ongoing, and searches of other literature and additional databases, including Web of Knowledge, Cancerlit, and PsycINFO, will follow.

Results: This initial search found 1367 citations from which we included 29 studies. Twenty of these used qualitative methods: semi-structured interviews and focus groups, seven were quantitative, and two used mixed methods. Studies mostly focused on people from South Asian and Black Caribbean communities (n=19). Seven studies were with informal carer participants, six with patients, and five with health care professionals (HCPs). Ten studies were with patients, informal carers, and HCPs combined. Specific settings identified were hospitals (n=9), hospices (n=6), and community (n=5).

Conclusions: More primary research studies of EoLC for people from minority ethnic groups have been published in recent years. Our initial search of three databases identified 29 studies, and the remaining searches including additional databases will add to this. Our final review will present full, detailed information on current knowledge in this field.

P 7.048 Building a Partnership: Palliative Partners in Head and Neck Cancer (PP-HANC)

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Background/aims: Northern England has some of the highest head and neck cancer (HNC) incidence rates linking with high socio-economic deprivation. There are socio-economic inequalities in outcomes e.g. poorer survival; increased hospital deaths (44% in most deprived versus 38% in least deprived areas). One in five people die within the first year but little is known about healthcare needs, resource utilisation and service provision during this time. Our aim is to establish a HNC palliative care partnership within Northern England; develop research priorities; identify high quality routine data sources and utilise these to address key research priorities.

Methods: A snowballing approach was used to build the network of patient and public involvement (PPI) representatives, healthcare professionals, researchers and 'routine data' specialists. Purposive sampling recruited members with 'low update' occupations and in low research

activity areas. To facilitate PPI, representatives were assigned a 'buddy' to support involvement and identify research training needs. A Delphi consensus process has commenced to define research priorities and potential routine datasets from national and local providers will be used to address the identified research questions.

Results: PP-HANC network members (n=121) include patients, specialist nurses, psychologists, doctors in oncology, surgery and palliative care, radiographers, dietitians, speech and language therapists, general practitioners, community nurses, data specialists and researchers. Thirty-three key statements about potential research priorities, developed from systematic reviews, were circulated for the first of two Delphi rounds (completion by February 2023).

Conclusions: A dedicated team, with PPI at its centre, has been established, focused on improving palliative care for incurable HNC patients. Future activity will focus on identifying key research priorities relating to inequalities and healthcare utilisation and assessing to what extent routine data can address these.

P 7.049 The Impact of COVID-19 on the Quality of Palliative Care for People with Intellectual and Developmental Disabilities

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Background/aims: There is increasing awareness of the palliative care needs of people with intellectual and developmental disabilities (IDD). However, it is unclear what impact the COVID pandemic has had on the quality of palliative care for people with IDD. This study aims to gain insight into the impact of the COVID pandemic on the palliative care of people with IDD in the period of 2020 and 2021 worldwide.

Methods: A team of researchers developed an online survey based on 13 consensus norms described in the European Association of Palliative Care White Paper on Palliative Care for People with Intellectual Disabilities (2015), covering key areas of palliative care delivery for this population. For each norm, respondents were asked how the COVID pandemic affected the norm in 2020 and 2021. The response options were: "No influence", "Better during Covid-19", "Worse during Covid-19" or "Unknown". There was room for comments. The results were analysed using descriptive statistics in SPSS and qualitative analysis software.

Results: In total, 726 respondents from 22 countries participated (most of them were professionals working in the direct care of people with IDD). The pandemic of COVID-19 had little impact on some areas (e.g. telling people with IDD they are terminally ill, involvement of people with IDD and their carers in End-of-Life decisions). However, a negative impact was seen in other areas (e.g. support of needs, access to hospital and palliative care, involvement of families during terminal phase and accessibility of funerals). These areas were negatively affected by a lack of physical contact, strict rules, use of protective equipment, digitalization, fear of infection, increased workload and higher absenteeism.

Conclusions: The COVID pandemic has had a variable impact on palliative care for people with IDD in 2020 and 2021. In the event of a new pandemic, challenges in these negatively affected areas must be proactively addressed to optimize the palliative care for people with IDD.

P 7.050 Is Training in Spiritual Care Discriminatory? Results of an Umbrella Review

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Background/aims: A problem in the field of spiritual care (SC) is bridging the gap between SC education/training and implementation in practise. In addition, researchers have found that in the field of education, consideration of different denominations is neglected. The aim of this study was to find out whether the gap between SC education/training and implementation in practise has narrowed and to identify aspects of neglect of multi-confessionalism by focusing on the dominant religion in each case.

Methods: A systematic literature search was conducted in PubMed, CINAHL, Web of Science databases as well as a hand search in scientific journals. Systematic reviews published between 01/2012 and 01/2022 were included. Ten reviews were selected to answer the research question. A quality analysis based on criteria of Joanna Briggs Institute and a synthesis of the results were performed.

Results: Five themes were highlighted that can help bridge the gap between SC training and implementation in practise: 1. working with chaplains 2. learning methods 3. role models/mentors 4. time, relationships and working environment 5. training models and protocols for SC. However, some studies have raised concerns about whether the respective trainings could be discriminatory. This is because in some trainings the predominant religions are covered without considering other denominations. Other trainings focused on the concept of SC without specifically addressing religions.

Conclusions: Evaluation results as a basis for training concepts are essential for sustainable progress. Not only positive but also negative results need to be evaluated, analysed and conclusions for practice must be drawn from it. To this end, there needs to be a focus on exploring how training can address members of different denominations and correspond to a multi-denominational world.

P 7.051 How Accessible Is the Evidence Base for Providing LGBTQ+ Inclusive Palliative Care? An Evaluation of the Potential Impact of "Paywalls" on Critical Learning

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Background/aims: LGBTQ+ people experience higher burdens of life-limiting illnesses, worse health outcomes, additional barriers to accessing palliative care, and are historically underrepresented in research compared to non-LGBTQ+ populations. Although health and social care professionals and policy makers should have access to robust up-to-date evidence to inform their practice, not all research is open access. This study aimed to assess the accessibility of literature related to LGBTQ+ inclusive palliative and bereavement care.

Methods: Rapid scoping review of the evidence related to LGBTQ+ inclusive palliative and bereavement care to determine open access status. Articles from three published systematic reviews were included (2012, 2016, 2020). The reviews were updated and assessed using the

original search and inclusion/exclusion strategies. All included articles were searched for in Google Scholar, ensuring institutional sign-ins were deactivated, to assess 'accessibility'.

Results: Between 1993-2022, we identified 66 articles related to LGBTQ+ palliative and bereavement care, of which 21% (14/66) were open access. Overall, articles were most commonly (21%) published in LGBTQ+ focused journals, with only 17% published in the palliative care-focused journals which palliative care clinicians are most likely to have access, and the remainder published in social science, psychology, cancer and aging journals. Recently, there has been a shift in target journal with the majority of articles since 2018 (55%, 6/11) published in palliative care-focused journals.

Conclusions: Access to research evidence is central to enabling health and social care professionals to deliver high-quality person-focused palliative and end-of-life care. Marginalisation in research, and publication, limits accessibility of vital research evidence related to LGBTQ+ populations. Evidence to support equitable palliative care accessibility for all should be accessible to all.

P 7.052 Increasing Access to Palliative Care Services for Beneficiaries from Disadvantaged Communities

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Background/aims: In Romania, the palliative care needs were covered at 11.6% in 2017, according to the Romanian Palliative Care Services Catalogue 2018, considering the recorded number of deaths certifies the increased need for these services. According to an Analysis report on the situation of the palliative care services suppliers in Romania in 2019, the services were offered in the following forms of support: 87 in-patient units, 9 home care services, 7 outpatient centers, 3 day centers, 1 support call center. The existing palliative care services cannot cover the entire need and clear limitation can be observed in accessing these services, especially by patients from the rural areas.

Methods: Ensuring adequate access to palliative services for patients suffering from progressive chronic illnesses, from rural and disadvantaged small urban communities, by developing integrated and coordinated models of palliative care services.

A group of experts was assembled in order to draft up 3 integrated collaboration models between the specialized palliative care team and the team of professionals that could provide basic palliative care services within the rural communities.

Results: These models were submitted to a consensus process involving both the members of the specialized palliative care teams and the professionals from within the rural communities in 5 areas of the country. The answers to the questionnaires are trying to clarify various aspects regarding: beneficiaries, care providers, facilitating structures, implementation monitoring. The questionnaires were sent to a group of 201 professionals both from the specialized palliative care teams and professionals from within the communities.

Conclusions: Even though the need for palliative care services is high, the GP's are facing on one hand the lack of time and specialization in palliative care but also financial regulations regarding the visits they could perform in the community for their patients.

P 7.053 Inventorising Existing Approaches and Resources for End of Life Care Planning with People with Intellectual Disabilities: A Scoping Review

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Background/aims: The importance of involving people with intellectual disabilities (PwID) in end-of-life care planning is recognised, but there is

a lack of knowledge around the availability and effectiveness of approaches and resources to support EOLCP for PwID and their family/staff carers in adult ID services.

AIMS: To inventorise what end-of-life care planning (EOLCP) approaches and resources for PwID are currently available in

- (a) the international literature and
- (b) voluntary sector organisations in the UK.

Methods:

- (a) Rapid scoping review incorporating existing reviews, empirical research and grey literature;
- (b) Online survey of voluntary sector organisations and calls on social media, in order to include unpublished information.

The quality of resources and approaches collected through the scoping review and survey was critically appraised using an adapted version of the AGREE II tool with results discussed with the project's co-design team.

Results: The survey identified specific resources used by staff/family carers in EOLCP and descriptions of approaches to EOLCP. The literature review identified papers which described approaches to EOLCP, made recommendations for effective EOLCP and referred to approaches to EOLCP within descriptions of the experience of EOLC. A limited number (6) of papers described or evaluated the quality of specific resources currently available for EOLCP for adults with ID. These resources focused on staff training and communication.

Conclusions: Paid and family carers describe using a range of in-house and publicly available resources to support EOLCP, including resources designed for PwID and generic resources. There is a lack of peer reviewed literature which focuses on the evaluation/quality assessment of currently available resources and approaches to EOLCP for people with learning disabilities and their families/staff in adult ID services.

P 8 - Psychosocial and Cultural Challenges

P 8.001 Spirituality Meanings through the Eyes of Healthcare Professionals: A Content Analysis

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Background/aims: Spirituality is a broad and complex concept, with different interpretations depending on cultural, religious, and academic backgrounds. There is a burgeoning debate in this context about the most accurate meaning and the possibility of having a single universally agreed-upon definition for this concept.

This study aims to move forward on this discussion, presenting a content analysis of the spirituality concept, and identifying its main constructs.

Methods: A qualitative descriptive study was performed based on the secondary analysis of the following question "What words/expressions/questions do you use to address spirituality?". This question was part of an e-survey addressed to healthcare professionals about spiritual care. The content analysis was established from the identification of terms or expressions used by Portuguese healthcare professionals.

Results: In total, 180 healthcare professionals completed the study. Most of the participants were female (82.2%), nurses (43.9%), worked in the Palliative Care field (58.9%), and only 12.2% referred they did not have spiritual or religious beliefs. They considered spirituality as a "connection" or "faith" (54%), which offers (or is the quest for) purpose or meaning for being (48%). Our findings also stress that the sense of spiritual connection occurs with God or Higher Power (39%), with something transcendent (30%), through self-connection (26%), or with nature (10%). In a less relevant way, there are connections with the sacred (8%) and spiritual beings (5%).

Conclusions: Our findings can help to map how healthcare professionals understand and express spirituality, allowing them to make it operational. In this sense, it is relevant to build a common ground where elements of different components of spirituality can be understood in a comprehensible scenario, assisting healthcare professionals to better assist and comprehend patients' spiritual needs.

P 8.002 Provision of Psychological Assessment and Support in Palliative Care: A Survey of Hospices in England

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Background/aims: Psychological distress is a common reason for referral to specialist palliative care support. Distress is a barrier to effective management of physical symptoms. Our aim was to evaluate how healthcare professionals working in hospices perceived their competence in psychological assessment and screening. UK hospices provide care, free of charge to patients with advanced disease requiring specialist support as in-patients, out-patients and in the community. Availability of psychological support was considered in relation to 2004 National Institute of Healthcare and Excellence (NICE) guidance for improving supportive and palliative care for adults with cancer.

Methods: Ethical approval was obtained. An anonymised online survey was emailed to 164 hospices in England and was requested to be cascaded to multidisciplinary healthcare professionals. Questions asked individuals about levels of training, self-perceived competence in screening, assessment, therapies and clinical supervision.

Results: One hundred and forty responses were returned from 38 hospices. Many professionals perceived training and supervision in assessing for and delivering psychological support to be lacking. Gaps in training and competency was noted for communication skills. Approximately two thirds of nurses and allied healthcare professional and 43.8% of others did not feel competent at either providing information at an appropriate level, explaining the psychological problem or ability to provide information on treatments available. Access to specialist psychological services was difficult in some areas and some staff felt unable to screen and assess patients for referral to specialist services.

Conclusions: Knowledge, training and supervision of staff working in hospices varies considerably. There is a need to develop a consistent and standardized training and supervision programme for psychological support. This may enable timely and effective intervention for patients with psychological distress thus improving patient outcomes.

P 8.003 Effects of Dignity Therapy on Palliative Care Patients and their Partners. A Randomized Controlled Study

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Background/aims: Despite well-established palliative care services, there is still a lack of interventions addressing existential issues experienced by patients approaching death. Furthermore, we believed that partners should be involved much more in end-of-life care due to the high degree of interdependence that exists between patients' and their partners' stress levels.

This study tests whether the inclusion of a patient's partner into Dignity Therapy (DT+), a brief psychotherapeutic and existential intervention,

can mitigate distress in the patient nearing the end of life and whether DT+ can reduce bereavement-related distress in partners.

Methods: This multicenter study applied DT in a controlled trial design, including only patients with clinically relevant stress levels (Hospital Anxiety Depression total score; HADS_{tot} ≥ 8). A total of 68 patients with a life expectancy <6 months and their partners were randomly assigned to DT, DT+ with their partner, or standard palliative care (SPC) in a 1:1:1 ratio. Patients and their partners were requested to fill in a set of questionnaires pre- and post-intervention.

Results: Our study revealed no significant pre-post intervention and group differences with respect to primary and secondary outcomes. However, we found a statistically significant group-by-time interaction effect: while the HADS_{tot} of the patients in the Dignity Therapy group remained stable over the pre-post period, the control group HADS_{tot} increased (F=4.33, df=1, 82.9; p=0.044), indicating a protective effect of DT. Most patients and their partners found DT useful and would recommend DT to other individuals in their situation.

Conclusions: The implementation of DT within the scope of randomized-controlled study in palliative care is difficult. However, in a clinical context, DT is a simple intervention that enables a guided appraisal of meaningful moments and memories in life while creating a unique written legacy for their families.

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P 8.004 Anxiety of Patients with Pancreatic Cancer Admitted to a Palliative Care Unit

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Background/aims: Pancreatic cancer is known to be accompanied by psychosocial difficulties such as anxiety. Although psychological wellbeing is an area that is emphasized in such patients, few reports have described anxiety they experience and associated factors. This study was conducted to evaluate the anxiety experienced by patients with pancreatic cancer and to explore its associated factors through comparison with other cancers.

Methods: This retrospective observational study assessed cancer patients admitted to a palliative care unit during August 2018 – November 2019. According to medical records, data related to the patient background, Support Team Assessment Schedule Japanese version (STAS-J), Palliative Prognostic Index (PPI), and medical care progress were collected.

Results: We assessed 293 patients including 44 patients with pancreatic cancer. Between groups with pancreatic cancer and others, no significant difference in anxiety level on admission was found (p=0.359). However, after two weeks, the anxiety level had increased more frequently in pancreas group than in others (p=0.049). No significant difference was found in the PPI total score on admission and actual survival period (p=0.317 and 0.768). No significant difference was found in scores for pain and other physical symptoms, or for Palliative Performance Scale (PPS) on admission (p=0.551, 0.592 and 0.442).

Conclusions: Anxiety in patients with pancreatic cancer increases more frequently than in patients with other cancers. We reported earlier that physical symptoms and disability of daily living are associated with patient anxiety. However, at admission, no significant difference was found between groups for the scores obtained for these factors. Also, the general conditions presented with the PPI total score on admission and survival period were not significantly different between these groups. Future studies should be conducted to explore factors associated with anxiety in pancreatic cancer patients.

P 8.005 Spirituality and Decision-making in Palliative Care

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Background/aims: Decision-making in palliative care can be a complex process due to uncertainty, surrounding fears and personal values. It is known that spiritual and cultural beliefs/values influence healthcare decisions, however determinants of the decision-making process are not completely understood. This study aims to explore the influence of spirituality on healthcare decision-making in palliative care patients.

Methods: A cross-sectional study was developed with 95 palliative outpatients. The participants answered a sociodemographic questionnaire, the Decisional Conflict Scale, FACIT-Sp, and a semi-structured interview. Statistical analyses involved descriptive statistics, Mann-Whitney test and correlations, and an analysis based on the interpretative phenomenological process for patients definition of spirituality.

Results: Greater spiritual wellbeing was associated with less decisional conflict and uncertainty. Patients with higher spiritual wellbeing showed greater satisfaction with one's decision. Those who were able to implement their decision presented lower decisional conflict and higher levels of spiritual wellbeing and of quality of life. Receiving spiritual care was associated with better scores of spiritual wellbeing, quality of life and less decisional conflict. Spirituality was considered important during illness and patients pointed that spiritual support and a specialised care, considering ones' values and beliefs, could enable decision-making in health.

Conclusions: Spirituality is key of overall wellbeing and it impacts the process of patient decision-making. Promoting patient involvement in decision-making and considering patients spiritual and individual needs are essential components of individualised care and of patient dignity, empowerment and autonomy.

P 8.006 The Impact of Compassionate Neighbours on Patients'

Social Networks: A Social Network Analysis

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Background/aims: Volunteers have a key role in supporting people with life-limiting and long term conditions (LTCs) redressing experiences of loneliness, and has been used to good effect in a range of health conditions.³⁻⁵ The organic development of new relationships with non-healthcare professionals is compromised by the disabling socio-material world. Consequently, people with LTCs, and their informal carers, are likely to have reduced social networks with few opportunities for expanding their interpersonal relationships

Aim: To understand the impact of compassionate neighbours on people with life limiting conditions and their carer's relationships and social networks.

Methods: Social network analysis (SNA), which is a methodology that foregrounds the exploration of relationships and networks, to enhance understandings of community. Within the SNA, data were drawn from two focus groups (with a total of 14 compassionate neighbours), interviews with five people with long term conditions and two informal carers.

Results: Compassionate neighbours had a positive impact on increasing social contact and reducing loneliness. While compassionate neighbours tended to have busy and varied social lives, the support networks of people with long term conditions seemed to consist of mostly family, very close friends and health professionals. The range and type of contact between compassionate neighbour and person with long term condition appeared to be tailored to shared interests; hence the matching process works well. However, critically, new connections beyond the

one-to-one relationship had not developed, so more extended and dense social networks had not materialised.

Conclusions: Increasing the reach and impact of compassionate neighbours could be enhanced by encouraging the development of wider and denser networks, beyond the one-to-one relationships.

P 8.007 Perceived Dignity in Hospice Care, Which Losses Impact Dignity, Implications for Future Hospice Care

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Background/aims: Preserving dignity is important in hospice care. It is never explicitly described how this is performed in daily practice. Insight into dignity related distress, support a practical approach of dignity conserving care in hospices.

Aim: To study dignity related distress in hospice patients.

Methods: A cross sectional quantitative design using structured interviews was performed with patients admitted to hospices in the Netherlands from XX to XX. All hospices participating in the HOPEVOL project were invited to participate. Patients admitted to hospice were eligible if they were >18 and able to communicate in Dutch or English. All eligible patients were invited to participate. Main outcome was dignity related distress, assessed by means of the Patient Dignity Inventory (PDI). Data analysis was performed with descriptive statistics.

Results: In total 45/51 hospices responded to the invitation, median 2 patients per hospice were enrolled. Structured interviews took 10-30 minutes.

93 patients participated; median age 80; 57% women; 50% without active stated philosophy of life and 80% diagnosed with cancer and an estimated life expectancy < 3 months.

Three items of the PDI were experienced by >70% of patients: inability to continue with usual routines 77(83%), physically distressing symptoms n=67/72% and inability to carry out tasks associated with daily living n=66/71%.

Five most distressing sources, experienced by >40% patients were: reduced privacy 60%, no control over my life 59%, feeling no longer who I was 52%, inability to attend bodily functions independently 51% and not being able to continue usual routines 48%.

Conclusions: Besides physical symptoms and loss of function, loss of privacy, autonomy, identity, attend bodily functions, and usual routines are sources of distress that affect dignity most and are common in hospice care. Hospice teams could ensure dignity conserving care by structural and explicit attention to specific sources of distress.

P 8.008 The Construct Validity of the Social and Spiritual Items of the Utrecht Symptom Diary – 4 Dimensional

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Background/aims: Patients facing a life-limiting illness experience multidimensional symptoms, problems, and needs requiring personalized care. The Utrecht Symptom Diary-4 Dimensional (USD-4D) is a Patient Reported Outcome Measure (PROM) that supports multidimensional symptom management through identification, monitoring and discussing of multidimensional symptoms and concerns. Construct validity is defined as the "degree to which the scores of a PROM are consistent with hypotheses based on the assumption that the PROM validly measures the construct to be measured."

Aim: To establish the construct validity of the social and spiritual items of the USD-4D

Methods: A retrospective analysis of data from two cohorts: 1) hospice cohort and 2) MuSt-PC cohort. Patients included in the hospice cohort were adult patients, admitted to hospice, with an estimated life-expectancy < 3 months. The MuSt-PC cohort comprised adult patients with an estimated life-expectancy of < 12 months in the home, care home, hospital, or hospice setting. Since the USD-4D does not measure a single construct, the construct validity was assessed through hypotheses testing per item, following the criteria of the COSMIN initiative (COnsensus-based Standards for the selection of health Measurement Instruments). Construct validity was established when $\geq 75\%$ of the hypotheses were confirmed. A total of 19 hypotheses were formulated and tested.

Results: 897 patients were included in the final analysis. Of these patients 53% was female, 81% had cancer as their primary diagnosis and 85% received care in a hospice. For all but one item, 100% of hypotheses were confirmed. Only, one hypothesis for the item 'I can let my loved ones go' was rejected, resulting in 75% of hypotheses confirmed for this item.

Conclusions: This study confirmed the construct validity of the social and spiritual items of the USD-4D for Dutch hospice patients in the palliative phase of their illness. The USD-4D is suitable for monitoring multidimensional symptoms and needs.

P 8.009 Ketamine or Placebo in Patients with Major Depressive Disorder Undergoing Palliative Care: Preliminary Results from the KODIAC Trial

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Background/aims: To report preliminary results from the KODIAC study, designed to evaluate the effect of intravenous ketamine for patients with cancer diagnosed with major depressive disorder (MDD) and undergoing palliative care (PC).

Methods: KODIAC is a randomized, double-blind, placebo-controlled clinical study which evaluated the effects of an intravenous dose of ketamine hydrochloride (0.5 mg/kg) compared with placebo and escalating dose of escitalopram in patients diagnosed with MDD by a specialized psychiatrist. The primary outcome was depression as per the Brief Edinburgh Depression Scale (BEDS) 3 weeks post-intervention. This study is registered at clinicaltrials.gov (NCT04471818).

Results: Currently, 50% of the calculated sample has been accrued. Eight patients (n=4 controls; n=4 experimental) completed the study. Baseline characteristics were similar among both study groups, as well as baseline BEDS scores. Mean BEDS scores showed improvement as early as 1-week post-intervention. At three weeks post intervention, patients included in the experimental arm had a significant reduction in mean BEDS depression scores compared with patients in the control arm (3 [SD: 2.160] vs. 11.75 [SD:3.594]; $p=0.006$). The most common adverse event was post-infusion drowsiness and nausea. No serious adverse events were reported.

Conclusions: Preliminary results from this study highlight that ketamine is a rapid onset and robust potentializing anti-depressant for patients with cancer and MDD undergoing palliative care. These preliminary observations require confirmation once the study completes accrual but shed light on the potent effect and safety profile of ketamine for this patient population, warranting further investigation should the final findings be consistent.

P 8.010 "Rongoā, Potentiality of Peace": Indigenous Healing Practices from Aotearoa New Zealand

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Background/aims: Indigenous cultural care preferences are crucial to appropriate palliative care provision. Examination of the use of indigenous traditional healing practices, including plant medicines, alongside a western palliative care approach, is required. The aim of the study was to investigate traditional healing customs, including the use of rongoā Māori (natural healing), among one Indigenous cohort at end-of-life.

Methods: The Pae Herenga study employed qualitative methods to identify and record traditional end-of-life care customs used by Indigenous New Zealanders. Face-to-face interviews were conducted with 103 participants including families, natural healers, spiritual practitioners, and indigenous health workers across four sites. Sixteen digital stories about Indigenous care customs were produced during three workshops. A Kaupapa Māori Research lens informed an inductive thematic analysis.

Results: Families are reclaiming their right to use Indigenous natural healing to provide comfort and healing at end-of-life. Most health professionals are unaware of Indigenous healing customs, and some actively discouraged their use. Several participants opted out of western palliative care treatment and used only traditional healing, including plant medicines. Some patients concealed plant medicine use from their health professionals. Others expressed a preference for traditional plant medicines to be used alongside western palliative care treatments. Research on Indigenous plant medicines will help to inform health professionals how to guide and support patients and families who wish to use their traditional customs, alongside western palliative care treatments.

Conclusions: Health professionals would benefit from specific training in Indigenous end-of-life healing preferences and customs. Open communication about plant medicines could foster stronger relationships with families leading to greater transparency and more informed palliative care choices leading to better outcomes for patients and families.

P 8.011 Interventions to Manage Distress in People Living with Cancer: A Systematic Review

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Background/aims: Psychological distress is common in cancer, especially in the advanced stages. It can interfere with physical and psychological wellbeing and hinder the management of physical symptoms.

Our aim was to evaluate interventions for cancer-related psychological distress at all stages of the disease, by conducting a systematic review.

Methods: Following PRISMA guidelines, we searched 8 online databases. The inclusion criteria was randomised or non-randomised controlled trials published 2002-2022 where psychological distress was a primary outcome. Data were collected on outcome measures, modes of delivery, resources and evidence of efficacy. Quality was assessed using the Mixed Methods Appraisal Tool.

Results: We included 59 studies with 17,628 participants and 32 studies showed significant improvements in distress. Over a third of the interventions included mindfulness and various talking therapies such as cognitive behavioural therapy, dignity therapy, counselling or telephone therapy. Many of the 17 measures of distress used had limited evidence of validation for use in cancer. Statistical significance was most prevalent for mindfulness techniques, followed by talking therapies. Heterogeneity of studies precluded pooling of data. Quality of studies was variable, with 35 failing to report outcome assessor blinding and in 27 studies less than 80% of participants completed the intervention. Sample-size calculation and adverse events were often not reported.

Conclusions: Mindfulness techniques and talking therapies were the most beneficial interventions for reducing distress. However, unlike

mindfulness interventions, the types of talking therapies widely varied with no single technique being prevalent. Mindfulness techniques have the advantage of being quick to teach and can be administered in a variety of settings. For this reason, we suggest that mindfulness interventions merit further investigation, especially in palliative care patients, using adequately powered, high-quality studies.

P 8.012 Experience-based Support Needs of Patients Requesting Euthanasia and their Relatives: An In-depth Interview Study of Lived Experiences

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Background/aims: Palliative care (PC) professionals are increasingly confronted with patients requesting euthanasia where the practice is lawful. There is a lack of insight into how to provide effective support and meet the needs of patients and their relatives in relation to these requests. The aim was to identify the support needs of patients requesting euthanasia and their relatives.

Methods: We conducted a qualitative interview study with patients requesting euthanasia and their relatives in Flanders, Belgium. Data were collected in 2022 using purposive sampling and snowballing. We performed inductive thematic analyses.

Results: We interviewed 15 patients and 21 relatives. Identified support needs can be categorized into six areas of support: 1. Understanding the wider context of the request and the euthanasia procedure, e.g. the need to understand the nature of the patient's suffering; 2. Facilitating social connection, e.g. the need to share final moments with important others; 3. Giving meaning to life and death and navigating existential questions, e.g. the need to evaluate whether the life of the patient has been worth living; 4. Psycho-emotional regulation, e.g. the need to deal with anticipatory grief; 5. Organizational support, e.g. the need to plan the details for the performance; and 6. Maximizing daily functioning and quality of life (only in patients), e.g. the need to travel independently to health services. These support needs may vary and seem to be largely determined by the specific phase in the illness trajectory, the care and support settings, and patients' and relatives' social embeddedness and autobiographical identities.

Conclusions: Some of the identified support needs strongly align with those described in PC frameworks, e.g. psychosocial, existential, and physical needs. Thus, our findings make a sound case for involving (specialized) PC professionals immediately when patients voice a wish for euthanasia or to hasten death given their highly developed skills in dealing with such needs.

P 8.013 Wellbeing and Burnout of Professionals Confronted with Death and Patient Suffering: An Integrative Model

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Background/aims: Palliative care and oncology generate a risk of burnout and psychological distress. This study proposes to identify both psychopathological and positive factors related to work mental health. The aims are to develop an integrative model of mental health and to identify (i) frequency and impact of confrontations with death, (ii) prevalence

of psychological distress, (iii) psychological profiles of professionals, and (iv) determinants of burnout and well-being.

Methods: A cross-sectional study was conducted in palliative care and oncology with questionnaires evaluating confrontations with death, coping, burnout, psychological distress, personality, self-esteem, well-being and meaning at work. Regression, clustering, and structural equation modelling analyses were performed.

Results: 114 professionals participated: 30% witnessed an intolerable suffering at least 9 times a month, informal support was the most used one, 45% reported moderate to high level of emotional exhaustion, 39% anxiety and 11% depression.

Three profiles appear: (i) a "distressed profile" with a majority of clinicians at the patient's bedside, (ii) a "disengaged profile" with clinicians working as second-line consultants, (iii) a "wellbeing profile" with the administrative and research teams.

The determinants of burnout are: conscientiousness ($b=0.18$, $p=.040$), neuroticism ($b=0.23$, $p=.002$), work meaning ($b=-0.25$, $p=.020$) and well-being ($b=-0.25$, $p=.020$) ($R^2=0.44$). The determinants of well-being are: work meaning ($b=0.46$, $p<.001$), depersonalization ($b=0.18$, $p=.006$), self-esteem ($b=0.14$, $p=.010$), fulfilment ($b=0.15$, $p=.020$), and confrontations with death ($b=-0.16$, $p=.004$) ($R^2=0.71$).

Our integrative mental health model includes both well-being (self-esteem, conscientiousness) and psychopathology (neuroticism, anxiety) parameters.

Conclusions: An integrative approach is essential to understand the full range of mental health issues for professionals. Meaning at work is a key factor in an interventional perspective.

P 8.014 Psychosocial and Spiritual Intervention Strategies in Palliative Care: Evidence from a Cohort Study

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Background/aims: Interventions in palliative care (PC) on the psychological, social and spiritual domains encompass the support on the adaptation process of disease or proximity of death, as well as of the overall suffering manifested by the patients or family and ensure an answer to the psychosocial and spiritual needs. Analyse, describe and characterize the psychosocial and spiritual intervention of a psychosocial care team (PCT) on patients and relatives.

Methods: Exploratory retrospective descriptive study based on the analysis of clinical records on the psychosocial support of patients and relatives followed by a PCT, from admission to discharge, from January to September 21.

Results: A total of 385 patients were identified, 51.4% male ($n=198$), median age (71.3 years), 89.4% with main oncology diagnosis; and 440 relatives, 71.1% female, with a median age of 54.5 years. The construction of the categories of analysis is based on the guidelines of psychological intervention in PC of the Portuguese Psychology College. For patients and relatives, 3 major categories and 28 subcategories were identified. As most prevalent we point out: "active listening", "emotional support and facilitation" and "emotional expression facilitation" for patients (75.8/70.1/69.6%). For relatives, "active listening", "emotional support and facilitation", "facilitation of emotional expression" stand out (98.9/85.9/81.8%). Note that "family assertiveness and communication training", "conflict management and negotiation", are the least frequent interventions in the patient group (15.8/13.3%) and for relatives are "promoting dignity in the family", "promoting autonomy" (13.6/11.1%).

Conclusions: The results demonstrate the role of psychosocial and spiritual intervention in patients and relatives in PC. The bonds established in the empathic relationship validate the suffering of the other, have an

impact on well-being and grief experience, allowing a greater humanization of the end-of-life process.

Funding: None; No conflicts registered.

P 8.015 Care of Families through Loss: A Grounded Theory Interview Study of Parents' Experiences Supporting their Children Following Parental Death

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Background/aims: In the UK, 41,000 children are bereaved of a parent each year. 5,200,000 children worldwide experienced the death of a primary caregiver to COVID-19. Bereaved people need a supportive response from those around them. However, little is known about support following parental death. This study explored how parents support bereaved children and how existing networks may contribute.

Methods: Using a constructivist grounded theory approach, in-depth interviews were conducted with parents of parentally bereaved children. Interviews were analysed using constant comparison following the key stages of open, focused and theoretical coding.

Results: Seventeen bereaved parents participated (10 mothers and 7 fathers). Four broad categories were constructed describing support experiences: 'realising the enormity and trying to cope', 'being picked up and carried', 'challenges supporting the kids', and 'becoming alienated'. Findings showed that initially, families were well supported by those within their networks, but this was not sustained. Throughout, parents' main concern was their children. They expected a professional would automatically support their children, which seldom happened. Some struggled to access professional support. Parents showed their emotions; however, many found their children could not bear to see them upset after time, requiring parents to learn to control their grief. Despite good initial support from their existing networks, as time passed following the death, a lack of understanding of the impact and longevity of grief meant parents masked their grief, and support dwindled.

Conclusions: Parents feel alone and out of their depth supporting their bereaved children. Parents see parental bereavement as an issue requiring professional help. Parents want information about available support services, guidance and reassurance from professionals and peers with lived experience. Bereavement services must proactively contact families to deliver this support.

P 8.016 A Systematic Review of Stakeholder Perspectives of Dignity and Assisted Dying

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Background/aims: The debate on assisted dying (euthanasia and physician-assisted suicide) has evolved with the advancing of the right to dignity movement. While shaped by local, legal, and sociocultural considerations, appreciation of how patients, healthcare professionals

(HCPs) and lawmakers relate notions of dignity to self-concepts of personhood and the desire for assisted dying can better inform palliative care of patients wishing to hasten death.

In this paper, the authors study arguments in the assisted dying debate through the lens of the Ring Theory of Personhood (RToP) to answer the primary question, "What is the relationship between dignity and wish to hasten death (WTHD)?", and the secondary questions, "How is dignity conceptualised by patients with WTHD?" and "What are prevailing perspectives on the role of assisted dying in maintaining dignity?".

Methods: A systematic scoping review guided by the Systematic Evidence Based Approach was conducted to map perspectives of dignity, WTHD and personhood featured in six key databases and four key palliative care journals.

Results: 6947 abstracts were identified, 663 full text articles reviewed, and 88 articles included. The four domains identified include: concepts of dignity through the lens of the RToP; the relationship between dignity and WTHD; patient, HCPs, and lawmaker perspectives of dignity; and dignity-conserving measures. These domains revealed a dynamic concept of dignity that influence positions taken with respect to requests for assisted dying that spur support, opposition and different dignity-conserving measures to circumnavigate assisted dying.

Conclusions: Concepts of dignity are dynamic throughout the patient's end of life journey. Understanding when and how these concepts of personhood change and trigger attacks on dignity resulting in suffering and WTHD can direct timely, individualised, and person-centred dignity-conserving measures. We believe a RToP-based tool can fulfil this role, enhancing dignity-conserving care in palliative medicine.

P 8.017 What Does «Are You Feeling at Peace» on the Integrated Palliative Care Outcome Scale (IPOS) Actually Measure? – A Qualitative Case Study

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Background/aims: The spiritual dimension is integral to palliative care. Yet, spiritual or existential distress as measured in routine proxy reported outcome measures (PROM) is poorly understood as a construct in and of itself.

The aim is to understand the meaning and extent of spiritual distress as measured by the Integrated Palliative Care Outcome Scale (IPOS) in palliative patients and explore its course.

Methods: Multiple explorative, qualitative case study of four patients on the inpatient care ward of a teaching hospital. The ward uses routine outcome measurement incorporating IPOS. Purposive sampling based on disparate spiritual distress scores (Q14 in IPOS) at entry and its type/course of change. All free-text notes in electronic patient health records were thematically analysed using Mayring's qualitative analysis. Notes were coded and categorised inductively.

Results: Five themes «somatic problems», «coping/resources/improvement», «psychological/existential distress», «decision-making», and «network/carer support» emerged. Among the four cases, three distinct patterns of category frequency were observed over the episode of care. For case #1 with persisting spiritual distress until discharge, notes increasingly focused on the category «psychological/existential distress» while «somatic problems» showed improvement both in the IPOS and in free-text notes. For three cases with improvement in Q14, the category «psychological/existential distress» was analogously scored more frequently in the second half of their stay with far less instances being scored before discharge or death. Addressing «somatic problems» or increased mentioning of «coping/resources», «decision-making» or

«network/carer support» characterised cases experiencing improved spiritual distress.

Conclusions: High spiritual distress may indicate both somatic problems as well as further forms of psychological and existential distress. This case study supports the content validity of Q14 on the IPOS.

P 8.018 It's Not Just How You Say it but Where You Say it. A Qualitative Case Study Exploring Victorian Nurses' Perspectives of the Effects of the Ward Environment and Language in Palliative Care

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Background/aims: In metropolitan areas of Victoria, Australia, people may receive end-of-life care in Palliative Care Units (PCUs) with specialist staff. In contrast, many regional areas provide end-of-life care in general medical or surgical inpatient wards that are clinical and noisy. In addition, diagnostic/prognostic conversations may be led by generalist physicians who are not experienced or comfortable leading them.

This study aimed to explore the experiences and perceptions of nurses who provided palliative and end-of-life care in regional and metropolitan Victorian hospitals, particularly the effects of the environment (the built, natural, social and symbolic environments), and the delivery of diagnostic/prognostic information to patients and their family members.

Methods: A qualitative case study was designed and informed by the Therapeutic Landscapes framework. After University ethical approval, registered nurses who provided palliative care were recruited via social media advertisements. Semi-structured interviews were conducted online between March to May 2022, audio recorded, transcribed verbatim and thematically analysed.

Results: Six online interviews were conducted. Four nurses worked in regional hospitals and two Nurse Unit Managers (NUM) worked in PCUs in metropolitan hospitals. Three themes were developed, namely 'Family meetings', 'Palliative care practice' and 'Ward aesthetics'. The PCUs had home-like ambiance and aesthetics and experienced staff but most family meetings occurred prior to admission, whereas home-like ambiance and aesthetics and experienced palliative care staff were not prioritised in the acute hospitals where most of the conversations took place.

Conclusions: More research is needed to explore the inpatient palliative and end-of-life care environments in acute regional hospitals in Victoria, Australia to improve the ambiance and aesthetics and the experience of patients and family members during a diagnostic/prognostic conversation.

P 8.019 Associations between Quality-of-Life Scores and Spiritual Well-being Scores on the Finnish Translation of the EORTC QLQ-SWB32 for Palliative Care Eligible Patients in Finland

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Background/aims: Palliative care is holistic care, and includes addressing patients' spirituality, meaning how individuals seek and express meaning and purpose, and how they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. The World Health Organization urges the inclusion of spirituality as essential for palliative care.

Measurements of spiritual well-being (SWB) are used as indicators of an individual's spirituality and to explore associations with quality-of-life (QOL). The EORTC QLQ-SWB32 (SWB32) measure of spiritual well-being, developed by the Quality of Life Group of the European Organisation for Research and Treatment of Cancer (EORTC) has been validated for

cancer patients in palliative care in 14 countries, but not yet in Finland, nor with patients with conditions other than cancer. The SWB32 has five scoring scales, and a single global SWB item (G-SWB).

We aimed to validate the Finnish SWB32, and explore the relationship between SWB and QOL in Finnish patients with or without cancer eligible for or receiving palliative care.

Methods: The SWB32 was translated into Finnish and validated alongside existing validated QOL-questionnaires for cancer patients (EORTC QLQ-C30) and non-cancer patients (15D). We recruited patients across Finland.

Results: 101 patient participants with cancer; 89 with other conditions. SWB32 scores and QOL scores were significantly moderately correlated. SWB scores were higher for participants without cancer than those with cancer.

Mean G-SWB score (cancer): 62.2 (SD 30.4); (non-cancer): 74.3 (SD 21.6)
Mean QOL score (cancer): 60.1(/100) (SD 23.4); (non-cancer): 0.84(/1) (SD 0.13)

Correlation G-SWB and QOL (cancer): 0.34; (non-cancer): 0.42 ($p < 0.05$)

Conclusions: The Finnish SWB32 is valid in Finland; participants' SWB scores correlated positively with QOL measured by QLQ-C30 or 15D for people with or without cancer eligible for palliative care, with non-cancer patients' SWB scores consistently higher than cancer patients.

P 8.020 Understanding the Relationship between Empathy and Compassion Fatigue on Oncologists and Health Professionals in Cancer Care

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Background/aims: The compassion and behavioral aspects of oncologists and healthcare professionals significantly influence the capacity of the healthcare workers to understand and support the emotional and health status of patients within contemporary medical care settings. Multiple factors influence compassion satisfaction, fatigue and empathy levels of healthcare professionals, which ultimately affects the quality of medical care. The current research explores the self-reported levels of compassion fatigue as mediated by burnout and traumatic stress within the healthcare environments.

Methods: Five surveys including one demographics questionnaire was utilized for this study. The surveys included: 1) Demographic Survey, 2) Jefferson Scale of Physician Empathy (JSPE) developed by Hojat (2007), 3) the Professional Quality of Life Scale (PROQOL-5) developed by Stamm (2005), 4) Difficulties in Emotion Regulation Scale (DERS) developed by Gratz & Roemer (2004), and the 5) Impact of event scale (IES) developed by Horowitz, Wilner, and Alvarez (1979).

Results: Results established from the analysis of data indicate the positive associations manifesting between empathy and compassion fatigue, based on the incremental nature of positive beta values.

Conclusions: Although low levels of fatigue are desired within healthcare settings, the levels of self-reported compassion fatigue were portrayed to be moderately high, which affects the provision of empathic support to cancer and general patients. From a broader perspective, there is a significant relationship and the same was confirmed on the mediating roles of distress and emotional regulation. Therefore, a healthcare model that considers mitigation policies to eradicate distress and optimization of emotional regulation was reported to hold the capacity to build empathetic tendencies that lower compassion fatigue while increasing compassion satisfaction.

P 8.021 How Do Palliative Care Professionals' Understandings of Spiritual Care Compare with the Understandings of Spiritual Wellbeing of People Receiving Palliative Care?

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Background/aims: Spiritual care is central to palliative care and the well-being of people receiving palliative care, but still under-researched and poorly understood. We compared results from two studies, one investigating what spiritual wellbeing (SWB) meant to patient participants, the other exploring what palliative care professionals gave as examples of spiritual care.

Methods: An EORTC QLQ-SWB32 measure of spiritual wellbeing (SWB32) was validated in an international study led by members of the Quality of Life Group of the European Organisation for the Research and Treatment of Cancer (EORTC), on which the authors were co-PIs. Patient participants completed and commented on the SWB32, including a question asking what SWB meant to them. The authors were also lead investigators on an EAPC Spiritual Care Task Force study, surveying EAPC members and other palliative care professionals and exploring their understandings of spiritual care.

Results: The SWB32 validation had 451 patient participants in 14 countries/ten languages. Collaborators in ten countries/six languages collected 310 participant responses to the SWB question. We identified three main themes: relationship with self; relationships with others; and religion, and two secondary themes: death/dying/afterlife; and philosophical/existential.

The EAPC survey had 501 responses, 465 to substantive questions, and 228 giving examples of spiritual care. Main themes echoed all the SWB32 validation themes. Secondary themes were specialist involvement; staff needs for support and training; and practical/organisational issues, such as funeral planning or providing quiet spaces.

Conclusions: Examples of spiritual care given by palliative care providers who responded to our survey broadly matched how patient participants in the SWB32 validation defined SWB. Differences centred on organisational or practical matters, e.g. staff training and support, and specialist involvement. Guidelines should focus on how attention to these can better facilitate spiritual care.

P 8.022 Monitoring Home Palliative Care Professionals' Levels of Burnout and Psychological Morbidity: A Lesson Learned from the COVID-19 Pandemic

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Background/aims: The COVID-19 pandemic strongly challenged health-care workers, disrupting their work routine and impacting on their professional life. The pandemic has made clear that monitoring their psychological health is becoming even more necessary.

The study aimed to track the levels of burnout and psychological morbidity among home palliative care professionals (HPCPs) before, during and after one year of the COVID-19 pandemic.

Methods: A total of 145 HPCPs, physicians and nurses, took part in this study. The results conducted during the first wave of COVID-19 (T1) were compared with both pre-pandemic data collected in 2016 (T0) and one year after (T2) in the same setting. Maslach Burnout Inventory and General Health Questionnaire-12 scores were used to monitor and compare burnout symptoms and psychological morbidity. A qualitative analysis conducted with a semi-structured telephone interview allowed to go deep into the experiences and issues reported by HPCPs.

Results: During the COVID-19 emergency, HPCPs presented a lower burnout frequency ($P < .001$) with a higher level of personal accomplishment than in 2016 ($P = .047$). Conversely, the risk for psychological morbidity was significantly higher during the pandemic ($P < .001$). The frequency of burnout remains nearly constant between T1 and T2, except for a marginally higher level of emotional exhaustion ($P = .049$) reported in T2; the percentage of cases showing psychological morbidity significantly decreased.

Conclusions: Results indicate that sense of professional satisfaction and personal accomplishment appear to be key factors preventing HPCPs from high levels of burnout and psychological morbidity. This lesson learned from the age of COVID-19 should drive future actions aimed to preserve the psychological health of HPCPs.

P 8.023 The Development of a Holistic Needs Assessment in an Acute Oncology Inpatient Setting; A QIP

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Background/aims: Holistic needs assessments are integral to oncology care. Whilst Macmillan Holistic Needs Assessment (HNA) has embedded in outpatient cancer care in the UK, acute oncology admissions largely focus on immediate medical need rather than patient's wellbeing.

Methods: To establish which elements of HNA are important to patients, compare this with staff perception and establish if these needs are assessed during the admission process at a tertiary cancer centre. An inpatient survey asked patients to rate what areas of the HNA were important between November 2021-March 2022. Patients rated the extent they felt needs were asked about and addressed. Nurses responsible for clerking patients also rated importance of HNA items. Thematic analysis was undertaken of responses to describe concordance and areas for improvement.

Results: 42 patients and 15 nurses completed the surveys. 95% of patients reported information sharing with the MDT/family as important, 79% wanted more support for family/carers, 78% reported concerns surrounding body image, 40% reported low mood. Respondent needs regarding information sharing (50%), family/carer support (50%), body image, and mood (64%) were not asked about on admission/unmet. Nurses reported that sharing information with patients (100%), respective next of kin and mood (86%) were the key holistic needs to patients. Nurses also placed high importance (100%) on discussions regarding ACP and DNACPR, which only 12% of patients felt was important as part of their initial assessment.

Conclusions: Healthcare professionals understanding of patients' needs broadly concurred with patient feedback, the emphasis on ACP and DNACPR discussions did not reflect patient concerns. Despite concordance, patients felt that their holistic needs were not established, suggesting there are barriers to putting knowledge into practice during admission. Further work on this area will establish systems to embed HNA in the acute oncology admission process.

P 8.024 Clinical Experiences using the "Patient Dignity Question (PDQ)"

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Background/aims: The Patient Dignity Question (PDQ) is a simple means of inquiring about personhood: "What do I need to know about you as a person to give you the best care possible?". PDQ was developed within the Dignity in Care model that fosters a sense of dignity and helps the

team to care for their patients in a more personalised way (H. Chochinov, 2015).

Aim: To explore patients, interviewers and professionals' experiences using PDQ.

Methods: Descriptive exploratory study with convenience sampling. Advanced cancer patients cared by a palliative care consultant team participated (n=20). The PDQ protocol and two questionnaires designed ad hoc to explore acceptability and feasibility were applied. Interviewers made field notes on the process. Informal conversations were conducted and noted down with clinicians caring for patients.

Analysis: Descriptive statistical for numeric data and thematic analysis of qualitative data was conducted

Results: After ethical approval and informed consent, 25 patients were approached and 20 (80%) accepted. 20 professionals and 2 interviewers shared experience. The average time of the interview was 8 min of conversation other 15 min writing the summary and adding to the clinical records. The patients felt that the summaries were accurate and complete. All participants would recommend PDQ to others. In the conversation, the follow themes emerged: patients reflect on relevant aspects of care such as listening, closeness or intimacy, on physical symptoms, on personal or family relationships. Aspects related to personal, religious, or spiritual identity were also addressed. Interviewers perceived the need to clarify the PDQ with examples. Clinicians described the summary as very useful. They felt that helps to understand the patient better and to get closer to him or her.

Conclusions: The PDQ is an acceptable, feasible and useful intervention in our setting. Our results also support further research to better adapt the question and the intervention to our population and setting.

P 8.026 Healthcare Burden of Cognitive Impairment: Evidence from the Singapore Chinese Health Study

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Background/aims: While individuals with cognitive impairment (CI) are more likely to have emergency department (ED) visits and unplanned hospital admissions, they are less likely to receive aggressive treatments and often have higher mortality rates.

We examine whether those with CI incur higher health expenditures and healthcare utilisation compared to those without CI, both annually and over five years.

Methods: Using government administrative data linked to the Singapore Chinese Health Study cohort, we estimated regression-adjusted differences in annual healthcare utilization and costs by CI status determined by modified Mini-Mental State Exam, controlling for demographics and health measures. Estimates were stratified by ex-ante mortality risk constructed from out-of-sample predictions using a Cox model applied to the full sample, with a separate analysis restricted to decedents. These estimates were used to project differential healthcare costs over five years.

Results: Patients with CI have higher annual cost of about \$700 (p < 0.01) compared to those without CI (\$4,870 vs. \$4,177) mainly due to more ED visits and subsequent admissions. This difference was greater among those with higher ex-ante risk of dying, and not statistically significant among those with lower risk of dying. Total expenditures were not significantly different in the last year of life. Accounting for mortality

differences, individuals with CI are expected to cost \$2,500 (95% confidence interval, 95%CI: 1,000 to 4,200) to \$3,600 (95%CI: 1,300 to 6,000) more over five years depending on age.

Conclusions: Whereas patients with CI have greater healthcare spending while alive, the net difference is attenuated due to lower survival and similar healthcare utilization patterns in the last year of life. A better understanding of treatment choices and their consequences for patients may inform on ways to reduce CI burden, which may include efforts to reduce ED visits and unplanned hospitalization.

P 8.027 Desire to Die in a Multi-site Cohort of Patients with Amyotrophic Lateral Sclerosis

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Background/aims: Previous studies have shown that thoughts about hastening death, or even interest in assisted suicide, are not uncommon for patients with Amyotrophic lateral sclerosis (ALS). This study aims

- 1) to examine the intensity of a desire to die in patients with ALS and
- 2) to explore influencing factors (illness-related, psychological and social).

Methods: 128 patients with ALS from five European countries, (Germany, Ireland, Italy, Netherlands and UK) were included in this multi-site study. Sociodemographic factors, medical data and psychological measures were obtained using a researcher-administered questionnaire. The Schedule of Attitudes Toward Hastened Death (SAHD; total score range 0–20) and a single item asking „could you currently imagine to end your life?“ (numeric rating scale from 0-10) were used to assess patients' desire to die.

Results: Mean SAHD-score was 4.24 (SD=3.5). 16 patients (12.5%) had a score ≥ 8 , indicating a strong desire to hasten death. 26 patients (20.3%) stated that they could currently imagine to end their life (score ≥ 8). Both, desire to hasten death and thoughts about ending their lives, were associated with a lower functional status, reduced quality of life, loneliness, depression and feeling like being a burden (all p<0.05). Patients with higher anxiety and those with a longer duration of disease reported higher SAHD scores, but these factors were unrelated with thoughts about ending their life. Yet, those who thought about ending their life were more often female and reported more feelings of guilt toward their families.

Conclusions: Desire to die is prevalent in patients with ALS. This should be recognized and health care professionals should proactively engage in discussions with patients on wishes to hasten death, thoughts about ending their life and underlying psychological and social factors.

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P 8.029 An International Exploration of the Impact of COVID-19 on Palliative Care Social Workers and Service Delivery

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Background/aims: The SARS-Cov-2 (COVID-19) pandemic generated life-defining challenges on a global level, affecting the working conditions of professionals, who faced the same public health threat as their patients. This study aimed to survey palliative care social workers who worked during the pandemic.

Methods: Design: A cross-sectional survey-based design was used, which adhered to the STROBE checklist. Participants were palliative care social workers aged 18+. Convenience sampling was employed to recruit participants via email from members of the European Association of Palliative Care (EAPC) Social Work Task Force and the World Hospice Palliative Care Social Work (WHPCSW) Network. Invitation emails contained a Qualtrics web-link to the participant information sheet and online survey. Formal ethical approval was granted by research ethics committees across participating universities. The survey was translated from English into Czech, German, Italian, Slovak, Spanish and Portuguese, to widen participation. It contained quantitative (n=15) and qualitative (n=3) questions capturing demographic data, services provided pre-COVID, and how COVID-19 impacted referrals received, the workforce and service provision.

Results: We received 362 survey responses (85% female), representing 21 countries, with a mean age of 44.57 years. The full range of social work services could no longer be delivered, existing services changed and 65.3% reported higher levels of pressure, linked to the intensity of work (67.2%), higher levels of staff absence (36%), increased patient numbers (36.9%), additional duties (45.6%) or due to COVID-19 restrictions (65.27%).

Conclusions: Our findings indicate that restrictions to limit the spread of COVID-19 resulted in changes to service delivery, increased pressure on staff, higher levels of staff absence, additional duties and moral distress. All members of the palliative team need support and supervision to ensure effective interdisciplinary working and team cohesion.

P 8.030 The Impact of Death and Dying on the Personhood of Senior Nurses at the National Cancer Centre Singapore (NCCS): A Qualitative Study

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Background/aims: Nurses face challenges ethically, professionally, and psychosocially when caring for the dying, which in turn shape the way they perceive their professional roles. Without adequate support to face these challenges, nurses succumb to burnout, and may even leave the profession. To better support nurses, there needs to be a better understanding of how caring for the dying affects the professional identity formation (PIF) of nurses.

Methods: Krishna's Systematic Evidence-Based Approach guided the design and piloting of the semi-structured interview tool. The theoretical lens of the Ring Theory of Personhood (RTOP) framed the discussion

on how caring for the dying impacts the values, beliefs, principles, professional identities, and personhood of nurses.

Results: Analysis of interviews with eight senior nurses in Supportive, Palliative and Oncology care revealed three domains: Identity

- 1) Formation;
- 2) Conflict and
- 3) Refinement.

Identity Formation occurs early in a nurse's career, when they first begin caring for the dying. In doing so, nurses faced Conflicts between aspects of their personhood and their professional values. These Conflicts in values, beliefs and principles manifested as conflicts within ('disharmony') and/or between ('dyssynchrony') the rings of the RTOP. Nurses adapted to these Conflicts through Identity Refinement, where experience and timely support allowed them to make changes to self-concepts of personhood and professional identity. Identity Refinement, and the development of a consistent, 'rooted identity' helped nurses adapt in the face of Conflict.

Conclusions: Caring for the dying may lead to significant Conflicts among nurses. To help nurses during the process of Identity Refinement, institutions should provide structured, longitudinal, accessible, and personalized assessments and support.

P 8.031 Dignity Conserving Care, a Qualitative Exploration of the Health Care Providers' Perspective

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Background/aims: Hospice patients are at risk of losing dignity due to illness progression. Palliative care services and guidelines state the importance of dignity. A practical description of dignity conserving care is lacking.

Aim: To explore the caregiver perspective on dignity preserving care in the last year of life.

Methods: Hospice caregivers were invited for online focusgroup interviews (Jul 2020-Sep 2021). Maximum variation was sought in experience, (in)formal profession/background. Participants per group were limited to 5 to optimize online interaction. The initial question: "What is dignity for you?" a mutual understanding of dignity between participants was build. Practices of dignity conserving care was explored using a negative example to open the conversation. A 6-step inductive thematic analysis was performed.

Results: 19 caregivers aged 36-79, 14 women, participated in 4 focus groups: 2 patient representatives, 6 informal caregivers, 1 nursing aid, 8 nurses, 1 GP, and 1 chaplain, all trained in hospice care, 7 had specialized education.

Three themes describing dignity and how to conserve dignity.

- 1 Respect for personal values and priorities. Exploring what the personal values and priorities are and supporting to preserve these even if it means accepting that personal values differ from caregiver perspectives. To provide care in accordance.
- 2 Autonomy and actorship. Supporting the patients' ability to decide for himself, providing information needed and not deciding to withhold questions but accepting 'no' as an answer.
- 3 Participation, belonging and being of value. The sense of belonging and being of value can be supported in the ability to participate in what matters for this specific patient.

Competences supporting dignity conserving care are reflection and communication.

Conclusions: Dignity conserving care is difficult due to the tendency to be implicit. The use of tools could support caregivers to actively attune to patients.

P 8.032 Prevalence and Risk Factors of Clinically Significant Depression in Cancer Patients Using the PHQ-9 and ESAS-r Scales: Patient-reported Outcomes

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Background/aims: Depression is a common comorbidity among cancer patients. However, the reported prevalence of depression in cancer patients varies widely across studies. The present study assessed the prevalence and associated factors of clinically significant depression among cancer using the PHQ-9 and ESAS-instruments.

Methods: A cross-sectional study was conducted among a convenient sample of cancer patients in a tertiary care cancer center in Riyadh, Saudi Arabia. Depression was assessed using PHQ-9 and ESAS instruments. The prevalence of depression was assessed by PHQ-9 and ESAS instruments and then compared in terms of diagnostic accuracy. Risk factors of depression were identified using logistic regression.

Results: A total of 301 cancer patients were included in the study. The majority of participants were females, 217(72.1%), and with solid tumors, 262 (87%). The prevalence of clinically significant depression assessed by PHQ-9 and ESAS-r was 35.2% and 27.9%, respectively. In the multivariate regression analysis, Rural residence (OR 3.03; 95% CI 1.37–6.69), Tiredness (OR 1.22; 95% CI 1.04–1.43), Drowsiness (OR 1.22; 95% CI 1.07–1.38), Loss of appetite (OR 1.29; 95% CI 1.13–1.47), anxiety (OR 1.22; 95% CI 1.08–1.39), wellbeing (OR 1.21; 95% CI 1.04–1.41) were identified as a predictor of clinically significant depression. The inter-rate accuracy of the PHQ-9 and ESAS-r showed a significant moderate agreement ($\kappa = 0.480, p < 0.001$).

Conclusions: The present study findings demonstrate a high prevalence of clinically significant. This warrants the need for a well-structured screening and treatment approach to improve patients' mental wellbeing.

P 8.033 The Impact of Meaning Making Intervention on Family of Pediatric Palliative Patients

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Background/aims: Palliative care is a holistic approach for patients with life limiting illnesses and aims to alleviate suffering using a Bio Psycho Social Spiritual approach. Frankl (1985, 1986) concluded that the will to meaning and self-transcendence are essential for survival and healing. Suffering without meaning will lead to despair and depression. Meaning makes suffering more bearable. Meaning Centered therapy has been studied in adult cancer population. In this study we apply a modified approach centered in meaning making activities for families of pediatric palliative patients to study its effect on healing and self-transcendence.

Methods: A total 25 participants were approached based on convenience sampling with 20 participants enrolled. Most interview were conducted and the Paed Ward including Paediatric Intensive Care Unit (PICU). Screening for eligibility was based on palliative care clinician referrals. The 3 sessions involved semi-structured oriented toward eliciting the sequence of experiences and decisions that led to selected answer on the NIH Healing Experience of All Life Stressors (NIH-HEALS) and meaning making activities.

Results: The overall theme that emerged indicated a strong emphasis on meaning making through the relationship with divine entity, development of meaningful relationship with family, friends and compassion towards others, and the other theme is the less stressor which mean develop meaning in the process of psychosocial spiritual healing.

Conclusions: This study provides crucial information for future studies across all palliative care populations specifically paediatric palliative through the use of thematic analysis research methodologies to improve sample diversity, increase sample sizes, and improve generalizability of

results. More work is needed to provide a foundation for the implementation of our intervention to reduce suffering of dying children and their family members, thereby advancing the science of symptom management in vulnerable populations.

P 8.034 Dignity in Hospice Care, a Qualitative Exploration of the Patient Perspective

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Background/aims: In hospice care patients are at risk of losing dignity due to illness progression. Hospice services and guidelines state the importance, a definition of dignity conserving care is lacking.

Aim: To explore the patient perspective on dignity in the last year of life.

Methods: Semi structured interviews were performed (Oct 2020 -Jul 2022). Maximum variation sought in age, gender, estimated life expectancy, physical status. By the initial question "What is dignity for you?" a mutual understanding of dignity between interviewer and patient was build. The meaning of dignity/dignity conserving care provided by professionals was explored by using a negative example to identify positive actions and attitudes.

A 6-step inductive thematic analysis was performed. Data saturation was reached after 10 interviews.

Results: 11 participants, mean age 69, seven women. Interviews lasted 30 – 75 minutes. Although dignity is personal, the expression of dignity is similar for patients. The sense of dignity is related to both the individual and sense of self-worth and social interaction.

Five themes were revealed:

- 1 Respect, being able to be yourself and others let you.
- 2 Autonomy and actorship, deciding and acting for yourself
- 3 Empathy, active attention for you as a person.
- 4 Participation, belonging and being of value.
- 5 Feeling safe, being in good hands and able to relax.

When patients lost dignity due to physical decline, the ability to accept the situation restored their sense of dignity. Patients developed a personal repertoire to support their sense of self-worth. Patients with low sense of self-worth depend on others for conserving their more vulnerable dignity.

Conclusions: Respect, autonomy, empathy, participation and feeling safe were the revealed themes. Dignity of patients with a sense of self-worth is relatively stable; patients with low self-worth are at risk in losing dignity and suffer from it and need to be supported by caregivers to conserve their dignity.

P 8.035 Identifying, Exploring and Integrating Spiritual Issues in Proactive Care Planning: A Mixed Methods Evaluation of a Communication Training Intervention for Multidisciplinary Palliative Care Teams

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Background/aims: Patients receiving palliative care value attention given to their spiritual needs. However, these needs often remain

unexplored as healthcare professionals lack the skills to identify and explore them and to integrate this information into care plans.

Methods: Three palliative care teams participated, including nurses (N=21), physicians (N=14) and spiritual caregivers (N=3). A mixed methods pre-post design was used, including self-assessment questionnaires, evaluation of videos with simulated consultations (applied competence), and medical record review (implementation).

Results: The questionnaires showed an improvement on 'Patient and family-centred communication' of the End-of-life professional caregiver survey (+0.37, $p < 0.01$); the 8-item S-EOLC (+0.54, $p < 0.01$) and regarding the Spiritual Care Competence Scale, on the three subscales used (+0.27, $p < 0.01$, +0.29, $p < 0.01$, and +0.32, $p < 0.01$). Video evaluations showed increased attention being paid to patient's aims and needs. The medical record review showed an increase in anticipation on the non-somatic dimension (OR: 2.2, 95%-CI: 1.2- 4.3, $p < 0.05$) and, using the Mount Vernon Cancer Network assessment tool, addressing spiritual issues (OR: 10.9, 95%-CI: 3.7-39.5, $p < 0.001$).

Conclusions: Our training intervention resulted in increased palliative care professionals' competence in identifying and exploring patients' spiritual issues, and their integration in multidimensional proactive palliative care plans. The intervention directly addresses patients' spiritual concerns and adds value to their palliative care plans.

P 8.036 Experiences of Patients and Family Caregivers in Inpatient Specialist Palliative Care: A Scoping Review

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Background/aims: Patients in inpatient specialist palliative care (SPC) settings are often older with lower functional status. Given the potentially amplified need for future inpatient SPC services due to population demographic changes, an understanding of patient and family caregiver (FCG) experiences may enable recommendations for practice improvements and future research. We aimed to examine the literature on patient and FCG experiences in inpatient SPC settings using a scoping review.

Methods: We searched Medline, Embase+Embase Classic, CENTRAL, PsycINFO, CINAHL, Cochrane's Database of Systematic Reviews, and DARE from database inception to September 17, 2020, and conducted citation and grey literature searches. Search terms included 'patient', 'family caregiver', 'experience', and synonyms. Screening was conducted in duplicate using pilot-tested criteria. Records with adult patients receiving inpatient SPC and/or their FCGs were included. Non-English records and books were excluded. Data was extracted from full-text records using a pilot-tested data extraction form. Frequency counts and descriptive qualitative content analysis were used to aggregate key concepts into themes.

Results: From 4190 records, 104 were included. Of these, 26 included patients only, 54 included FCGs only, and 24 included both patients and FCGs as participants. Quantitative methods were used in 56 records, qualitative in 36, and mixed methods in 11. Three themes were identified: i) perceptions of care, interprofessional care team, and care environment; ii) communication with the interprofessional care team; and iii) impacts on quality of life. Patients and FCGs were mostly satisfied with care but reported unmet information and psychological support needs and misconceptions about palliative care.

Conclusions: This scoping review identified a need for further supports to enable delivery of patient-centred care, and patient and FCG education on the concept of SPC. Further research is needed on patients' experiences of inpatient SPC.

P 8.038 CommuniCate: Family-oriented Communication in the Intensive Care Unit

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Background/aims: The goal of this prospective observational study was to gain more insight in the current conversation techniques and topics intensivists address during bad news conversations and if there is room for improvement. The following hypothesis was formed: intensivists can learn from the perspective of palliative care nurses (PCN) with regard to subjects of conversation during end-of-life (EoL) conversations.

Methods: The conversations between intensivists and patient's relatives were audio-recorded and observed from April – June. The transcripts were thematically analysed, feedback was given by the PCN and a survey on the relatives' opinion on important subjects in conversations was administered. Thematic analysis was iteratively performed using the generally accepted principles of primary, secondary and tertiary coding, and applying constant comparison.

Results: The conversations' qualitative analysis (n=11) showed that the treatment restrictions, EoL-care topics and patient's wishes and spirituality were discussed in 8 conversations. Quality of life was discussed in 6 conversations. The PCN's feedback was that the physicians were empathic, genuinely involved and interested in the relatives and patients; they delivered the message professionally and were clear and understanding in their communication. Points of improvement were to more frequently and in more depth clarify the family relationships, to provide more room for the relatives' emotions, to discuss spirituality broader than religion only and to have the conversations in more suitable rooms. The main results of the survey among relatives (n=9) showed that the relatives' valued discussing the medical context, the patient's goals and wishes, the patient's and relatives' emotions and feelings, meaning of life and spirituality.

Conclusions: The PCN's feedback was valuable and the communication can be improved with regard to subjects such as family relationships, spirituality and providing more room for the relatives' emotions. Funding not applicable

P 8.039 A Short Mindfulness Program for Cancer Patients in Palliative Care: A Pilot Study and Reflection about the Feasibility and Acceptability of Such Program

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Background/aims: Mindfulness has been the subject of an increasing amount of scientific research in recent years : demonstrating that mindfulness can improve the quality of life of cancer patients and alleviate certain symptoms (like fatigue, anxiety, sleep). Mindfulness 8-week group programs have been studied specifically for cancer patients but most often these studies included patients in the curative phase or after treatments.

The purpose of this study was to explore how mindfulness could be offered to palliative care patients.

Methods: Based on the results of an initial exploration of the symptoms experienced by palliative cancer patients, we developed a short individual mindfulness program in 14 days: 3 sessions in face-to-face and daily meditations through a digital platform. Patients were randomized into 2 groups, experimental group and waiting list group. Quantitative data were collected on their physical (pain score), emotional and psychological state before and after their participation in the program (like acceptance, positive and negative affects). Qualitative data were collected during the sessions on their expectations, satisfaction and meditation experience during program.

Results: 22 patients were included (Mage=62, SD=XX, 14 women) at palliative stage: MKarnofsky 70%, 15 ambulatory, 21 undergoing oncological treatment. 2 patients left the trial early due to deterioration of global health or an intercurrent event. Nearly all participants completed the entire program and experienced a benefit.

All participants express satisfaction for the program and 30% want to continue practising. Quantitative and qualitative analysis are in progress.

Conclusions: This short one to one meditation program for patients meet a need in this population that could not participate in an 8-week group practice.

The qualitative analysis of the interviews will precise the benefits and the limits of this program: by their expectations, their preconceived ideas and the meditative experience expressed during the sessions.

P 8.041 Posttraumatic Growth in Cancer Patients: A Review of Systematic Reviews and Meta-analyses

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Background/aims: Cancer is a traumatic illness, and treatments have life-altering side effects. Cancer patients may experience posttraumatic growth (PTG)—positive psychological changes that result from an individual's struggle to cope with life-threatening events. The existing systematic reviews and meta-analyses of PTG in cancer patients are exploding, but the quality and topics vary./To appraise quality and synthesize topics of published systematic reviews and meta-analyses of PTG in cancer patients to identify gaps in current knowledge.

Methods: Five electronic databases were systematically searched using keywords "Cancer OR neoplasm OR oncology" and "posttraumatic growth" with limits to systematic review and meta-analysis. Two authors independently screened all the studies and appraised their quality with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, scores range: 0–27) and Critical Appraisal Skills Programme Systematic Review checklist (CASP, scores range: 0–20). Inter-rater reliability of search strategies and quality appraisal by Kappa (95% CI) is 0.90 (0.86, 0.95) and 0.78 (0.81, 1.00), respectively. This study was registered on PROSPERO (CRD42022345971).

Results: Included were 22 reviews and meta-analyses. Quality (mean [SD]) on PRISMA (22.0 [3.6]) and CASP (17.2 [2.6]) scales was variable and moderate at best. Most reviewed/synthesized cross-sectional studies. Topics included 1) relationship between PTG and psychosocial (63.6%), spirituality (27.3%), and quality of life (13.6%), 2) predictors of PTG (45.5%), 3) effectiveness of interventions on PTG (27.3%), and 4) mechanisms of PTG (13.6%).

Conclusions: In this first review of systematic reviews/meta-analyses of PTG for cancer patients, several knowledge gaps were identified. Quality of existing studies is moderate at best. No studies synthesized scores of PTG. Few longitudinal studies observed the trajectory of PTG. Few studies identified mechanisms of PTG to guide further interventions.

P 8.042 Exploring the Relationship between Finding Strength in Faith and the Psychological Status of Advanced Cancer Patients

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Background/aims: This study aimed to describe the psychological outcomes and quality of life (QOL) of Filipino patients with advanced solid

cancers and to investigate demographic and faith-related factors that are associated with these outcomes.

Methods: Participants were 195 advanced cancer patients recruited from inpatient/outpatient settings of a major hospital treating cancer patients in the Philippines. Participants completed self-reported surveys on QOL (FACT-G), psychological outcomes (HADS), and religious coping (finding strength in faith). Multi-variable regression models were performed.

Results: The average total FACT-G score was 65.39 (SD = 13.76). Among the various quality of life dimensions, social well-being had the highest average subscale score (M = 19.59, SD = 4.38) while physical well-being had the lowest average subscale score (M = 14.14, SD = 5.92). The average HADS-total score was 14.46 (SD = 5.77). Participants reported a mean HADS-anxiety of 6.09 (SD = 3.20), and 8% met threshold for probable anxiety (HADS-anxiety > 10). While participants reported a mean HADS-depression score of 8.38 (SD = 3.60), 27% met threshold for probable depression (HADS-depression > 10). Participants aged 35 to 49, compared to those below 35 years old, reported increased social well-being ($\beta = 2.71$, $p < .05$, CI: 0.26; 5.16). Majority (81.9%) find strength in their faith or spiritual beliefs. Participants with higher strength in their faith reported less depression ($\beta = -1.20$, $p < .05$, CI: -2.25; -0.15).

Conclusions: Our results showed that higher strength in faith was associated with reduced depression, underlying the vital role that faith can play in improving not only the spiritual well-being but also the psychological health of advanced cancer patients in the Philippines.

P 8.043 Meanings of "Home" in a Palliative Situation at Home

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Background/aims: Since the early 2000s, the development of home hospitalization structures (HAD) has facilitated the coordination of complex care and the possibility of staying at home in a palliative situation.

For caregivers, the patient's "home" is thought of as a wish to return home. For patients, the frequently idealized return home can be relationally and organizationally difficult.

In such a context, is the demand for "home" reducible to the home or does it cover other realities?

This study aims to better understand what constitutes "home" and what this request covers as a subjective reality for these patients in a palliative situation. What does it mean for them in this singular moment to come back "home"?

Methods: 14 non-directive interviews were carried out with patients in a palliative situation. (cancer, acute heart disease, deterioration of general condition) – 6 men and 8 women aged 57 to 95.

Analysis of the corpus with the thematic textual analysis software ALCESTE. Classification method for extracting classes of meaning made up of significant words and phrases in order to extract the dominant themes from the corpus.

Results: The first results indicate that:

- "At home" is not limited to the home.
- "At home" is inseparable from the presence of a family environment and the maintenance of emotional ties.
- "At home" is linked to a nostalgic quest for freedom, mastery of time, and relationships.
- "At home" is the expression of a search for identity supports, memories, or a familiar environment in a moment at the risk of depersonalization.

Conclusions: The demand for "home" in a palliative situation covers multiple realities, little elaborated in patients struggling with many anxieties and problems of daily management.

Living and staying at home in a palliative situation reflects a quest for identity stability and reflects a search for internal security at a time when projecting oneself into a future has become uncertain.

P 8.044 Implementation of a Personhood Headboard to Improve Person-centred Palliative Care in an Inpatient Hospice

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Background/aims: Person-centred palliative care (PC) strives to make the whole person visible and prioritizes the satisfaction of spiritual, existential, social, and psychological needs to the same extent as physical needs. Assisi Hospice (AH) in Singapore provides inpatient (IP), day care (DC) and home care (HC) services for PC patients. The IP team typically admits patients facing life-limiting illnesses with estimated prognoses of 3 months or less. All inpatients are cared for by an interdisciplinary team (IDT) comprising doctors, nurses, medical social workers, pastoral care counsellors, physiotherapist, occupational therapist, therapy aids, art therapist, music therapist, speech therapist and volunteers. The aim of this project was to improve person-centred care in AH by facilitating IDT understanding of every patient's personhood through the implementation of an individualised personhood headboard (PHB) upon IP admission.

Methods: A PHB with sections on 'Call Me', 'I enjoy', 'What comforts me', 'I dislike', 'I want you to know' and 'Tips to care' was created. This was piloted in a single ward for new IP admissions from 4 to 18 April 2022. A survey to study awareness, usage and helpfulness to patient care was conducted for all staff involved in the pilot. Following review of the survey results, amendments were made to the PHB and the finalised design was rolled out to all wards from 30 May 2022. Remaining staff were surveyed from 19 to 28 July 2022. Audits of the PHB were conducted and the contents were reviewed by the team. The study team also gathered feedback from patients and families regarding the PHB.

Results: The survey in July had 52 respondents and a response rate of 52%. All were aware of the PHB but only 50% had filled or updated it. Nineteen out of 52 (36.5%) were fairly confident and 6 out of 52 (11.5%) were very confident in filling up the PHB. 73% of staff felt that the PHB had helped in patient care. Results of PHB audits and feedback from patients and families are pending.

Conclusions: Pending

P 8.045 The Symptom Experiences, Palliative Management and Spiritual Wellbeing of Indonesians with Advanced Cancer

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Background/aims: The prolonged multifaceted physical and psychological symptoms-distress eventually affected heavily upon many advanced cancer patients (ACPs). The aim of this correlational descriptive research was to explore the symptom experiences, palliative management, and spiritual well-being of Indonesians and examine the prevalence, frequency, severity, and distress and the effectiveness of management in relation to the personal, communal, environmental, and transcendental domains of spiritual well-being.

Methods: A cross-sectional descriptive design was applied based on the Dodd's Symptom Management Theory, and the use of instruments: 1) The Demographic Background Questionnaire [DBQ], 2) The Portable Mental Status Questionnaire [PMSQ], 3) The Memorial Symptom Assessment Scale [MSAS], 4) The Palliative Managements Questionnaire [PMQ], and 5) The Spiritual Well-being (SWb)-SHALOM Questionnaires.

Results: Participants were 120 ACPs ranging from 18 to 73 years. The mean symptom was 15 (range 2-27). The most prevalent symptoms were lack of energy, pain, worrying, hair loss, feeling sad and difficulty sleeping; most frequently reported symptoms were lack of energy, problems with sexual interest, numbness/tingling, difficulty swallowing, and difficulty sleeping; most severe symptoms were hair loss, weight loss, lack of energy, swelling of arms/legs, and difficulty swallowing; and most distressing were pain, the lack of energy, lack of appetite, vomiting, and nausea. Patients most appreciated their 'beloved immediate family and friends'; and the most effective reported management was 'relying upon the only Mighty Powerful/Most High Being/God to provide miraculous Divine Healing'.

Conclusions: The findings from this study provided empirical evidence to understand the symptom experiences, palliative management, and spiritual well-being in ACPs. The health care providers need to design appropriate and culturally sensitive intervention programs for ACPs, particularly on spiritual wellbeing.

P 8.046 Validation of the Schedule of Attitudes toward Hastened Death (SAHD-Mx) in Patients Undergoing Palliative Care in Mexico

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Background/aims: The suffering entailed by advanced, incurable diseases many times derives in a Wish to Hasten Death (WTHD) by patients undergoing these conditions. The Schedule of Attitudes Toward Hastened Death (SAHD) has emerged as a valid and reliable tool to assess this condition among patients diagnosed with advanced cancer, however the instrument has never been culturally adapted and validated for patients in Mexico. This study sought to validate and abbreviate the SAHD tool for using among patients attending the Palliative Care Service of the Instituto Nacional de Cancerología in Mexico.

Methods: The SAHD was culturally adapted from a previously published validation in patients from Spain. Eligible patients included Spanish literate subjects treated as outpatients in the Palliative Care Service, with adequate clinical conditions, and an ECOG performance status of 0-3. Patients were asked to answer the SAHD-Mx instrument as well as the Brief Edinburgh Depression Scale (BEDS).

Results: A total of 225 patients were included in the study. Median positive response in the SAHD-Mx was 8 (range 5-18). A positive correlation was identified between the SAHD-Mx scale and ECOG performance status ($rs=0.174$, $p=0.009$), as well as BEDS ($rs=0.483$, $p<0.001$). SAHD-Mx displayed strong internal consistency ($\alpha = 0.85$), and adequate reliability from test-retest phone interviews. A structure composed of 4 factorial components was identified. Last, an abbreviated 6-item scale was constructed, which included items 4, 5, 9, 10, 13 and 18.

Conclusions: The SAHD-Mx emerges as a valid and reliable tool for assessing WTHD among patients diagnosed with cancer undergoing palliative care in Mexico. Further research is warranted to assess a cutoff point for detecting WTHD using the abbreviated 6-item scale proposed in this study.

P 8.047 Obstacles and Facilitators for Spiritual Care among Portuguese Healthcare Professionals

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Background/aims: Spirituality and spiritual care competency are core values for all healthcare providers (e.g. nursing, medicine, and psychology). Regardless, there is little evidence of Spiritual Care (SC) competency in practice.

This study aims to a) assess the facilitators and obstacles of SC among Portuguese healthcare professionals; b) relate them to sociodemographic and professional variables.

Methods: A correlational study was conducted with 180 healthcare professionals who responded to an e-survey. The questionnaire included: sociodemographic and professional variables, the Facilitators for Spiritual care scale (12 items), and the Obstacles for the Spiritual care scale (12 items). The scale items were evaluated using a 5-point Likert scale, from 12 to 60 points (Median=46). The data were analysed using descriptive and inferential statistics.

Results: Participants have an average age of 42.4 ± 11.3 years; 17.8% were male, have worked for an average of 15.6 ± 10.2 years, 58.9% working in palliative care, and 87.8% were identified with spiritual or religious beliefs.

Concerning the facilitators for SC, participants scored a mean of 55.2 ± 4.5 points, revealing high recognition of the essential elements of SC. Regarding obstacles to SC, they were also recognised by participants (Mean=38.7; SD=7.9). Compared to the other participants, palliative care professionals were more attentive to identifying the threat of the obstacles to SC. We also found that participants with spiritual or religious beliefs revealed better recognition of facilitators for SC ($p=0.004$) and were more attentive to obstacles to SC ($p=0.022$). Age, sex, and years of professional experience were not related to the facilitators and obstacles for SC.

Conclusions: Our results emphasised high awareness of facilitators and obstacles to SC, especially for palliative care professionals who are more aware of these obstacles. Further studies are necessary to capture SC facilitators and obstacles more fully.

P 8.048 Patients' Perceptions of Dignity in Palliative Medicine: A Systematic Scoping Review

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Background/aims: Defining dignity in a socioculturally appropriate way is a necessary component of effective and holistic palliative care. However, dignity continues to be poorly conceptualised. Addressing this lack of understanding and enhancing dignity-conserving end-of-life care is pertinent and requires a review of current concepts of dignity.

The primary research question is "How do palliative care patients conceive the concept of dignity?". The secondary research questions are "What factors affect patient perceptions of dignity?" and "How are prevailing dignity-conserving care practices perceived by patients?"

Methods: A Systematic Evidence Based Approach guided Systematic Scoping Review was conducted. To enhance reliability and accountability, the Ring Theory of Personhood (RTOP) was used as its theoretical lens. Using thematic and content analyses, three separate teams

independently analysed articles identified from structured searches of seven databases. Themes and categories identified were compared and combined to create domains which guided the discussion.

Results: 14,795 abstracts were identified, 418 articles were reviewed and 103 articles were included. The first domain identified definitions of dignity described by patients across differing sociocultural contexts. The second domain identified various internal and external influences on their perceptions of dignity, aligned with the four rings of personhood. The final domain looked at existing dignity-conserving care practices, how dignity is addressed in palliative care and further areas for improvement.

Conclusions: This review affirms the notion that dignity is intimately related to palliative care patients' self-concepts of personhood. Furthermore, factors affecting the dignity of patients are multi-faceted and individualistic. Effective dignity-conserving measures used in palliative care must be guided by and sensitive to the patient's personal concept and understanding of dignity.

P 8.049 Oncology Patient's Hope and Interaction with Psychological Distress

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Background/aims: Background: Hope has been positively associated with health while plays an important role in managing illness and accompanying losses. For the oncology patient hope is a prerequisite for effective adaptation to the disease but also a strategy for dealing with physical and mental upheavals. Hope enhances disease management, psychological adaptation, and quality of life.

Aims: Due to the complexity of hope's effect on the patient generally and specifically the patient under Palliative Care, its role and relationship to anxiety and depression is a challenge.

Methods: This is a correlated study, performed at a palliative care unit in Athens, Greece. A member of the unit interviewed the patients to elicit background medical history, demographic data, mental health status, and current condition. 130 patients with cancer completed the Greek version of Herth Hope Index (HHI-G), and the Greek version of Hospital Anxiety and Depression Scale (HADS-GR).

Results: In unifactorial analysis HHI-G hope total score was highly negatively correlated with "HADS anxiety" ($r=-0.491$, $p<0.001$) and "HADS depression" ($r=-0.626$, $p<0.001$) respectively. Patients with ECOG 0-1 and without radiotherapy presented higher values of HHI-G hope total score compared with those with ECOG 2-3 ($p=0.002$) and with radiotherapy ($p=0.009$) respectively. The multivariate regression analysis revealed that people who did radiotherapy have 2.49 points higher score of HHI-G hope compared to those who did not (interprets 3.6% of Hope, $p=0,007$). An increase of 1 point in depression results in a 0.65 point decrease in HHI-G hope score (interprets 40% of Hope, $p<0,001$).

Conclusions: Understanding of the common psychological concerns and hope of patients with serious illness can help improve the clinical care of the patient. Mental health care in context of illness should focus on managing the psychological symptoms such as depression and anxiety to enhance and maintain patients' hope.

P 8.050 The Provision of Culturally Appropriate Palliative Care at a Large Teaching Hospital in the UK

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Background/aims: Palliative care is a holistic approach aiming to improve quality of life of those with life-limiting illness and their caregivers. Care should be individualised in line with what is important to the patient/their family. To meet these needs an understanding of the cultural preferences of an individual is essential. Despite this, results from a national audit show that less than a third of families feel we meet the spiritual/religious needs of their loved one at the end-of-life.

We aimed to do a service evaluation of current practice in a large teaching hospital in the UK, to determine whether the cultural needs of patients were assessed during their final admission to hospital.

Methods: A retrospective case note review of 200 patients who died between August-October 2021 in a large teaching hospital in the UK. We examined whether discussions had been had with the patient or family regarding cultural requirements. Frequencies/percentages were reported for categorical variables and chi-square statistics calculated to explore the relationship between variables and any discussion.

Results: 104 (52%) were male, median age 82. Demographic characteristics were not routinely recorded. Ethnicity was recorded for 143 (71.5%) patients, religion for 82 (41%), and nationality for 136 (68.0%). Where it was documented, 88.1% were white and 98.5% were British. Discussions were only documented in 34 (17.0%) cases. If specialist palliative care input was sought, cultural preferences were more likely to be discussed ($p < 0.001$). When discussions were documented, patients were more likely to be referred to chaplaincy ($p < 0.001$).

Conclusions: In this service evaluation, cultural preferences at the end-of-life were often not documented and possibly not being discussed with patients and families. Education is needed on the importance of assessing and addressing these needs.

P 8.051 Our Positive Resources: Experiences of a Training Programme Designed to Strengthen the Sense of Coherence

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Background/aims: We developed interventions to increase job satisfaction and keeping hospice professionals in the field. The Path analysis revealed that a greater sense of coherence (SOC) was associated with lower levels of subjective stress, depressive symptoms and positively correlated with wellbeing. SOC can also be developed in adults through various interventions that, by adequate coping, can contribute to the well-being of workers exposed to stress and benefit patients in the long run.

By developing the SOC training programme, our aim was to identify the difficulties and protective factors of the healthcare professionals and teams, and to strengthen positive resources.

Methods: The study consisted of two parts:

- 1 A 4-hour training programme was conducted with the participation of workers in a hospice institution (N=12, mean age 49.33 yrs; SD = 11.08 yrs) and a hospice home care group (N=10; mean age 47.5 yrs; SD = 9.58 yrs). The activities to strengthen SOC were aimed at raising awareness of individual and organisational, positive and negative aspects of hospice work, and reframing tasks as challenges.
- 2 The experiences of the participants (N=6; N=3) were collected in focus group discussions. During the analysis of the verbatim texts we developed codes and categories. The vertical content analysis was based on the frequency comparison of interpretations.

Results: The majority of the focus group participants considered it important to practice the meaningfulness element of the SOC, i.e. looking at life events as challenges. For the element of manageability, i.e.

responding adequately using existing resources, special emphasis was laid on separating work life and personal life. The majority also pointed out the positive effect of reducing worker turnover.

Conclusions: Our qualitative research has confirmed that the training programme contributes to the development of varied and effective educational and training programmes for hospice professionals.

P 8.052 Feasibility Test of a Resource-oriented Coordinated Rehabilitation and Palliative Care Intervention for People with Advanced Cancer

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Background/aims: People with advanced cancer are particularly challenged by fatigue and other symptoms affecting their everyday lives, wherefore they need to balance their resources and energy to optimize possibilities for enjoyment and quality of life despite limited life expectancy. A resource-oriented intervention was developed to enhance balance in everyday activities and quality of life with a coordination of rehabilitation and palliative care to uphold functioning and alleviate suffering. The aim was to test the feasibility of a resource-oriented intervention for people with advanced cancer.

Methods: A feasibility study with a repeated-measurement design without a control group was conducted at a research clinic. In total, 22 home-living adults (≥ 18 years) with advanced cancer who reported challenges in everyday life participated. An interdisciplinary resource-oriented intervention consisting of workshops on balancing energy and everyday activities, activities of enjoyment with creative expressions and movement was conducted. Data were collected at baseline, during and after a 5-day residential stay, after 6 weeks, and after a 2-day follow-up stay. Data were collected by use of questionnaires, participant observations and focus group interviews, and were analysed using descriptive statistics and thematic analyses.

Results: Data on fidelity, dose, reach and mechanism of impact are currently being analysed. By the time of the congress the results will be available and ready for presentation.

Conclusions: This study presents a new approach in rehabilitation and palliative care by focusing on resources instead of on problems. The results from the feasibility study will contribute with important knowledge to further develop interventions coordinating rehabilitation and palliative care. The intervention will be pilot tested in Danish municipalities and evaluated as per effect and process.

The Danish Knowledge Centre for Rehabilitation and Palliative Care and the Danish Cancer Society fund the study.

P 8.053 Social Worker as a Bearer of Information about Palliative Care

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Background/aims: Palliative care has been offered in the Czech Republic for 25 years. First in the form of Inpatient Hospices, later Home Palliative Care Services, and currently it is also Hospital Palliative Care Support Team and implementation of palliative principles in social services. The social worker should be among the first to offer the patient and their family an appropriate palliative care service. Who will explain the advantages and disadvantages of individual types of care with regard to the social background of patient. This research deals with the role of the social worker in informing patients about palliative care options.

Methods: Semi-structured interviews with 32 relatives in Czech Republic were conducted. Participants were required had to live with someone

who uses palliative care at the time of the research. Interview transcripts were thematically analysed.

Results: Several themes emerged to the topic during the analysis of the twenty five interviews. The participants did not have enough information about palliative care. They had to actively search for information themselves. If they had any information, it was usually provided by a GP. The participants met a social worker for the first time as part of palliative care. The social worker is not perceived as the bearer of information about possible forms of palliative care.

Conclusions: EAPC White Paper: Core Competencies for social work in palliative care in Europe emphasizes the role of the social worker in palliative care. Despite this, social workers are generally perceived as unimportant and replaceable by any other profession in the Czech Republic. The results of our research also correspond to this. About the causes of this condition can only be argued. Low prestige of the profession, impossibility of specialized education, lack of finances and others.

P 8.054 The Role of Companion Animals in Advanced Cancer: An Interpretative Phenomenological Analysis

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Background/aims: There is evidence that a companion animal (CA) or 'pet' can be helpful during the management of chronic illness. However, the psychological effects of CAs and the mechanism by which they can be beneficial to individuals managing life-limiting conditions is unknown. This study addresses this gap and provides the first examination of the lived experience of CAs among community-dwelling adults with advanced cancer.

Methods: Semi-structured qualitative interview study consisting of a homogenous sample of 6 individuals with an advanced cancer diagnosis, who either self-selected to the study or were recruited through a regional charity that supports palliative and end-of-life care patients in maintaining a connection with their CA. Data were transcribed verbatim and analysed using Interpretative Phenomenological Analysis.

Results: Four superordinate themes occurred in the data: a protective relationship, positive behavioural change, facilitating meaningful social connections and increased loss-orientated cognitions. The findings suggest that CAs offer de-arousing and socially protective supports that mitigate physical and psychological sequelae experienced by people with advanced cancer. However, as their illness progresses, individuals may also experience thoughts related to not meeting their CA's needs currently and in the future.

Conclusions: CAs provide emotional, practical, and social supports to individuals diagnosed with advanced cancer that can improve individual psychological wellbeing. Consequently, it is important that CAs are considered in advance care planning processes and that services are available to mitigate any negative effects of CA ownership, in order to maximise the benefits CAs confer to individuals managing advanced cancer.

P 8.055 "What Is it Like to Be Human?" Swedish Health Care Staff's View on the Existential Dimension

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Background/aims: Palliative care must provide care with a holistic view of the person based on physical, psychological, social, and spiritual/existential dimensions. The dimension that has been least developed and defined is the spiritual/existential dimension. EAPC's definition states

that the spiritual/existential dimension relates to how people experience, express and/or search for meaning and is not limited to religious issues. This broad definition enables us to investigate and work with the spiritual/existential dimension in a country like Sweden, which is regarded as largely secular.

Aim: To identify what the staff consider to be existential issues, what existential care means and who is providing that care. Another aim was to investigate what support and training the staff had received and/or would need regarding existential issues.

Methods: The staff in specialized palliative care, oncology clinics and municipal elderly care have been asked in a survey what they consider existential questions, - needs and - care are.

Results: The analysis is ongoing but preliminary result point to existential questions being understood as thoughts about life and death and what the meaning of life is. The staff regard the existential dimension as important. Existential care is seen as performed by all staff categories. There is an interest and need for education, reflection, and guidance in existential matters. The staff reports no knowledge of any existing rating scale of existential needs, translated into Swedish.

Conclusions: Even though Sweden is a largely secular country, existential questions are considered to be important by the participants in this study. It is therefore important to raise the existential dimension in reflection and training so that the staff can meet patients and their loved ones in these matters.

P 8.057 On-line Self-compassion Training - A Pilot Study in Melbourne, Australia

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Background/aims: This pilot project, undertaken during the COVID-19 pandemic replicated a self-compassion program to support healthcare professionals in palliative care settings. It was anticipated that undertaking this program would enhance participants' psychological wellbeing.

Methods: Because of the COVID-19 pandemic, we decide to offer the programme online. It comprised once weekly gatherings for six weeks. Participants were recruited from an area of Melbourne, Australia, using convenience sampling from palliative care services. Three survey rounds with identical questions were conducted prior to, immediately after, and three months after training. Surveys consisted of six scales: the Self-compassion Scale, the Santa Clara Brief Compassion Scale, the Cognitive and Affective Mindfulness Scale, the Depression Anxiety Stress Scale, the Professional Quality of Life Scale, and the Interpersonal Reactivity Index Scale. Paired-sample t-test and repeated Measures ANOVA analyses were used to compare participant responses.

Results: Nine participants working in palliative care completed the training and the three surveys, which also included qualitative responses. The program experience was overwhelmingly positive, with comments specifically relating to the online delivery mode. Self-compassion ($F=14.44$; $p<0.05$) and mindfulness ($F=18.44$; $p<0.05$) scores significantly increased post-training; these changes were picked up in a short time and endured over time. The emotional state improved by compassion satisfaction showing a positive improvement three months post-training, from the baseline; along with there being no changes in compassion satisfaction, burnout, and dispositional empathy.

Conclusions: Even against the difficulties caused by the COVID-19 pandemic, a short online self-compassion program proved effective, assisting participants to cultivate their inner resources, to sustain their well-being. Expansion of the training as part of ongoing organisational education may benefit the wider palliative care workforce.

P 8.058 End-of-Life-Dying MattersJ.M. Carter¹, M.J. Carey²¹University of Southern Queensland, Nursing and Midwifery, Toowoomba, Australia

Background/aims: The hidden nature of death in contemporary biomedicine is well documented in the current literature and experienced by many people towards the end of their lives. In modern ideology, the notion of living a long life is paramount. However, the quality of a longer life comes into question with the advancement of modern medicine. This groundbreaking study included eight people who shared their experiences via social media and are confronting their mortality. Aim: A deep exploration of the issues pertinent to people towards the end of life (EOL).

Methods: A longitudinal study via storytelling commenced at the point of diagnosis until (in some cases) death. The research focused on van Manen's (2014) hermeneutic phenomenology; data was centred on the life-world existential themes of corporeality, temporality, relationality, spatiality, and materiality and collated into main overarching themes, these being the crucial point of diagnosis followed by restoration and transcendence towards the EOL.

Results: The first significant and new finding was that a terminal diagnosis is a catalyst for a conscious awareness towards increasing the quality of life. The second substantial and new finding was how these people rebuilt their lives in the face of their mortality. Gaining resilience empowered them towards their future as they aimed for an increased quality of life towards the EOL.

Conclusions: The urgency of time was no longer critical for the people experiencing the EOL. However, the concept of limited time became paramount as people preferred to focus on the quality of life rather than the quantity of life. The arts, in the form of poetry, song and prose, were essential towards gaining deeper insight into the core of the Self and a connection to the ethereal world. There was an urgency to meet others experiencing the EOL in an open and honest non-confronting way exposed during this study; for people with a terminal diagnosis, the psychosocial concepts of dying matter.

P 8.059 Barriers to the Assessment of Spirituality in Primary Health CareN. Rodrigues¹, R. Matos²¹ACeS Marão Douro Norte, Núcleo de Cuidados Paliativos, Vila Real, Portugal

Background/aims: The aging of the population, the increase in chronic diseases, and the growing importance of a holistic approach made it important to define and incorporate spirituality in the daily life of health care. There is little information about the evaluation of spirituality in primary health care in palliative patients, therefore, this review aims to understand the barriers of doctors and nurses in the assessment of spirituality.

Methods: Literature and critical review by searching reviews, clinical trials, books, and relevant articles in Pubmed, Scielo, and Web of Knowledge (ISI), in Portuguese, English, and Spanish, published in the last 10 years.

Results: The studies analyzed include spirituality as an important concept in the evaluation of patients with chronic or palliative pathologies. Spirituality and religion are described individually or as interconnected or aggregated concepts in the studies. The difficulty in defining spirituality is one of the obstacles in the investigation and approach of this concept in health. The barriers in approaching and evaluating spirituality focused on health professionals, as well as on patients or family members. The health professional feels uncomfortable with the topic due to various reasons like lack of time, uncertainty, fear, lack of formal spiritual education at university, lack of privacy with the patient, and unfamiliarity with the theme. The approach to spiritual care is assumed to be the chaplain's responsibility. For the patient, spirituality and religion are usually similar concepts, which creates confusion during the evaluation. The

relationship of trust and respect with the family doctor or nurse is seen as a facilitating factor.

Conclusions: The studies analyzed include spirituality as an important concept, but the evaluation can be compromised. There are described many barriers, namely the lack of time and education, and the fact that the spiritual assessment is not always performed by the health professional.

P 8.060 'A Giant Step. How the Dutch Government Created an Infrastructure for Spiritual Care for the Elderly and Adults and Children in the Palliative PhaseG. Schurmann¹¹Agora, Bunnik, Netherlands

Background/aims: How the government supports people now that they live at home longer. In the palliative phase, people prefer to be at home. In the palliative phase, people have existential and spiritual needs. Now that people are staying at home longer, they want to be provided for there. The government fills a gap.

The government has decided to use spiritual care in the home situation to compensate for the gap in the need for meaning and meaning.

A national infrastructure must be built.

Methods: A national infrastructure has been found in the structure of the Palliative Care Networks. The qualification of the chaplains takes is guaranteed by the Dutch chaplaincy quality register.

Chaplains are qualified professionals in meaning. Unique for the Netherlands is that the government facilitates these chaplains.

In the spiritual care at home is a strong focus on cooperation. This is in line with the guideline Meaning and spirituality in the palliative phase. There has been broad collaboration in practice, education and research. In the design, financial structures are crucial. Initially through the Palliative Care Networks, now directly through so called Centres for questions of life.

Results: In three years' time, a national infrastructure has been realised.

There are more than 200 chaplains who are largely self-employed.

The present time requires chaplains who can be deployed flexibly: knowledge of multiple religions, at home in their own spiritual source.

Conclusions: Spiritual care in the home situation meets the new needs of the elderly and adults and children in the palliative phase. This is a unique situation in Europe.

Spiritual care at home provides a new ecosystem.

The use of spiritual care in the home situation offers new perspectives for cooperation in care and social care.

P 8.061 The Pressure Inside the Glass Dome. Gay Men Who Live with HIV Give Meaning and Shape to Seropositivity and Self. An Interpretative Phenomenological Analysis StudyF. Thanasko¹, M. Nikoloudi¹, K. Antoniadou Anemi¹, K. Mystakidou¹¹National and Kapodistrian University of Athens, School of Medicine, Palliative Care Unit, Athens, Greece

Background/aims: Due to the spectacular improvements in the field of treating HIV with combined anti-retroviral therapy, a turn in HIV infection from a fatal to a chronic disease has been occurred. People who live with HIV question if meaning exists in their suffering. The qualitative research on the effects of the HIV on meaning making is insufficient and rare in Greece.

Aims: To explore how Greek gay men, who live with HIV, give meaning to seropositivity and to investigate how HIV shapes the self.

Methods: Seven semi-structured in-depth interviews were conducted. Two main topics were addressed: (1) what does living with HIV mean to you, and (2) were your love affairs and/or stable relationships shaped by

seropositivity? If yes, could you describe how? Interpretative Phenomenological Analysis was applied to the data. The interpretation of the textual material was carried out by the first three authors separately conducting investigator triangulation. This type of triangulation can bring confirmation of findings, adding breadth to the phenomenon under study.

Results: Two super ordinate themes emerged from the analysis. Here the first one is presented: Giving meaning and shape to seropositivity and self. Seropositivity means loss, which “makes everything more stirred” and “really – really small”, “broken”, “damaged” by “an explosion” looking “like a scattered puzzle” and a “grey” “element of my character” leading to a transition to “adulthood”.

Conclusions: HIV diagnosis is not just a medical condition or just related to stigma; it's a part, a function, an element of self, catharsis and palliation from the fear of the HIV itself. Palliative care development in Greece is very low as it belongs to group 2: capacity building activity. Palliative care professionals in Greece should be aware of the meaning of seropositivity for the people who live with HIV and to the mental health issues that may arise as a reaction to HIV, affecting their adherence to HIV medication.

P 8.062 Spiritual Care in Palliative Care: A Physician's Perspective

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Background/aims: As a palliative care physician, I aim to explore and meet the needs of my patients and their loved ones. As I am specifically trained as a specialist in assessing and treating ‘pain and other physical symptoms’, I consider myself a generalist in psychological, social and spiritual issues.

In this study I aim to explore and describe two approaches to assess spiritual needs in palliative care.

Methods: Two different approaches are described and explored: an analytical approach in which instruments may be used, and a holistic approach, in which the quality of the clinical encounter and the clinical language of the physician is essential.

Results: The analytic approach to map spiritual needs entails using an instrument that measures spiritual well-being or spiritual needs, and measuring the quality of life, with specific attention to spiritual issues. Second, a holistic approach is promoted. In the integrity of the clinical encounter patients are encouraged to tell their personal narrative as they know it, and medical, ethical and spiritual issues may be discussed. A prerequisite is the development by the physician of a personal ‘clinical language’, with specialist's and generalist's topics moving in a natural way between medical information, spiritual valuing, and ethical aspects. Inspiration of colleagues in interdisciplinary collaboration may be supportive to develop such a personal clinical language.

Conclusions: Both analytic and holistic approaches are used in palliative care to assess the patient's suffering, including spiritual suffering. A holistic approach implies developing a personal clinical language enabling us to encourage patients to share their narrative as they know it and their needs, including spiritual needs. Self-reflection, interdisciplinary collaboration and specific training may be supportive to develop this clinical language, which is the bearer of our witnessing the patient's suffering and discussing the support that matches the patient's needs as much as possible.

P 8.063 Wish to Hasten Death in Mexican Palliative Cancer Patients: A Phenomenological Study

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Background/aims: The wish to hasten death (WHD) presents as a reaction to the considerable suffering which accompanies a life-threatening diagnosis and for which the patient cannot see another way out but to accelerate death. WHD may present in response to several social, psychological, existential or psychiatric conditions, and represents a novel construct which has not been fully explored amidst Mexican culture. This study aimed to explore the WHD among Mexican patients with advanced cancer treated at a palliative care service.

Methods: We performed a phenomenological interpretative study from June 3rd-August 30th 2019 at the Instituto Nacional de Cancerología, Mexico (INCan). Interviews were analyzed following the categorical content technique and coded, through systematic identification of central concepts. Through information triangulation, we identified thematic axes which answered similar concepts.

Results: Nine participants were included in this study. After the interviews were analyzed we identified 4 main themes which answered the experience pertaining WHD: 1)the illness, 2)emotional suffering, 3)attitude towards death and 4)the wish to live.

Conclusions: Patients enrolled in this study show a complex relationship towards death, which acquires different nuances in the course of disease progression. Among the participants the most frequently cited uncontrolled symptoms included fatigue and sadness, the latter was accompanied by a sense of hopelessness and existential guilt. In context with the recently described aspects of sustained suffering and functionality loss, patients diagnosed with advanced cancer experience death as their only way out, and the WHD appears. Conversely, two conditions are perceived as limiting the WHD, including family bonds and obligations and spirituality, which can refer to faith in a superior being or fear of God. Our approach towards patients it is necessary to discuss thoughts related to death and dying, and the relevance of assessing the WHD differently to suicidal ideas.

P 8.064 Knowledge, Attitude and Practices Regarding Advance Directives among Resident Physicians in Vicente Sotto Memorial Medical Center

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Background/aims: One of the essential roles of a physician is to assess a patient's worth and support them in making decisions regarding their future preferences when it comes to medical care. Advance Directives is a patient-centered approach which is linked to a better-quality treatment at the end of life.

Methods: An analytical cross-sectional study was conducted at Vicente Sotto Memorial Medical Center. There was a total of 129 respondents who gave their consent and was given survey questionnaire containing the demographic profile, knowledge, attitude and practices. Categorical variables were presented as frequency and percentage. Chi Square Test was used to determine the association of demographic profile with knowledge and attitude. Man-Whitney U test was utilized for the association of age with knowledge and attitude.

Results: Out of 129 respondents, 36.59% were in favor towards self-determination and autonomy. Majority of the respondents revealed an adequate knowledge and positive attitude regarding advance directives. Based on the results, there were no significant correlations between sociodemographic of the residents towards to knowledge and attitude. Over 66.7% of the respondents had used Advance Directives to their

patients but 25% were not comfortable about it. Though most of the respondents was able to discuss AD with their patients, 7.0% of them are not willing to open the topic to the family.

Conclusions: VSMHC is a tertiary hospital which also caters Hospice, Palliative and Supportive care to the patients. One of the services offered is initiating Advance Directives which may be a factor for a positive knowledge, attitude and practices towards this topic

P 8.065 Mindfulness with Palliative Cancer Patients, What Should Be Taken into Account? A Qualitative Analysis

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Background/aims: According to the concept of Total Pain proposed by Cicely Saunders, treatment of pain in palliative patient requires taking into account its multidimensional nature: physical, social, psychological and spiritual aspects.

Mindfulness has been the subject of an increasing amount of scientific research in recent years : demonstrating that mindfulness can improve quality of life of cancer patients and alleviate certain symptoms, but mostly for patients in the curative phase or after treatments.

The purpose of this study was to explore how can the expressed needs of palliative patients be taken into account in mindfulness practice?

Methods: Fourteen semi-structured interviews were conducted in two French institutions (Mage=68, SD=7.19; 8 women). The interview guide explored physical suffering (e.g., pain), social suffering (e.g., isolation), psychological suffering (e.g., emotional state), spiritual suffering (e.g., the place of spirituality in the experience of illness), connection to nature, and patients' internal/external resources. Thematic content analysis was used to analyze the interviews.

Results: From the meaningful verbatims, different themes and sub-themes emerged describing total pain in these different dimensions.

Based on the funding principles of meditative practice, we have identified 3 major themes described by the patients linking total pain and mindfulness: acceptance, interdependence, impermanence. Despite experiencing total pain, palliative patients describe what is acceptance of the prognosis of illness and eventually death, they seem to experience the interdependence and impermanence of different phenomena related or not to the illness.

Conclusions: Describing the experience of palliative patients in terms of the mindfulness foundations can help to develop meditation programs suitable and to identify areas for research on the benefit of the practice. It may also help mindfulness teachers to anchor the practice in the daily lives of these patients or to be alert to their frailty.

P 9 - Paediatric Palliative Care

P 9.001 Development and Initial Validation of a Novel Outcome Measure for Use with Children and Young People with Life-limiting and Life-threatening Conditions

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Background/aims: Development of a patient-centred outcome measure (PCOM) for children and young people (children) with life-limiting and life-threatening conditions (LLTTC) is a priority. This study aims to

develop a PCOM (C-POS) for use by children with a LLTTC and their families, and establish face and content validity, comprehensiveness, comprehensibility, and acceptability.

Methods: A multi-phase mixed methods study following Rothrock and COSMIN guidance on outcome measure development, including semi-structured interviews, systematic review, Delphi survey, item generation meeting, cognitive interviews and patient and public involvement (PPI) work with children.

Results: Priority outcomes identified during the qualitative interview study (n=106), Delphi survey (n=82) and PPI work (n=22) informed face and content validity and showed that children with LLTTC require a holistic approach to care that incorporates physical, social/practical, emotional and spiritual/existential aspects, with a cross-cutting theme of normality. Evidence on measure design such as recall, and response options were informed by the qualitative interview study, systematic review and PPI work. This evidence enhanced feasibility and acceptability of C-POS. An item generation meeting (n=22) informed five developmentally appropriate versions of C-POS (self and proxy-report) that maximise acceptability. Cognitive interviewing (n=48) helped to refine the prototype C-POS versions, particularly to enhance acceptability for parents of non-verbal children and to further inform appropriate recall periods and response formats. This has further strengthened face and content validity of C-POS.

Conclusions: We have developed multiple versions of C-POS and conducted initial validation. Each version is acceptable for the different age/developmental stages of children with LLTTC and their families. The novel C-POS suite of measures is now ready for psychometric testing.

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P 9.002 Exploring the Experiences of Hospice Healthcare Workers Caring for Adolescents and Young Adults with Advanced Cancer: An Interpretative Phenomenological Analysis

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Background/aims: Adolescents and young adults living with advanced cancer are a distinct population who are emotionally challenging to support and require specialised care. The aim of this study was to understand the lived experiences of healthcare providers who support adolescents and young adults living with advanced cancer.

Methods: Using an interpretative phenomenological analysis approach, healthcare providers (n=18) were purposively sampled from four paediatric hospices across Canada. Data collection was via semi-structured in-person interviews. Interviews were transcribed verbatim and analysed inductively, where coding focused on meaning and experience, in which superordinate themes developed.

Results: Two superordinate themes were generated: balancing on the tightrope of uncertainty; and acting as a proxy. First, balancing on a tightrope related to healthcare workers need to do their best and be the hero with an emphasis on the fear of failure. Healthcare providers took the path of least regret while sometimes having to be uncomfortable with decisions made by families. Second, acting as a proxy was focused on the importance of having honest conversations and the cycle of protection between adolescents and young adults, families, and healthcare providers.

Conclusions: Healthcare providers caring for adolescents and young adults demonstrate an action-focused orientation: the need to do and the need to protect. Through the notion of doing and protecting, this study illustrated the ways in which healthcare providers cope with supporting adolescents and young adults along with an understanding of the transitional hero narrative, the need for advance care planning and the importance of building connections.

P 9.004 Design and Administration of Patient-centred Outcome Measures: The Perspectives and Preferences of Children and Young People with Life-limiting/Life-threatening Conditions and their Family Members

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Background/aims: Self-reported health data from children with life-limiting and life-threatening conditions (LLTTC) is rare, partly because suitable outcome measures do not exist. To improve acceptability and feasibility of patient-centred outcome measures (PCOMs) for children, they need to be designed in line with their preferences and priorities.

Aim: To identify preferences regarding PCOM design and administration mode among children with LLTTC, their parents/carers, and siblings.

Methods: Semi-structured qualitative interviews with children with LLTTC, their parents and siblings. Participants were purposively sampled across nine UK sites. Verbatim transcripts were analysed using Framework analysis.

Results: 79 participants were recruited: 39 children (5-17 years), 26 were living with LLTTC and 13 were siblings, and 40 parents of children (0-17 years) living with LLTTC. Children emphasised the importance of being able to discuss their PCOM responses with a member of their healthcare team. Children as young as five were able to use response scales anchored in faces and most children preferred visually appealing response formats, mainly faces scales. A minority of teenagers preferred numerical response scales. Parents generally agreed that visually stimulating response scales appeal to children. Children suggested short recall periods of a few days up to a week. All groups preferred short measures, with 10 items or fewer. While parents consistently assumed that children prefer electronic completion methods, some preferred paper.

Conclusions: To enable children with LLTTC to self-report their health outcomes, PCOMs should be simple to complete. They should be brief, with short recall periods, and expressive and visually appealing response scales. Additionally, children should be able to choose how they complete PCOMs. Importantly children should be given the opportunity to discuss their responses with healthcare professionals.

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P 9.006 The Health of Fathers of Children with a Life-limiting Condition

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Background/aims: Existing research tells us that the social, emotional, psychological, physical, and financial implications of caring for a child with a life-limiting condition can leave parents susceptible to a range of negative outcomes including poor physical and mental health. Importantly, fathers are significantly underrepresented in parental samples, meaning that subsequent service recommendations are likely founded upon the experiences of mothers. Contemporary family

dynamics call for studies that address this imbalance. Understanding the impact of fathers' experiences on the health and wellbeing of fathers is important for identifying the level and content of support that they may need as well as in ensuring they feel able to care for their child. The aim of this study is to explore the health, wellbeing and caregiving experiences of fathers of children with a life-limiting condition to gain an in-depth understanding of their perspectives and potential support needs.

Methods: Fathers were recruited via UK children's hospices and through social media. Semi-structured interviews were carried out and analysed using thematic analysis. The views of parents of children with a life-limiting condition were used to inform the study.

Results: Preliminary coding shows that fathers were rarely asked about their own health by professionals and found it difficult to take the time to address any concerns they had in relation to their health. They experienced stress as a result of battles with services rather than as a direct result of caregiving itself. Many fathers experienced sleep deprivation and exhaustion that adversely affected their health & wellbeing. They described ongoing trauma, starting from the time of the child's diagnosis and continuing throughout their child's condition and treatment.

Conclusions: Although further theme development is needed, it is clear that there needs to be a recognition of the importance of the health of these fathers so that they feel better supported in caring for their child.

P 9.007 Reporting of Symptom-associated Distress by Children and Young People with Life-limiting and Life-threatening Conditions and their Proxies

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Background/aims: Children and young people (CYP) with life-limiting and life-threatening conditions (LLTTC) experience multiple symptoms towards end-of-life. Research on symptom experience in this population often relies on proxy reports of carers and focuses on CYP with cancer. This study aims to elicit the symptom-associated distress of CYP with a range of LLTTC from the perspectives of CYP and proxies.

Methods: This is a prospective longitudinal study conducted between March 2016 and July 2019. The Memorial Symptom Assessment Scale (MSAS) 7-12yrs and 8-17yrs was adapted to include other commonly reported symptoms in CYP with LLTTC. MSAS 7-12 is scored using a 4-point Likert scale; 8-17 uses a 5-point scale. CYP 5-17yrs, carers of CYP 2-17yrs, and nurses completed the MSAS minimum weekly. This study looks at reported symptom distress. Data were analysed using descriptive statistics.

Results: Data from 49 CYP and/or their proxies is presented (CYP median age 12 years; 84% had cancer). The proportion of the top two Likert scores is reported. CYP 7-9yrs and proxies of CYP 2-9yrs reported higher median distress than CYP >10yrs and proxies (56.5% vs 31.5%). Proxies perceived physical symptoms such as pain and physical symptoms most distressing. CYP 2-9yrs also found pain distressing (100%), whereas CYP >10yrs reported highest distress from hair loss (75%) and problems urinating (66.7%). Proxies and CYP 7-9 were more likely to report psychosocial distress such as sadness and worry in younger CYP vs >10yrs.

CYP 7-9yrs reported fewer symptoms highly distressing (≥50% reporting high distress) vs proxies. For CYP > 10yrs, carers reported the lowest number of symptoms highly distressing (CYP and nurses reported the same).

Conclusions: CYP < 9yrs and their proxies report higher symptom distress than older CYP. Nurses and especially carers of CYP > 10yrs underestimate the distress caused by symptoms. Proxies unreliably estimate CYP-reported distress. Clinicians should be aware that proxies may have differing perceptions, particularly in older CYP.

P 9.008 Staff Burnout in UK Children's Hospices: A National Survey

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Background/aims: The psychological wellbeing of healthcare staff is key to the delivery of sustainable, high-quality care. One measure of psychological wellbeing is burnout, which can be defined as exhaustion due to prolonged exposure to work-related stress. There is some indication that hospice care staff may experience lower levels of stress and burnout compared to those working in other settings where patients die, but there is no robust evidence to support this. This study aimed to explore staff burnout levels in UK children's hospices.

Methods: The study employed a national survey of hospice care staff, and used the Copenhagen Burnout Inventory to determine burnout prevalence. All children's hospices in the UK were invited to take part with data collection taking place between May and December 2020.

Results: A total of 583 staff from 31 hospices responded to the surveys. Overall prevalence of burnout (a score higher than 50 on the CBI) was 11.0% for all staff participants, and the mean burnout score was 32.5 (SD: 13.1). Most staff (56.2%) were experiencing intermediate levels of burnout (CBI = >25 <50). Of the three dimensions of burnout measured by the CBI, Personal Burnout had the highest mean score at 44.5 (SD: 16.1), followed by Work-related Burnout (M: 39.8, SD: 17.3), and Client-related Burnout (M: 13.1, SD: 13.0). Additional analysis showed no evidence that burnout scores differed because of their working arrangements during Covid-19 i.e., whether staff were working from home, furloughed, or working in the hospice as normal.

Conclusions: Burnout levels for staff in children's hospices in the UK were lower than those reported for staff working in other palliative care generally (17.3%). There may be learning from children's hospice settings that can support staff wellbeing in other palliative care settings and in other healthcare settings where patients have life-limiting conditions.

P 9.009 Recruitment and Retention Challenges and Strategies in Randomised Controlled Trials on Psychosocial Interventions for Children with Cancer and their Parents: A Collective Case Study

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Background/aims: Recruitment and retention in psychosocial intervention studies is challenging, especially when recruiting dyads of children with cancer and their parent(s). We aim to provide an oversight of recruitment and retention strategies in performing randomised controlled trials of psychosocial intervention studies for children/young persons with cancer and their parents, based on previous experiences.

Methods: We conducted a collective case study. To identify studies, we searched Pubmed, ClinicalTrials, and ISRCTN for studies testing psychosocial interventions in children/young persons with cancer and their parents in an individually randomised controlled trial. We held online semi-structured interviews with research staff members of selected studies. A combination of deductive and inductive analysis was used.

Results: In total, 234 studies were screened, of which 9 adhered to our inclusion criteria. For 7 the main researchers accepted participation to our study. Participants indicated that children with cancer and their parents are an overburdened population arguing that an enrolment rate of 30 - 40% should be anticipated for research. Several strategies before implementation of the trial were regarded as crucial: engaging recruitment sites and candidate participants early in the study design and piloting the study. Allowing flexibility in terms of timing is important, because parents often feel overwhelmed and children's variable health situations complicate adhering to study timelines. Throughout the whole study period, make sure to optimize communication and collaboration with healthcare professionals who have a role in referring patients for the study and provide continuous training for data collectors.

Conclusions: Our study emphasizes several essential strategies to optimize participant recruitment and retention, that can help researchers optimize their protocol and implementation of the trial and contribute to better psychosocial care for children with cancer and their parents.

P 9.014 The Dutch Multidisciplinary Clinical Practice Guideline for Paediatric Palliative Care

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Background/aims: In 2013, the first Dutch multidisciplinary Clinical Practice Guideline (CPG) for paediatric palliative care was developed, providing recommendations on relief of symptoms, decision-making and organization of care. Evaluation of the CPG revealed a need for revision of the recommendations and inclusion of new recommendations on topics such as psychosocial and bereavement care, advance care planning and shared decision-making. The aim of this research is to improve provision of paediatric palliative care in the Netherlands by developing an revised version of the Dutch CPG for paediatric palliative care.

Methods: A multidisciplinary guideline panel reviewed literature on paediatric palliative care by conducting systematic literature searches. The GRADE methodology was used to grade the evidence and to formulate recommendations. Recommendations were formulated and refined based on the evidence (if available), clinical expertise, and patient values.

Results: The updated systematic literature searches identified a total of 40 newly published studies (14 randomized controlled trials, 4 systematic reviews and 22 qualitative studies) that prompted refinement of recommendations. For 19 out of 38 formulated clinical questions, no evidence was found. Based on evidence (if available), clinical expertise and patient values, more than 100 recommendations on various topics in paediatric palliative care were generated.

Conclusions: The updated guideline uses existing evidence and national expertise to develop transparent and easy-to-use recommendations to facilitate provision of high quality paediatric palliative care. The guideline promotes interdisciplinary collaboration and opens opportunities for international research into the identified knowledge gaps to further improve paediatric palliative care.

P 9.016 Integrating Curative and Palliative Care in the Therapy of Children with Ewing Sarcoma - The Experience of IIIrd Pediatric Clinic Timisoara, Romania

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Background/aims: Ewing sarcoma (ES), a rare pediatric malignancy that occurs predominantly in adolescents and young adults. Although the diagnosis and survival of both non-metastatic and metastatic ES has improved, unfavorable prognosis justifies palliative care.

We conducted a retrospective analysis of ES cases from IIIrd Clinic of Pediatrics during 15 years, following the curative/palliative interface of treatment.

Methods: The study included 32 patients. The data collected included clinical, laboratory and imagistic data. The group was statistically analyzed: percentages, Student's t-test and Kaplan-Meier survival curves.

Results: The symptoms at onset showed: 82.75% pain and/or fracture; time elapsed from first symptom to diagnosis: 31% were diagnosed in the first month, 34% within 1-3 months, and the remaining 35% after a period over 3 months. At diagnosis, 55.17% were in metastatic stage and 44.83% in localized stage. Neo-adjuvant chemotherapy according to the Euro Ewing 99/04 protocol was instituted in all patients, followed by surgery in 58.6%, and in 25.8% autologous bone marrow transplantation. From the analyzed group 12 patients (34.5%) died and the palliative care was continued until the moment of death. It aimed to control the pain (21%, 7 patients had pain difficult to control with morphine and co-analgesics), other symptoms (dyspnea was progressive in 6 patients with lung involvement). Psycho-emotional and spiritual support was offered to all patients and their families – in 3 adolescents we encountered difficulties in communication due to non-acceptance of disease progression. The advanced stages correlated with decreased overall survival which in the first year was 69%, at 3 years dropped to 63%, and at 5 years to 59%.

Conclusions: This study shows us that ES remains a problem that must benefit from a multidisciplinary approach and the palliative care is required from the onset. Even in the localized forms the risk of relapse exists.

P 9.018 Feasibility of a Family Centered Neonatal End of Life Care Protocol in NICU: A Mixed-methods Study

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Background/aims: Some high-risk newborns admitted to neonatal intensive care units (NICU) face death despite caregivers' best efforts. Managing a deteriorating infant and their parents can be a massive challenge for NICU nurses within insufficient support systems. Developing neonatal end-of-life (EOL) care protocol will serve as valuable educational material for NICU nurses. However, the protocol should reflect the family's perspectives. In this study, a family centered EOL care protocol was developed, and its feasibility was evaluated and reported.

Methods: A scoping review of the literature and other protocols and interviews of bereaved parents were performed to develop the family centered protocol draft. The protocol was refined based on a Delphi study and experts' reviews. A mixed-method was conducted to examine

the protocol's feasibility. Eighteen nurses of a level IV NICU used the protocol after an hour of video training. The nurses' neonatal end-of-life (EOL) attitude, competency, and satisfaction with the protocol were examined pre- and post-application of the protocol. In addition, an in-depth focus-group interview was conducted with some of the nurses (n=4).

Results: The nurses' neonatal EOL attitude ($p=.001$) and competency ($p=.001$) levels were increased after the protocol application. The mean score of satisfaction with the protocol was 3.54 out of 4. In the focus-group interview, nurses reported:

- (1) ambiguity at the start point of EOL care;
- (2) the need for methods and examples for parental participation;
- (3) insufficient staffing and space; and
- (4) lack of perceptions of neonatal EOL care among parents.

Conclusions: Nurses' perceptions and competency were improved after the neonatal EOL care protocol application. However, there were some barriers to applying this protocol. To expand the application of the family centered neonatal EOL care protocol, encouraging parental participation and institutional support should be accompanied in South Korea.

P 9.020 "YouTube" Outcomes for Children with Gastrostomies Who Are Fed Home-blended Diets

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Background/aims: There are growing numbers of children with complex health conditions who are dependent on gastrostomy feeding. Children with gastrostomies in the UK are still predominantly recommended to use formula due to concerns over tube blockage, infection and nutritional content of home-blended feeds. This study aims to compare the safety, outcomes and resource use of those on a home-blended diet compared with a formula diet.

Methods: This prospective cohort study recruited children and families via healthcare settings and collected data at baseline, 12 and 18 months on gastrointestinal symptoms (primary outcome), quality of life, nutritional and anthropometric outcomes, parental quality of life and resource use. Propensity scores from deprivation status were used in the main regression analysis.

Results: 180 children and families completed baseline data collection (104 home-blended, 76 formula fed). Children who were home-blended diet were similar in terms of age, underlying medical conditions but tended to live in areas of lower levels of deprivation and parents had higher educational levels compared to children fed formula diets. After propensity score matching and in multivariable regression modelling, children with home-blended diets had significantly better gastrointestinal scores than those who were formula fed (13.9, $p<0.001$). The Quality of life and sleep of child and parents was similar across the groups. The blended diet group had more fibre in their diet but lower vitamin D when compared to the formula fed group. They also had lower gut and stoma site infections.

Conclusions: Children who were fed home-blended diets had lower burden of gastrointestinal symptoms and similar nutritional intake apart from higher fibre and lower vitamin D when compared to those fed a formula diet. There was no evidence of increased risk of infection in the home-blended group.

This study is funded by the National Institute for Health Research Health Technology Assessment programme (ref 17/76/06).

P 9.023 What Are Health Clinicians' Views and Experiences of Having Challenging Conversations with Families whose Child Has a Life-limiting or Life-threatening Diagnosis?

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Background/aims: Much literature examines clinicians' perspectives on their preparedness and factors affecting their ability to have challenging conversations, as well as the emotional impact of these conversations. Few studies examine these factors side-by-side, highlighting the need for a systematic review to examine both concepts. This study aims to explore clinicians' perspectives on:

- The knowledge and skills needed to have challenging conversations.
- The enablers of and barriers to challenging conversations.
- The emotional impact of challenging conversations.

Methods: CINAHL, MEDLINE, Web of Sciences, PsycINFO and British Nursing Index were searched for this systematic review and meta-ethnography in March 2022. Inclusion criteria were: primary qualitative research, peer-reviewed, focus on clinicians' experiences and/or emotional impact of having challenging conversations, and studies that were conducted in the West.

Results: 8 studies (740 participants total) were included. Data was extracted then synthesised by 2 researchers.

Overall, professionals lack confidence in having difficult conversations with families surrounding a child's palliative diagnosis for the following reasons:

5 studies found that professionals feel inexperienced in having these challenging conversations and that there is little education supporting their practice. 4 studies found that professionals felt there is often uncertainty surrounding the child's prognosis; therefore, they did not want to be seen as giving up on the child by discussing palliation. Challenging conversations were also found to have a high burden of emotional distress on professionals (four studies).

Conclusions: Professionals felt they lacked experience and education about how to communicate with families about end-of-life care. The review highlights the need for additional training about challenging conversations with families and to provide support for the emotional needs of professionals.

P 9.024 Development of a Simulation Teaching Programme for Children's Hospice Staff

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Background/aims: Although there is a growing interest in use of simulation teaching there is little evidence on the use of simulation teaching in hospice settings. We aimed to introduce and assess a simulation teaching programme to support the training of children's hospice staff (physical health and learning disability nursing-staff and non-nursing staff).

Methods: Weekly simulation sessions were run with 4 participants per session. Sessions comprised a 10-minute 'pre-brief'; 15-minute simulation; 35-minute debrief. To evaluate sessions participants rated how strongly they agreed with statements about the session using a 5-point Likert scale (1=strongly disagree to 5=strongly agree) with space for additional comments.

Results: 13 simulation sessions were run for 50 participants on acute (sepsis and the deteriorating child; seizure management) and 'palliative care' topics (care after death; advance care planning). Feedback was obtained from 46 participants (see table 1).

Conclusions: Simulation sessions were successfully introduced in a children's hospice. Debrief discussions included generic learning (e.g. communications skills with patients/families; communication/leadership

Table 1. Participant Rating of Sessions.

Statement	Mean Score	Range
I was well informed of the purpose of the simulation	4.98	4-5
I was adequately orientated to the clinical environment	4.84	3-5
The simulation helped me apply my knowledge to a practical application	4.84	4-5
Clinical simulation is a valuable tool that enables me to be a safe practitioner	4.96	4-5
I was able to use my communication skills in the simulation	4.59	4-5
I felt comfortable sharing my thoughts and feelings during the group debriefing session	4.76	3-5
The debriefing session helped my critically reflect upon my own performance	4.87	4-5
I plan to use what I learned today in my clinical practice	4.98	4-5

within a team); case specific learning (e.g. signs of sepsis; airway management); learning specific to the environment (e.g. logistics) and 'palliative care skills' (e.g. after death care; writing and following advance care plans). Sessions also highlighted areas where changes in hospice procedures could improve patient care and safety.

P 9.026 Pediatric Palliative Care Program Implementation in Low- and Middle-income Countries: A Systematic Review Using a Strengths, Weaknesses, Opportunities and Threats Analysis

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Background/aims: Of the estimated 21 million children world-wide who need access to pediatric palliative care (PPC), about 97% currently reside in low-and middle-income countries (LMIC). Access to PPC programs in LMIC are limited, and successful strategies and barriers to program implementation remain understudied. We conducted a systematic review to characterize the strengths, weaknesses, opportunities, and threats (SWOT) of PPC program implementation in LMIC.

Methods: Using PRISMA guidelines, we searched key databases from inception to April 2022 and reviewed references manually. Eligible abstracts and articles included content related to composition, role, function, purpose, development, or implementation of PPC programs in LMIC.

Results: From 7,846 titles and abstracts and 229 full-text articles, we identified 62 eligible abstracts and articles; 16 articles were added following manual searching of references, resulting in 78 items (28 abstracts, 50 articles). A total of 82 unique programs were described, including 9 from low-income, 27 from lower-middle income, and 44 from upper-middle income countries. Common strengths included presence of multidisciplinary teams and psychosocial care. Common weaknesses included lack of PPC training and research infrastructure. Common opportunities involved collaboration between institutions, government support, and growth of PPC education. Common threats comprised limited access to PPC services, medications, and other resources.

Conclusions: PPC programs are being successfully implemented in resource limited settings. Hospice and palliative medicine organizations should sponsor PPC clinicians to describe and disseminate more detailed descriptions of successes and challenges with program implementation to help build and grow further PPC initiatives in LMICs.

P 9.028 How to Provide Perinatal Palliative Care: A Systematic Review of Care Components

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Background/aims: When a severe diagnosis is made before or after birth, perinatal palliative care (PPC) can be provided to support the infant, parents and involved healthcare providers. A systematic overview of effectiveness and working components of existing PPC programs was needed.

Methods: A systematic search was conducted in MEDLINE, Embase, CENTRAL, CINAHL, PsycInfo and Web of Science. Study designs examining the effect of PPC compared to regular care; and study designs describing the components of care included in existing PPC initiatives were included. Three independent authors reviewed titles, abstracts and full texts against eligibility criteria. PRISMA guidelines were followed.

Results: 21.893 records were identified, 70 publications met inclusion criteria. 12 publications (17,1%) discussed the effect of a PPC program. Other publications concerned the description of PPC programs, most often by means of program description (22/70; 31,4%), guideline (15/70; 21,4%), or case study (10/70; 14,3%). Outcome measures envisioned 4 main target categories: care coordination, parents and family members, care for the fetus/neonate, and healthcare providers. No trials exist to date. Analysis of working components revealed components related to changes directed to the policy of hospital wards; and components involving actual care that is being provided within the PPC program, directed to the fetus or infant, the family, involved healthcare providers or external actors.

Conclusions: PPC is a growing research field where evidence consists mainly of descriptive studies and guidelines. New PPC programs can use this checklist of all mentioned working components of PPC to develop their initiative. PPC includes several important actors: the fetus/infant and their family, and included healthcare providers on both maternity and neonatal wards. This leads to a large variety of possible care components. However, while some studies show proof of concept, evidence base to determine which components are actually effective is lacking.

P 9.030 Approaching Parents for Autopsy Consent in Children with Diffuse Midline Glioma

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Background/aims: Diffuse midline glioma (DMG) is the most common malignant glioma in early childhood with median survival of only eleven months. It is diagnosed by MR imaging. Biopsies may be clinical indicated in atypical cases or for trial inclusion. Post mortem tissue collection is not regularly performed since approaching patients for this

matter is a sensitive issue, especially in pediatrics. Thus, material for further molecular pathology and targeted therapy research remains scarce.

Methods: Autopsy procedures in international clinics were reviewed and key points within implementation protocols pointed out.

Results: Especially in the USA/Canada, families of DMG patients are usually asked for autopsies/organ donations, while this is not the case within Europe. The timing for the interview approach must be individually adjusted. However, it proves helpful when parents have realized the death of their child. The wish to be of service to DMG therapy research is a sufficient reason for most families. The approaching physician should be a confidant of the family. She should be familiar with cultural/religious/social idiosyncrasies of the family in order to set the right tone and timing. Professional knowledge of the autopsy process can give her additional confidence. Furthermore, organizational requirements are high: The time between death and autopsy has to be minimized, as well as the time of the autopsy itself. Logistics (transport, costs, care of parents during autopsy, etc.) must be clarified in advance.

Conclusions: Tissue samples from childhood brain tumors are of high value for research. Autopsies in children are feasible and regularly performed in select North American centers. The affected families often show a remarkable willingness to donate and may thus give meaning to the death of their child. Finely tuned interdisciplinary interaction of the various departments is required. Medical personnel seeking consent from families benefits from advanced knowledge in performing autopsies.

P 9.031 Perception of Quality of Life in Children with Palliative Needs: Predictive Study of the Influence of the Socio-demographic, Disease and Psychological Variables

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Background/aims: Children with complex chronic conditions (CCC) and children in palliative care (CPC) may undergo high levels of distress and perception of poor health-related quality of life (pHRQoL), being very difficult to correctly assess the suffering experience.

To know the relation between the pHRQoL and socio-demographic, illness and psychological variables. Our hypothesis is that a specific interaction among mentioned variables correlates with pHRQoL.

Methods: A cross-sectional study.

Participants were children over 9 years old with CCC-CPC. Socio-demographics and disease variables were recorded by medical history; psychological assessment by specific tools about Emotional Regulation, Coping Strategies and Risk of Depression and Anxiety; and their pHRQoL by a scale ranged from 0 (bad) to 10 (good).

Descriptive means, standard deviations and linear regression models were calculated.

Results: 35 children of age of 15.23 years old, 37% girls; 63% CPC, 37% CCC; mean of pHRQoL: 7.14. Psychological assessments: 40% Emotional Symptoms; 37.2% peer relationship problems; 31.5% conduct problems; risk of Depression: 88.5% and Anxiety 85.7%; and 25% emotional regulation difficulties.

Coping strategies:

- highest: Planning (7.23) and Positive Reappraisal (7.14)
- lowest: Other-Blame (3.09) and Self-Blame (4.23)

Regression model (explained 71% of the variance of pHRQoL) controlling age, gender, CPC condition and oncological disease; showed that the risk of depression (-0.48, $p=0.01$) or Rumination score (-0.47, $p<0.01$) negatively predicted pHRQoL while Self-blame (0.24, $p=0.03$). and emotional regulation (0.08, $p=0.05$) positively predicted.

Conclusions: The results are consistent with previous research regarding of suffering and pHRQoL in children with CCC-CPC.

Socio-demographic and disease features are not enough to anticipate the suffering.

It is important to develop preventive strategies to improve pHRQoL, increase emotional regulation skills and reduce depression and rumination symptoms to better care for patients.

P 9.032 Dance of Discussions: How Do Paediatricians Prepare for End-of-Life Decision-making?

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Background/aims: Paediatricians and parents report preparation for end-of-life decision-making for children with life-limiting conditions is beneficial. Often these decisions arise in the context of having treatment options which could be offered in an effort to prolong life. However, the question arises as to whether we should embark on such treatments. Little is known as to how we arrive at such decisions, what preparation paediatricians find helpful and the role that parents play in this process. This study aims to understand how paediatricians prepare for end-of-life decision-making for children with life-limiting conditions.

Methods: This interpretative phenomenological study involved individual semi-structured interviews of 16 paediatricians following their participation in a clinical simulation with two medical actors playing the role of parents of a child with a life-limiting condition. The simulated clinical encounter involved a child being reviewed by each paediatrician at a time of prognostic uncertainty. Parent-actors were also interviewed following each simulation. Verbatim transcripts of interviews were thematically analysed.

Results: Three key themes were identified: (1) Paediatricians lead a dance of discussions to shift parents to incorporate the paediatricians' truth about the child's health, quality of life and suffering; (2) Paediatricians prefer to control the pace of these discussions; and (3) Paediatricians recognise the need for courage in the face of risk.

Conclusions: Paediatricians seek to guide parents to reflect on their child's health and articulate their worries about the child's future and suffering. They do so by controlling the pace and content of discussions when the paediatrician is convinced that the child is approaching the end of life. Courage is needed to explicitly raise discussions about the risk of the child's death, and without this courage, there is a risk that paediatricians and parents can mutually avoid this difficult topic and maintain a collusion of positivity.

P 9.033 Patient-reported Outcome Measures in Paediatric Palliative Care – Results of a Scoping Review

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Background/aims: The application of Patient Reported Outcome Measures (PROMs) in Paediatric Palliative Care (PPC) is increasing both in research and in clinical practice. PROMs can be useful for promoting the voice of the child or adolescent living with a life-threatening or life-limiting condition.

The aim of this study was to explore and summarize what is known from published research about PROMs in PPC from 2004 until 2021.

Methods: This scoping review followed the framework by Arksey and O'Malley. The identified citations had to report on PROMs in any PPC context, targeting children, adolescents, and young adults (CAYA) up to 25 years of age.

Results: A total of $n=2117$ studies were screened, and $n=99$ papers were eligible for review. The eligible studies included a total of $n=15532$ CAYA. A total of $n=77$ PROMs were identified. A majority of papers report on CAYA with cancer or organ failure (Association for Children's palliative care (ACT) group 1).

Conclusions: Current PROMs in PPC cover a broad range of phenomena relevant to all patient groups in PPC. However, a majority of PROMs are found in studies from high-income countries, mostly including CAYA with cancer or organ failure. Future research should aim at exploring PROMs in ACT groups 2-4 and in different parts of the world, to enable the voices of CAYA living with severe health conditions more opportunities to be heard.

P 9.034 Physiotherapy as Home Care: What Is Relevant for Parents of Children and Adolescents with Life Threatening or Life Limiting Conditions?

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Background/aims: In the physiotherapy, treatment approaches at home for children and adolescents with severe, life threatening conditions usually require the clear definition of which aspects are determinant for adequately fulfilling the demands and expectations of parents. This information enables the physiotherapist to conceive personally suited treatment strategies. Aim of the present study is to determine which aspects are relevant for parents of children and adolescents with life threatening and life limiting conditions in the context of physiotherapy assistance at home.

Methods: A qualitative study has been carried out, comprising semi-structured interviews with 03 mothers, 01 parental couple and 01 father. Prior to the interviews, each question was evaluated for relevance by a 04 members experts' committee. Quantitative Data for experience in physiotherapy, age, diagnosis, care and caring status were collected. The interviews have been transcribed, parents answers were compared and separated categories were determined.

Results: All interviewed parents consider the physiotherapeutic treatment an important support in their daily routines with a child with life threatening or life limiting issues. Physiotherapists provide support in the first phase at home, in which parents learn techniques for handling and dealing with daily, regular situations. Physiotherapists and parents together create a „tool box“. Parents consider important the confidence and the possibility of placing questions. Through physiotherapy, parents feel prepared for pulmonary crisis and the correct choice of supporting and care techniques or tools. In one case, in the time immediately prior to the deceasing of a daughter, physiotherapy was considered as „symptoms alleviating“ and „life quality increasing“. Parents consider it relevant to „find qualified physiotherapists“.

Conclusions: Parents consider physiotherapy at home as an important and relevant support at different levels. Further studies are necessary to confirm the observed results.

P 9.035 Siblings of Children with Life Threatening or Life Limiting Conditions - Public Health Nurses Experiences

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Background/aims: As all human beings, siblings (0-18) of children with life threatening or life limiting conditions (LT/LL) have the right to good health and for their quality of life to be promoted and taken care of. Previous research indicates that siblings to children with LT/LL are used to less attention than their sick brother or sister and are often silent about their thoughts and troubles. These children also experience that no one speaks with them about the imminent death of their brother or sister. Public health nurses working with children in schools have competency about children's development and needs and the opportunity to recognize children in need of support. However, evidence remain limited on public health nurses' knowledge about both children's palliative care, how they identify siblings to children in palliative care and what kind of support the public health nurses provide for these siblings. The aim of this study is to explore public health nurses' knowledge about children in palliative care and what kind of support the siblings of children with LT/LL receive.

Methods: This study has a has an exploratory qualitative design using focus group interviews to collect data. Four to six focus group interviews with public health nurses working with school children will be performed during the fall of 2022. We aim to include 4-6 participants per focus group to allow for a fruitful group dynamic. The interviews will be audio recorded and transcribed verbatim. The transcribed text will be analyzed with qualitative content analysis.

Results: We anticipate this study to shed light on the public health nurses' knowledge on palliative care for children in a community setting. Based on previous research we expect knowledge to be varied according to whether they have cared for children with LT/LL and their siblings. Preliminary results will be presented at the conference.

Conclusions: Conclusions will be presented at the conference.

P 9.037 Creative Approaches to Educating the Children's Palliative Care Workforce: Learning in the Affective Domain

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Background/aims: The Children's Palliative Care workforce in the UK is "in crisis" (Together for Short Lives, 2019), with insufficient numbers of professionals with the right skills and experience. Improving education must therefore be a priority for the sector.

Learning happens across three domains: psychomotor (doing), cognitive (knowledge and understanding), and affective (emotional) (Bloom's taxonomy of learning). The teaching of theories and practice is relatively straightforward, whilst teaching in the affective domain is significantly harder and often overlooked.

Methods: A programme of post-graduate education has been developed to meet learning objectives in the affective domain, including:

1. Improving confidence with communication skills: initiating conversations about palliative care and death, spiritual care, and hope.
2. How to the cost to ourselves when we are "truly present" with the distress of others.
3. How our own beliefs, experiences, attitudes and emotional responses can impact our communication and decision making.

To meet these objectives, a range of educational approaches have been developed, delivered and assessed including:

1. The use of simulation-based education, using actors and personalised scenarios.
2. Critique of palliative care scenarios filmed using actors and faculty.
3. The use of non-fictional documentary films showing real life scenarios.
4. Facilitated group discussion to reflect on the emotional impact of care. Positive role modelling by faculty is an important component of this.

Results: Whilst more rigorous evaluation of these methods is needed, feedback from education delivered is excellent and demand for all courses consistently outstrips demand.

Conclusions: Evidence from both literature and practice tells us professionals frequently feel ill-equipped and unprepared when communicating with patients and families about palliative care. A range of creative approaches can be used to successfully develop skills and confidence in this area.

P 9.038 Korean Caregivers' Experiences of Family Relationships after the Child's Deaths from Leukemia: A Qualitative Descriptive Study

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Background/aims: With the desperate need to care for life-limiting children, pediatric palliative care (PPC) sites have rapidly expanded in South Korea. However, bereavement care for the left family is limited. Because Leukemia child's caregivers devote most of their time to caregiving, the child's death causes a considerable change in their life. Arising problems in the family or social relationships prolong the period of mourning. A better understanding of their life will give crucial information to develop appropriate bereavement care services in Korea. This study aimed to describe the caregivers' experience of family relationships after the child's death from Leukemia.

Methods: A qualitative descriptive study was conducted using individual interviews with ten caregivers who lost their children within a year. After transcribing the interviews, a coding book was developed, and codes were analyzed and categorized.

Results: The experience of family relationships after the child's death was derived as following four themes. "Inability to fully share the grieving of losing a child with the spouse," "Feeling pity for the child who has left, and being cold-hearted to the children left behind," "Avoiding families who have difficulty mentioning child's death," and "Getting comfort in a relationship with other bereaved caregivers."

Conclusions: Due to the remaining patriarchal perception and death taboo culture in Korea, they could not fully empathize with or mourn the loss of a child with their closest spouse or family and experienced changes in family relationships. However, receiving support services to cope with loss from the end of life through a PPC program and coping activities such as psychological counseling and support groups helped to restore relationships and return to daily life. Therefore, the bereavement support system for pediatric Leukemia patients and their families should be connected to PPC before the child's death and established by considering the cultural characteristics.

P 9.039 The Family Talk Intervention – Supporting Families Affected by Childhood Cancer to Communicate about Strengths and Concerns

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Background/aims: Families in pediatric oncology report a need of psychosocial support for the whole family. Despite this, there are few family interventions scientifically evaluated for these families. Therefore, a manual-based family intervention, the Family Talk Intervention (FTI), originally developed for psychiatric care, was pilot-tested in pediatric oncology with objectives to facilitate family communication about illness-related subjects, support parenting, and making the children's needs visible. FTI consist of 6 meetings with the family often led by a social worker.

Aim: To explore the content in the FTI-meetings with families in pediatric oncology with focus on all family members' issues, and how these are addressed in the intervention.

Methods: In this qualitative explorative study, data included field notes from two social workers, while moderating FTI in a pilot-study with 26 families affected by childhood cancer. Half of the children had a CNS-tumor and 5/26 had died within six months after FTI. Field notes captured discussion topics, emotional reactions, and interventionists' reflections. Data was analyzed using Interpretive Description.

Results: Preliminary results show that the presence of childhood cancer in families brings matters to a head, as family problems are accelerated and magnified. Problem areas in conversations showed great variety in severity, ranging from practical everyday matters to conflicts and destructive behaviors. Families' objectives for participation included enhancing family communication and promoting healthy and ill children's wellbeing. In the conversations, supportive factors among families and their close networks were identified, as were families' own suggestions for how to solve their issues.

Conclusions: This study highlights the great variation of issues among families affected by childhood cancer. Although many of these issues are well known, this study adds that FTI covered and addressed these issues. Main funder: The Swedish Childhood Cancer Fund

P 9.040 An Individual Care Plan in Pediatric Palliative Care: The Parents' and Healthcare Professionals Perspective

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Background/aims: In 2015, the national Individual Care Plan (ICP) 1.0 for pediatric palliative care (PPC) was developed. The ICP transforms general guideline recommendations into an individualized care plan. ICP facilitates coordination, quality and continuity of PPC. Although the ICP was designed to promote early introduction of palliative care in all domains, in practice an ICP is mostly drawn up late in the course of illness and not all children are included.

Aim: To gain insight into the perspectives of parents and healthcare professionals (HCPs) towards the use of the ICP in PPC.

Methods: A mixed-method study using qualitative interviews and quantitative questionnaires among parents of children with an ICP 1.0 and HCPs who worked with ICP 1.0. The questionnaires mainly focused on the content and form of the ICP and the interviews on the process of the ICP. For the qualitative analysis, open and axial coding and constant comparison were used. The quantitative data were descriptively analyzed using mean, \pm SD, median and interquartile range.

Results: HCPs indicated to miss palliative sedation in the content of the ICP. The current form of the ICP, a Word document, is not user-friendly, makes it difficult to keep the ICP up-to-date and does not support collaboration between different HCPs. The ICP is drawn up mostly in the terminal phase, while parents indicate earlier needs of an ICP. The ICP helps to tailor care to the child and the family. It is important that responsibilities surrounding the ICP are properly arranged. However, it is often unclear who is responsible for a drawn up ICP.

Conclusions: The ICP is embraced by parents and HCPs, but adjustments can be made in the content and form of the ICP to ensure use in practice. Furthermore, agreements on process and responsibilities could be made to support HCPs in working with the ICP. We will do so, in close collaboration with parents.

Source of funding: ZonMw.

P 9.041 Home Care for Children with Advanced Cancer Managed at a Tertiary Center in Jordan

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Background/aims: Home care service at our center established in 2013 to offer palliative care at home.

Aim: To reduce the burden on families and patients who may suffer to reach the center, especially when the child is bed- or chair-ridden. Home services are not well established in Jordan, and this represents the first documentation of this service in Jordan and the region.

Methods: We collected the number of home visits done throughout (Jan 2016- December 2021). The visits were documented electronically on a special form for podiatric home team visits. After obtaining IRB approval, we collected relevant data on a sheet and used descriptive analysis to explore these data.

Results: Three hundred forty-five visits (121patients) were documented during the studied period. 95% (N=111) of patients were DNR-labelled. 75% (N=90) of patients were bedridden; 16% (N=19) were living far from the center, defined as needing more than one hour to commute to the center; documented psychosocial status revealed financial hardship in the majority of patients (85%, N= 102/ out of121) for financial burden; 90% for patients not willing to visit the center. Only 11 patients (9%) needed to visit the emergency room after initiating home visits.

There was no documentation of families refusing a home visit. By preparing this report, almost two-thirds of the patients had died (N=90). Most patients died in their homes (N= 60, 49%). Of note, communicating through WhatsApp was frequent, according to our staff but not always documented in the chart.

Conclusions: Home care provides support and lessens the financial and psychological burden of dealing with children with advanced and terminal cancer. The need for community-based home care for the vulnerable population is very important. Measuring the impact of these programs is very difficult; however, our experience in LMIC suggests that the program can significantly decrease the burden on families and the health system.

P 10 - Public Health and Epidemiology

P 10.001 Trends in Place of Death within the Adult Population in Sweden 2013-2019

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Background/aims: The strong force for home care have, during the past decade impacted the organisation and allocation of resources within the

Table 1. Living at home and dying in hospital versus dying at home - Univariable binomial regression analysis of trends in Sweden 2013-2019.

Year of death*	N and % of all deaths per year	OR (95% CI)	P-value
2013	30 138 (67.7)	1.00	<0.0001***
2014	29 939 (67.6)	1.00 (0.97-1.02)	0.00019
2015	30 454 (66.7)	0.96 (0.93-0.98)	<0.0001
2016	30 703 (66.1)	0.93 (0.90-0.96)	<0.0001
2017	30 778 (65.8)	0.92 (0.89-0.94)	<0.0001
2018	30 519 (65.3)	0.90 (0.87-0.92)	<0.0001
2019	29 113 (64.3)	0.86 (0.84-0.88)	<0.0001

*Ref. year is 2013

Swedish health service system. However, still in 2012 only 17.8% of all deaths occurred at home. National clinical practice guidelines and the first national guidance for palliative care on government initiative were launched in 2012. It is essential to follow up the impact of these policy initiatives. Hence, in this study, we aimed to investigate trends in place of death within the adult Swedish population 2013-2019, and to examine potential associations between place of death and individual, geographic, socioeconomic factors, hospital capacity, and health service utilization.

Methods: This population-level longitudinal study includes all deceased individuals 18 years or older in Sweden in 2013-2019 with a registered place of death (n=599 137). Death certificate data was obtained from public registers. To investigate trends in place of death and associations between place of death and independent univariable and multivariable logistic regression analyses were performed.

Results: Between 2013 and 2019 the total number of home deaths in Sweden increased with 1.9%. Among home dwellers, the likelihood of dying in hospital instead of dying at home decreased (table 1). Cross-regional variations were observed.

Conclusions: There seem to be a slight trend towards increase of home deaths in Sweden. Whether this is the result of policy implementation remains to be investigated.

P 10.002 Palliative Care for Lung Cancer: Using Big Data to Describe Changing Needs and Geographical Variation in National Indicators of Need and Quality

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Background/aims: 26,935 people died from lung cancer (2020) in England. Despite new therapies, 1 year survival remains low, so palliative care needs to be integrated early alongside treatment for lung cancer patients.

Aims: To use national linked Office for National Statistics mortality and hospital episode statistics (ONS-HES) to describe variation in geographical need and opportunities for improving palliative care (PC) for lung cancer patients.

Methods: A sub-set of an ONS-HES linked mortality-hospital episodes dataset for England of people who died with lung cancer as the underlying cause (ICD-10 C33-34) was analysed for: age at death, gender, need for early PC (1-year survival), and proxy indicators of quality: place of death, >3 emergency admissions in last 90 days (3+EAs), seen by Palliative Care Team (PCT) in final admission. Variation across Local Health Administrations (LHAs) was described.

Results: Provisional results. 51% of people dying from lung cancer in 2020 were aged >75 years and 47% female. Both age at death and % females have increased significantly over the past 2 decades. One year survival (2019) varied across LHAs from 40.2-57.7%. The % of lung cancer patients dying at home in England jumped from 33.3% (2019) to 44.0% (2020), home becoming the commonest place for the first time. However, this varied 31.6-57.2% across LHAs. 3+EAs dropped from 12.6% (2019) to 10.5%

(2020) but significant variation persistent across NHS Regions 9.5-12.0%. The % seen by (PCT) in final hospital episode increased from 33.2% (2012) to 45.5% (2019), varying 21.3-62.1% across LHAs.

Conclusions: Analysis of big-data enables changing needs of patients for palliative care to be described e.g. more older and female patients likely to have different needs and geographical variation in this. It also enables trends and variation in Key Performance Indicators of Care e.g. Place of death, 3+ EA and seen by PCT in last admission to described to national and LHA policy makers. These analyses will drive improvements in PC.

P 10.003 Did We Change for the Better? Changes in Coding Place of Death in Czechia, Estonia, Finland, Luxemburg and Portugal (2012-2021)

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Background/aims: Introducing changes in how we classify place of death (PoD) in death registrations is important if this improves the quality of the data and their usefulness. We aimed to examine changes in coding PoD globally, comparing pre- and post-change data.

Methods: We sought national PoD data from vital registries of 47 countries varied in UN Regions and Quality of Death Index. We asked whether PoD coding changed from 2012 to 2021 and if so how. We describe changes and compare pre-post change PoD data.

Results: Of 22 responding countries, PoD was recoded in Czechia (in 2013), Estonia (2019), Finland (2016), Luxemburg (annually) and Portugal (2014). Most notable changes were: Czechia: sub-categorisation of "medical institution" as "inpatient" vs. "other" and introduction of "not identified" PoD; Estonia: added "nursing home" and "workplace"; Finland: added "social care unit"; Portugal: sub-categorisation of "health institution" into "primary care centers" and "hospitals" (and within: "inpatient ward", "intensive care unit", "emergency department" or "other"). Luxemburg generated every year 10-18 sub-categories that emerged from free-text of the "other" category, the most frequent being "home of a family member" (0.2% in 2021). Data on 2.8 million deceased across the 5 countries (2012-2021) showed changes had minimal impact on existing categories (≤5% change) except in "health care facility" in Estonia (-6%) in favor of "nursing home" (12% in 2021) and in "other" in Finland (-13%) in favor of "social care unit" (23% in 2020).

Conclusions: 5 EU countries refined PoD data and unveiled key trends. This shows it is possible to change PoD coding for the better. Luxemburg's inductive coding of the category "other" represents added work but also value. The findings are informing the development of a pioneering international classification of dying places.

Funder: European Research Council.

P 10.007 Implementing Patient-reported Outcome Measures in Palliative Care Clinical Practice: A Systematic Review Update of Facilitators and Barriers

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Background/aims: Despite the development of patient-centred outcome measures (PCOMs) in the past three decades, their routine use in practice remains challenging in most countries. We aim to update a highly cited review by identifying and synthesising new evidence on facilitators, barriers, lessons learned, PCOMs used, models of implementation, implementation outcomes, costs, and consequences of implementing PCOMs in palliative care clinical practice.

Methods: Systematic review following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidance. We searched MEDLINE, PsycINFO, CINAHL, Embase, and BNI with no date or language limitations, supplemented by a list of studies from the expert advisory committee and hand-searching references of included studies. We included primary empirical studies using PCOMs in clinical care for adult patients with advanced disease in palliative care settings. We used the Gough Weight of Evidence Framework for the quality assessment of included studies and narratively synthesised the findings. Two reviewers did this independently and a third was consulted if needed.

Results: Preliminary results show that having a coordinator onsite and training clinicians are key to the initial implementation. Embedding outcome measures at the point of care is critical to ongoing implementation in clinical practice. Additionally, we have categorised factors on which facilitators and barriers stand, namely, patient/caregiver, condition, setting, model, outcome measure, policy/organisational, ethical, legal, implementation, environmental, and post-implementation outcome. Evidence for the cost of implementing PCOMs in clinical practice and implementation models is scarce.

Conclusions: Successful implementation of PCOMs continues to require embedding outcome measures at the point of care and tailoring the implementation process to local circumstances. Constant feedback on patient's outcomes to clinicians remains vital.

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P 10.008 Identifying Distinct Profiles of People with Dementia Based on their Healthcare Use in the Last Year of Life Using Routine Data

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Background/aims: People with dementia can access multiple healthcare services for their care needs. Among those approaching end of life, access and use of healthcare services vary considerably. We aimed to

characterise subgroups of people with dementia based on their healthcare use in the last year of life.

Methods: Retrospective cohort study using mental healthcare data of decedents who were ≥ 50 years old at dementia diagnosis in South London and Maudsley Hospital, United Kingdom, linked with national hospital data (2006-2020). We used latent profile analysis to group the individuals according to their patterns of healthcare use (planned & unplanned hospital admissions, length of hospital stays, outpatient visits, emergency visits, community nurse & therapist visits, mental health appointments). We used multinomial logistic regression with multiple imputation to predict sociodemographic and illness characteristics, and the outcome of dying in hospital, based on individual's group membership.

Results: 11,209 decedents with dementia were grouped into four distinct healthcare profiles: 1. minimal healthcare users (n=2,728, 24%) 2. occasional hospital in-patients & mental health care input (n=4,909, 44%) 3. frequent hospital & emergency department visitors (n=1,242, 11%) 4. specialist care recipients who spend long periods in hospital (n=2,330, 21%). Having a non-Alzheimer's dementia diagnosis, not receiving a care package, being diagnosed with dementia at older age, female, Black, Asian and other minority ethnicity were all associated with higher relative odds of being in group 2,3 or 4 compared to group 1. Compared to group 1, all other three groups had over four times higher relative odds of dying in hospital (p<0.000, CI 95% 4.3-5.1 for group 1 vs 3).

Conclusions: Distinct profiles of people with dementia exist based on their healthcare use in the last year of life. We identified policy targets for improving care, and need for exploring underlying mechanisms between sociodemographic factors, health and care use.

P 10.009 Cancer Pain in Australian Patients Seen by a Specialist Palliative Care Service: The Last Week of Life

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Background/aims: Half of patients with advanced cancer report moderate to severe pain, and more than one third report pain-related distress. Improving the clinical management of cancer pain for patients in the last days of their life remains a priority.

We aim to better understand the nature of moderate and severe cancer pain for patients seen by specialist palliative care in the last week of life and its relationship with other items assessed as part of routine care.

Methods: Adults with cancer who had ≥ 1 assessment of distress from pain using the Palliative Care Outcomes Collaboration (PCOC) Symptom Assessment Scale (SAS) in the seven days before death, died between 1st January 2018 and 30th June 2019 and received care from a PCOC-registered service were included. PCOC is an Australian national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care.

Data were tabulated and included patient-reported items (PCOC SAS) and clinician-rated items (Australia-modified Karnofsky Performance Status (AKPS), pain severity: Palliative Care Problem Severity Score).

Results: Of the 50,415 pain assessments completed for 27,513 patients, 54% were men and the median age was 74 years. 78% of assessments were taken when the AKPS was 30 or less.

21.9% of pain-related distress assessments were moderate or severe. The proportion of moderate or severe assessments was similar for distress from fatigue (23.2%) but lower for difficulty sleeping (7.3%) and bowel problems (7.7%). Participants with severe distress from other symptoms trended towards also having severe pain. Scores of pain-related distress reduced in the days closer to death. Pain-related distress peaked in the mid-range AKPS scores(40-70).

Conclusions: A small but significant proportion of the population die with moderate and severe cancer pain, although pain related distress reduces closer to death.

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P 10.010 Place of Death of People with Cancer in 12 Latin American Countries: A Total Population Study Using National Death Registers

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Background/aims: Almost all countries in Latin America rank cancer as the second cause of death. Knowing place of death and understanding the associated factors are relevant to ensure the provision of adequate end-of-life care in accordance with patients' needs and preferences.

This study aims to describe and compare the place of death of cancer patients in 12 Latin American countries, and to examine associated factors.

Methods: We carried out a total population observational study using death certificate data of the most recent full year available from Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Mexico, Paraguay, Peru, and Uruguay. Place of death was categorized as occurring at home, hospital, or elsewhere. The sociodemographic factors, cause of death, and ecological factors were estimated. A multivariable binary logistic regression analysis was conducted with the dependent variable being home death versus hospital death.

Results: Cancer causes 16% of the 3 088 109 total deaths, which ranged from 8% in El Salvador to 25% in Chile. Women made up 57.2% cancer deaths in El Salvador; this percentage dropped to 45.5% in Uruguay, it stayed above 50% in half of the countries. 40.7% die before the age of 64 overall.

Cancer deaths occurred at home between 14.9% in Brazil and 80.6% in Guatemala, whereas they happened in hospitals between 80.6% in Brazil and 13.3% in Guatemala. When compared to those under 50 years old, the odds ratios for cancer-related deaths at home were 1.6 (95% CI 1.6-1.7; $p < 0.001$) for cancer patients aged 50 to 79 and 3.0 (2.9-3.0; $p < 0.001$) for those 80 and older.

Conclusions: Country-specific factors determine where people with cancer die in Latin America. The large number of deaths at home does not imply an adequate care provision, particularly in countries with poor palliative care programs. Differences could be explained by the accessibility to health services. Current requirements are highlighted to develop policies aimed at enhancing the end-of-life care.

P 10.011 How Uncomfortable Would People Feel about Someone's Suffering and Dying? Results of a Cross-Sectional Survey among the General Population

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Background/aims: In the last decades, death and dying have become increasingly medicalised. The associated cultural estrangement of death may affect how comfortable we feel towards death and dying. Feeling uncomfortable around the topic of death may cause social stigma, discrimination or social avoidance of seriously ill people. This negates the role of social connections at the end of life and community involvement in care for the dying. We aim to examine how comfortable the general public in four municipalities in Flanders feels around the dying of others and whether these feelings are related to personal factors such as having a professional healthcare or family care experience.

Methods: We conducted a cross-sectional survey in a random sample of citizens in four municipalities in Flanders, Belgium. We adapted the Collett-Lester Fear of Death scale, subscale "The dying of others", to measure how comfortable citizens feel around the dying of others. Items were scored on a Likert scale ranging from 1 (not uncomfortable) to 5 (very uncomfortable). We calculated a total sum score for each respondent between 8 (not uncomfortable) and 40 (very uncomfortable).

Results: 4400 questionnaires were sent; 2008 were returned (response rate=45.6%). The total average scale score was 29.95 (SD=7.10). Having a professional healthcare experience, being culturally exposed to death and dying, having experience with dead or dying people and having a family care experience with care, illness, and death were positively correlated with feeling comfortable around the dying of others.

Conclusions: By increasing how comfortable a society feels around death and dying can contribute to gains in patient and family care satisfaction as well as decreases in social stigma. Future research could apply longitudinal study designs to assess whether increasing how comfortable populations feel can indeed be achieved by building their experiences around care, illness and death and if this has an impact on care delivery.

P 10.012 Public Health Palliative Care Interventions to Support the Dying: A Scoping Review

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Background/aims: Public health palliative care (PC) is a model of PC that views communities as an integral part of care delivery at the end-of-life. This community-based approach to PC has the potential to better serve groups that traditional PC services are unable to effectively reach. We aimed to describe current literature on interventions aimed at engaging community members in supporting and caring for patients at the end-of-life.

Methods: We searched 5 scientific databases using the terms "public health" or "community-based" AND "palliative care" AND "intervention." We included articles that described the evaluation of community-based interventions to support the dying and their caregivers. We excluded studies focused on hospital-based or clinician delivered care and those that evaluated bereavement support interventions. Two reviewers independently verified each selected article.

Results: The search yielded 2900 results, and 25 were included in the data extraction. Articles were divided into those that were patient or caregiver focused. Patient-focused interventions included creative arts programs, facilitated social interaction, helplines and guided discussions about death and dying. Caregiver-focused interventions involved social support mapping, psychoeducation, and community resource identification and facilitation. Both interventions were carried out by

key stakeholders such as community health workers, volunteers, peer mentors, religious institutions and pre-established support groups. Many interventions were found to improve participants' quality of life, loneliness, perceived social support, stress levels, and self-efficacy. Multiple researchers described the difficulty of finding appropriate tools to measure intervention efficacy.

Conclusions: There is a paucity of high-quality research aimed at engaging communities in the care of dying patients. Future research should focus on designing and testing interventions that utilize community resources to bolster support for patients at the end-of-life.

P 10.013 Evaluating Quality of Care at the End of Life: A Population-based Observational Study Using Linked Routinely Collected Administrative Databases

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Background/aims: Evaluating quality of care at the end of life may lead to opportunities for practice improvements. Preferably, this is accomplished with data from existing registries, to prevent additional registration or measurement burden for patients and healthcare professionals. The aim of this study was to assess quality indicators concerning place of death and utilization of care from hospital or general practitioner (GP) in the last month of life in people with diseases relevant for palliative care, using data from existing registries.

Methods: A retrospective nationwide population-based observational study was conducted, using routinely collected administrative data concerning persons who died in 2017 in the Netherlands with underlying causes relevant for palliative care (N = 109,707 (73% of all decedents)). Data from four registries were linked for analysis. Quality indicator scores were calculated.

Results: Main causes of death in the study population were cancer (41%), heart disease (24%) and dementia (16%). On average, 36% died at home, 36% died in a long-term care facility and 20% died in hospital. About one-third (32%) were admitted to hospital at least once in the last month of life, of which 86% were acute admissions. In addition, 24% visited an Emergency Department and 5% were admitted to an Intensive Care Unit in the last month of life. Persons who were registered with a general practice until death had an average of 6.3 GP contacts in the last month of life, of which 2.6 contacts in the last week. More than half (57%) of people who were registered with a GP practice until death had at least one GP out-of-hours contact in the last month of life.

Conclusions: Quite some persons received hospital care in the last month of life or died in hospital. To be able to monitor trends in utilization of care at the end of life and interpret its quality, it is important to perform future assessments on quality indicators concerning place of death and utilization of hospital care and GP care.

P 10.014 Potential Geographical Accessibility to Specialist Palliative Care Services in Germany: An Accessibility and Network Analysis

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Background/aims: Palliative care need will increase over the next 25 years, because of the rise in deaths from chronic illness and demographic changes. The provision of specialist palliative care (SPC) in Germany (palliative care units (PCUs), palliative home care teams and palliative care advisory teams in hospitals) has been widely expanded in recent years. Despite the increasing availability, there is still insufficient coverage and some areas are potentially underserved due to long travel times (> 60 minutes) to the next service.

The aim of this study is to quantify the spatial distribution of SPC services, to calculate the potential accessibility of facilities and to identify spatial under-provision of SPC services.

Methods: Retrospective cross-sectional study with regional analysis of SPC services in Germany. Addresses of SPC services registered in the online database of the 'Guide for Hospice and Palliative Care' were geo-coded and accessibility and network analyses were performed to calculate travel times.

Results: A total of 673 facilities were included. Their distribution is heterogeneous and more than every fourth district (27.4%) has no facility. In half of the area of Germany the existing PCUs and palliative home care teams are accessible within 30 minutes and in almost the whole country within 60 minutes. Hospitals providing palliative care advisory teams can be reached within 30 minutes in 17% of the total area with 43% of the population living there. 96% of the population who do not have close access to hospitals with advisory teams (12.6%) can potentially access PCUs.

Conclusions: A high percentage coverage of home care teams and PCUs indicates a good spatial distribution, but not a completely adequate provision of SPC services, especially among palliative care advisory teams. Due to the specific differences of the patient groups and their individual needs, it cannot be assumed that SPC services replace, but rather complement each other in the care and support of patients.

P 10.016 The Influence of Place of Care and Disease Trajectory on Burdensome Transitions at the End of Life: A Population-based Retrospective Cohort Study

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Background/aims: Background: End-of-life transitions to hospital can be burdensome for patients and may contribute to poorer end-of-life outcomes.

Aims: To investigate the influence of disease trajectory and place of care on end-of-life burdensome transitions among decedents in Ontario, Canada.

Methods: We conducted a population-based study of individuals aged 65+ who died in Ontario between January 1, 2015 to December 31, 2018 and were residing in long-term care (LTC) or receiving homecare 6 months before death. Decedents were grouped into disease trajectories of end-of-life functional decline defined by cause of death, including terminal illness (e.g., cancer), organ failure (e.g., heart failure), frailty (e.g., dementia), sudden death (e.g., accident), and other causes. Homecare recipients were classified according to whether homecare was delivered under an end-of-life (EOL) designation. BTs were defined as early (3+ transitions to hospital in the last 90 days of life) or late (1+ transition to hospital in the last 3 days of life). We used multinomial logistic regression to evaluate relationships between disease trajectory, place of care, and BTs.

Results: Among 110,776 decedents, 10.0% had an early BT and 11.1% had only a late BT. Compared to terminal illness, those in the frailty trajectory had a decreased odds of early BT (OR 0.93 95% CI 0.87-0.99) and

increased odds of late BT (OR 1.61 95% CI 1.49-1.74), while those in the organ failure trajectory had an increased odds of early (OR 1.10 95% CI 1.04-1.17) and late (OR 2.15 95% CI 2.00-2.32) BTs. Compared to LTC, those receiving non-EOL homecare had an increased odds of early and late BTs, while those receiving EOL home care had a decreased odds of late BTs but increased odds of early BTs.

Conclusions: Disparities exist in BT for non-cancer decedents (frailty, organ failure), suggesting a potential opportunity for care improvement. Receipt of palliative care may help reduce BTs, which could lead to better patient outcomes.

P 10.017 Chinese Diaspora Communities' Knowledge of and Engagement with Advance Care Planning: A Systematic Integrative Review

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Background/aims: Background: The Chinese diaspora, traditionally experience varying access to palliative care and little engagement with advance care planning (ACP). Whilst western cultures have led in the development of advance care planning, there is little evidence of socio-cultural considerations. There is a dearth of understanding of Chinese diaspora communities' engagement and understanding of ACP.

Aims: To synthesize evidence regarding Chinese diasporas' understanding, experience and factors influencing engagement with advance care planning.

Methods: A systematic integrative review using content analysis. Seven electronic databases (Embase, CINAHL, SCOPUS, Web of Science, Medline (OVID), PsycINFO, and The Cochrane Library) and grey resources were searched for studies from January 1990 to March 2022. Study quality appraisal was undertaken.

Results: 27 articles were identified and rated as moderate to good. Two overarching and interrelated themes were identified, 'Awareness and knowledge' and 'Engagement with advance care planning'. There are low levels of awareness, knowledge and engagement with ACP for Chinese diaspora. Findings highlight this is influenced by two key factors:

The geographic context and legal, cultural and social systems within which the Chinese diasporas are living, act as a potential catalyst to enhance awareness and engagement with advance care planning.

Aspects of Chinese diasporas' original culture, such as filial piety and a taboo surrounding death, were reported to negatively affect the promotion and engagement of advance care planning.

Conclusions: Chinese diaspora are intermediaries between two divergent cultures that intertwine to strongly influence engagement with ACP. Hence a bespoke culturally tailored approach should be accommodated in future research and practice for Chinese communities in multicultural countries, such as the UK. It would be beneficial to further advance palliative and end-of-life care awareness among this group.

P 10.018 Symptoms and Problems Reported by Patients with Non-cancer Diseases through Open-ended Questions in Specialist Palliative Care

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Background/aims: Since 2010, a comprehensive symptom assessment has been carried out in Danish specialist palliative care by using the EORTC QLQ-C15-PAL and the open-ended question "Write In three Symptoms/Problems" (WISP), which allows patients to report up to

three symptoms and problems (S/Ps) not included in the EORTC QLQ-C15-PAL. Little is known about which S/Ps patients with non-cancer diseases in specialist palliative care report on WISP. This study aimed to investigate the prevalence and severity of S/Ps reported on WISP by patients with non-cancer diseases in specialist palliative care, and to compare these S/Ps with results from a previous study on S/Ps reported on WISP by cancer patients in specialist palliative care.

Methods: Data from the Danish Palliative Care Database included adult patients with non-cancer diseases answering the EORTC QLQ-C15-PAL at admittance to Danish specialist palliative care in 2016-2021. WISP responses were qualitatively categorized, and their prevalence and severity were calculated.

Results: Of the 2,323 patients with non-cancer diseases answering the EORTC QLQ-C15-PAL, 812 (34.9%) listed at least one S/P using WISP. A total of 1,340 S/Ps were reported on WISP, of which 56.7% were not included in the EORTC QLQ-C15-PAL (i.e., were new), 29.3% were already included, 12.7% were diagnoses and 1.3% could not be coded. Among the new S/Ps, edema was most prevalent in patients with cardiovascular disease (10.5%), dizziness in patients with lung (8.3%) and kidney disease (11.4%), dysphagia in patients with neurological disease (12.3%) and existential problems in patients with other non-cancer diseases (12.0%). Overall, 88.6% of the S/Ps were scored as moderate-severe.

Conclusions: This study identified S/Ps experienced by patients with non-cancer diseases that are not measured by the standard questionnaire. Patients with non-cancer diseases reported S/Ps on WISP similar to cancer patients, except for dysphagia and existential problems.

P 10.019 Practices and Interventions to Improve Advance Care Planning in Hospitals: A Review

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Background/aims: Background: Advance care planning (ACP) is a key focus to improve patient centered care in the last phase of life. Until now, however, it has not been integrated into standard care in the hospital setting. This is surprising, since triggers to initiate ACP may occur in hospital. In addition, health care providers (HCPs) working in this setting may be able to explain the value of (future) medical interventions better than HCPs outside the hospital.

Aim: To provide an overview of international practices and interventions to improve ACP in the hospital setting.

Methods: Embase, Medline, and Web of Science databases were searched for studies about interventions regarding ACP in hospital setting. Primary and pediatric care, and non-hospital care institutions were excluded. The quality of studies was assessed using Downs and Black checklists. Two reviewers screened each study for eligibility and assessed their quality independently. Interventions were sorted into categories using a narrative synthesis.

Results: 425 articles were screened, of which 27 were included. 24 were studies conducted in the Western World, the other three in Asia. The interventions were focused on communication (n=6), Respecting Choices model (n=4), education (n=6), E-health (n=6) or alterations to the health care system (n=5). The outcomes varied greatly between studies: frequency of ACP activities, concordance with end-of-life wishes and received care, patient involvement, HCP related outcomes and patient quality of life outcomes. Yet, the education interventions consistently

found important increases in both HCP likelihood to engage in ACP and patient related ACP outcomes.

Conclusions: Multiple interventions to increase the use of ACP in hospital have been utilized, in a variety of domains. Outcomes vary greatly which makes the ACP interventions difficult to compare and integrate. Education interventions seem most likely to increase ACP interventions in the hospital setting.

P 10.020 What Are the Conditions for End-of-Life Support in France in 2021?

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Background/aims: In France, the fifth national plan for the development of palliative care and end-of-life support 2021-2024 aims to keep on developing the palliative care offer by strengthening the continuity of pathways between the city and the hospital.

In this context, we aimed to draw up an inventory of both needs and end-of-life support offer in France.

Methods: Data comes from different official national surveys and information systems. Data processing was supervised by a steering committee bringing together data producers and public health policy makers.

Results: The French population has been increasing steadily for several decades and is increasingly made up of elderly people : 10% is at least 75 years old (+11% since 2014). Mortality has also been increasing and achieved 657,000 deaths in 2021 (+20% in 30 years). More than half of French people die from cancer or cardiovascular diseases. More than half of French people die in hospital, a quarter at home and a fifth in nursing homes.

In 2021, France had 171 palliative care units (PCU) with 2,000 beds (2.9 PCU beds per 100,000 inhabitants), 5,561 identified palliative care beds (IPCB ; in units facing frequent deaths such as oncology units) spread over 903 establishments (8.2 IPCBs per 100,000 inhabitants) and 420 mobile palliative care teams (MPCT : 0.62 MPCTs per 100,000 inhabitants). Since 2013, 41 PCU (+32%), 550 PCU beds (+40%) and 900 IPCBs (+20%) were created but there are 11 MPCTs less (-2.5%). Even if 22 departments have no PCU, most of them have a higher density of IPCB than the national average. Too few data are available in France to describe the offer at home.

Conclusions: With increasing needs, the palliative care offer keen on growing up in France thanks to policies supporting the development of palliative care and end-of-life support. However, the development seems to slow down, especially regarding IPCBs and MPCTs. In addition, there are still territorial inequalities. The 5th plan aims to provide each department with at least one PCU.

P 10.021 Association between Potentially Inappropriate End-of-Life Cancer Care and Specialist Palliative Care: A Retrospective Observational Study in Two Acute Care Hospitals in the Netherlands

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Background/aims: Many patients with advanced cancer receive inappropriate end-of-life care. Improving their quality of care is a priority both for patients, families and public health.

To investigate the association between provision, timing and initial setting of hospital-based specialist palliative care and potentially

inappropriate end-of-life care for patients with cancer in two acute care hospitals in the Netherlands, we conducted a retrospective observational study using hospital administrative databases.

Methods: All adults registered with an ICD-10 code for solid tumors in the year preceding their death in 2018 or 2019 were included. Main exposure was hospital-based specialist palliative care initiated >30 days before death. Outcome measures in the last 30 days of life were 6 quality indicators of potentially inappropriate end-of-life care: ≥ 2 ED-visits, ≥ 2 hospital admissions, >14 days hospitalization, ICU-admission, chemotherapy, hospital death. Using multivariable logistic regression, adjusted odds ratios (AORs) and corresponding 95% CIs were computed for the association between specialist palliative care provision, timing, initial setting, and potentially inappropriate end-of-life care.

Results: We identified 2,603 deceased patients: 13% (n=359) received specialist palliative care >30 days before death (exposure group). Overall, 27% (n=690) received potentially inappropriate end-of-life care: 19% in the exposure group vs. 28% in the non-exposure group (p<0.001). Patients provided with specialist palliative care were nearly two times less likely to receive potentially inappropriate end-of-life care (AOR 0.55; 95% CI 0.41 to 0.73). Early (>90 days) and late (≤ 90 and >30 days) initiation as well as outpatient and inpatient initiation were all associated with less potentially inappropriate end-of-life care (AOR 0.49; 0.62; 0.32 and 0.64, respectively).

Conclusions: Timely access to hospital-based specialist palliative care was associated with less potentially inappropriate end-of-life care for patients with cancer. Outpatient initiation of specialist palliative care seems to enhance this result.

P 10.022 Population-based Cross-sectional Study of Associated Factors with Access to Palliative Consultations in General Palliative Care

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Background/aims: There are persisting inequities in access to palliative care, between as well as within countries. Working in the junction of general and specialised palliative care, palliative care consultation services (PCCS) support general palliative care providers. Previous evidence shows that factors as age, sex, income, symptom burden and cancer type may influence access. However, conclusions from these studies are constrained due to focus on specific care services or disease groups, leaving a research gap of influencing factors in the general population. Our aim was to explore factors that influence access to PCCS among adult patients.

Methods: Population study with cross-sectional design based on national register data for deceased people in Sweden between 2012-2019. Criteria for inclusion; age 18 and above, deceased within general palliative care services, reported expected death and registered in the national palliative care register. Factors related to patient characteristics, disease, social background and care context were tested for association with consultation of a PCCS last week of life through multivariable logistic regression models.

Results: 291 344 patients were included in the study. Several factors were associated with access to PCCS last week of life. Cancer as cause of death, death at home and a greater symptom burden increased likelihood of a consultation. On the contrary dementia, a higher age and death in a hospital made it less likely to see a PCCS.

Conclusions: Our general population study shows that persisting structures within health care that favour access to specialised palliative care for patients with cancer is also valid for PCCS. Patients of older age seems to be omitted to a larger extent than younger, and patients in some care contexts have constrained access. All in all, our findings motivate further research regarding reasons behind these inequities and to consider measures to change care culture and policy.

P 10.024 Analysing Blood Test to Help Care of the Dying

Discussions: How Do Blood Tests Look Like at the End of Life?

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Background/aims: Prognosticating patients in last phase of life can be difficult. In hospital settings, there is still tendency to repeat investigations and manage blood test results. This can result in prolonging 'dying' rather than 'life'. Doctors often are hesitant to have care of the dying discussions with patients and families. This study looks at evaluating data of blood tests towards the end of life.

Methods: We collected data evaluating blood tests in last days of life to review if there are any trends which can guide clinical team towards planning for care of the dying phase. Data was collected retrospectively from an acute general hospital.

Results: 60 patients (24 male) data was collected. All patients had cancer (commonest cancer was Lung – 17). Age range was 40 – 98 (Mean – M=77). Blood tests were evaluated from last 0 – 25 days (M =7 days). Following significant derangements were seen in patients: 67% had low Hb (M=105), 59% abnormal WBC (M=17.8), 54% abnormal neutrophils (M=10.4), 98% high CRP (M=116), 38% high creatinine (M=124.6), 66% high urea (M=12.2), 39% low EGFR (M=49.9), 50% high ALP (M=223.7), 25% high ALT (M=146.2), 91% low Albumin (M=24), 100% high D-Dimer (M=6714), 88% high Ferritin (M=3759) and 87% high LDH (M=1307).

Conclusions: There was strong association of blood tests derangement with last days of life. Strongest association was noted with high CRP, low Albumin, high D-Dimer, high Ferritin and high LDH. Low HB, abnormal WBC and neutrophils, high urea and high Alkaline phosphatase were also noted.

Implications: When patients with cancer have advanced disease and poor performance status, observing these derangements can support a clinician's discussion towards end of life care phase with patients and their families.

P 10.025 Socio-economic Determinants for the Place of Last Care: Results from the Acute Palliative Care Unit of a Large Comprehensive Cancer Center in a High-income Country in Europe

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Background/aims: Quality of care and place of last care carry importance for patients at the end of life. They are influenced by the realities of the social welfare and healthcare systems, cultural aspects, and symptom burden. Several studies have analyzed patterns of end-of-life

care and place of last care, reporting conflicting results. The aim of this study is to investigate the place of care trajectories of patients admitted to the acute palliative care unit of a comprehensive cancer center.

Methods: For the purposes of this single-center observational study, we reviewed the medical records of all patients hospitalized on the acute palliative care unit of a large comprehensive cancer center in the year 2019. Demographic, socio-economic and disease characteristics were recorded. Descriptive and inferential statistics were used to identify determinants for the place of last care.

Results: During the study period, 377 patients were hospitalized on the acute palliative care unit. Median age was 71 (IQR, 59–81) years. Of these patients, 56% (n=210) were male. The majority of patients was Swiss (80%; n=300); about 60% (n=226) reported a Christian confession; and 77% had completed high school or tertiary education. Most patients (80%, n=300) had a cancer diagnosis. The acute palliative care unit was the place of last care for 54% of patients. Gender, nationality, religion, health insurance, and highest level of completed education were no predictors for place of last care, yet previous outpatient palliative care involvement decreased the odds of dying in a hospital (OR, 0.301; 95% CI, 0.180–0.505; p-value <0.001).

Conclusions: More than half of patients admitted for end-of-life care died on the acute palliative care unit. While socio-economic factors did not determine place of last care, previous involvement of outpatient palliative care is a lever to facilitate dying at home.

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P 10.026 The Embedded Palliative Care Day Care Hospital in Oncology: A Model for an Ambulatory Shift

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Background/aims: Background: The increasing need for palliative care in Oncology and the lack of hospital capacity implies an ambulatory palliative care shift. The evaluation of new ambulatory palliative care pathways is a public health issue.

Aims: Describe the organisation of an embedded palliative care day care hospital (PCDCH) in Oncology and analyse the trajectory. Analyse all stays per patient through the PCDCH with description of the population, the healthcare providers, the technical acts required and the end-of-life trajectory.

Methods: Monocentric retrospective cohort study of all referred patients for the first time to the embedded PCDCH over an 8-month period.

Results: One hundred and sixteen patients were included (319 stays). At the first PCDCH, the median follow-up was 3 months. At this time, more than half of the patients had an anti-cancer treatment and 87 of them (75%) were in an unstable or deteriorating phase. More than two-thirds of the stays involved patients with an ECOG performance score (PS) \geq 3. The number of providers per stay, including the oncologist, was \geq 3 for 141 stays (44%). Blood tests and intravenous injections were the most frequently performed procedures. In the last month before death, 31 patients (10%) were hospitalized at least once, 16 patients (5%) received chemotherapy, 15 patients (5%) visited the emergency department, and for three (3%) the length of stay in palliative care units was less than 3 days. The median survival was 3 months. The type of primary cancer and gender were not prognostic in univariate analysis (p=0.47 and 0.83 respectively) unlike the PS score (PS=1-2 versus PS=3-4), p <0.01.

Conclusions: The PCDCH is a suitable place for a fragile population that may require technical care and the intervention of several healthcare providers. A randomised multicentre trial with quantitative analysis including a medico-economic component and qualitative analysis is in progress to explore the impact of embedded PCDCH on patient's trajectory and the use of resources.

P 10.027 Developing Compassionate Communities in an Urban Environment in the Netherlands

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Background/aims: In the past two decades a strong palliative care (PC) network emerged in the city of Utrecht (715.000 people) including homecare, nursing homes, hospices, PC volunteers, specialist PC consultation teams in all hospitals, and centres for chaplaincy in homecare. Although this network has had a strong impact on the quality and provision of PC in Utrecht, the connection with the social dimension and communities is limited. A few citizens' initiatives tried in 2017 to start compassionate communities (CoCo). Local government did not recognize the power of the concept at that time and decided not to support the initiative. In 2021 an inventory of citizens' initiatives and professional social organizations started in order to map and analyse stakeholders. Aim is to strengthen the original coalition with new stakeholders and prepare a city-wide initiative on death, dying and bereavement.

Methods: The project started interviewing participants of the original coalition, using a snowball-approach to find other stakeholders. We used a participatory action research approach, stimulating old and new participants to act as co-researchers. A thick definition of CoCo, including the concepts of Kellehear, Armstrong, aging cities, local policies on community development, is used for inclusion criteria. The focus is to develop death literacy, to start, connect or strengthen community support initiatives for EoL care and to develop a sustainable coalition CoCo Utrecht. We are in the first phase of an asset-based community development project. We are taking time to democratise the coalition in order to develop a sustainable community network structure.

Results: A primary coalition is developing, at the first meeting several stakeholders signed our Charter, with other initiatives we formed a national consortium for further development and research of compassionate communities.

Conclusions: The outlines of CoCo Utrecht are emerging, data of first phase available to start 2 PhD on the project.

P 10.028 Place of Death among Foreign-born Individuals: A National Population-based Register Study

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Background/aims: We know relatively little about where foreign-born individuals die and how region of birth might influence place of death. Thus, there is need for population-based studies investigating place of death and associated factors among foreign-born.

The aim of this study is to identify variations in place of death among foreign-born individuals residing in Sweden and to examine the association between place of death, underlying cause of death and sociodemographic characteristics.

Methods: The primary outcome variable was place of death. Percentages were calculated for distribution of place of death by underlying cause of death and other variables. Univariable multinomial logistic regression modelling was then performed to investigate variations in place of death and associated factors.

Results: Overall, hospital was the most common place of death. However, some variation in place of death was found to depend on the

region of birth. A high proportion of foreign-born individuals died at home, the majority of whom were born on the African continent.

Conclusions: Region of birth is one of several factors associated with place of death among foreign-born individuals. Further research is needed to explore both preferences and barriers to place of death among foreign-born individuals.

P 10.029 Narratives of Death and Dying in New Zealand: A Literature Review

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Background/aims: A literature review was conducted to inform a study exploring views, beliefs and attitudes of death and dying in contemporary, multi-ethnic New Zealand.

Methods: CINAHL, PubMed, Scopus and Google scholar were searched in September 2021 using keywords 'perceptions, beliefs, attitudes, views', 'migrant' and 'death or dying'. No date limit was applied.

Results: Death anxiety consciously and unconsciously affects human behaviour, as evident in response to the global pandemic where opportunities for creativity and meaning making were reported within the confinement and suffering and leading to personal transformation. Current discourse around the notion of the 'good death' is argued in context of today's westernised neoliberal and increasingly diverse, multicultural society where views, beliefs, and attitudes to death and dying are widely heterogeneous, even within similar ethnic and cultural groups; there is no 'one size fits all' approach to death. Yet there appears a common thread among experiences of the dying, whether older people in care homes, migrant, refugee, or indigenous people with life limiting illness, which is the need to be seen, deeply understood, connected, cared for, and loved in a profoundly intimate, individual, and relational way, or as Frankl concluded, 'The salvation of man is through love and in love.'

Conclusions: Studies exploring death and dying in contemporary New Zealand were limited in this literature review. The themes explored from this review will help to inform a qualitative study to explore views, beliefs and attitudes of death and dying in our diverse multi-ethnic population.

P 10.030 How to Reveal the Current State of Palliative Care to International Stakeholders? Inferences from an e-Survey among Users of the ATLANTES Observatory

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Background/aims: Despite a steady increase in palliative care-oriented research, factual engagement of stakeholders with findings seems underused. Given the ATLANTES designation as a WHO Collaborating Centre for the Evaluation of Palliative Care Development, we aim at exploring the usefulness of ATLANTES works to date and how to better connect with stakeholders.

Methods: An international e-survey among Observatory collaborators explored the usefulness of ATLANTES products for diverse stakeholders, key audiences, best way to reach them, and priority activities. Answers were evaluated from the perspective of the respondent's role (Academics, Policymakers, and clinicians) and towards impact on diverse key stakeholders. Correlation between respondent's role with the perception of usefulness, and with preferred products, was studied.

Results: 130 collaborators participated. Most useful ATLANTES activity was the regional evaluation of palliative care situation (81,5%), especially for advocators (0,65*) and PC professionals (0,55*). The advocacy/

lobbying with policymakers was useful to advocates (0,60*) and academics (0,52*). The Atlas was most valued research product, followed by the infographics and scientific articles. Collaborators suggested addressing activities to policymakers (5,6/7), professional associations (5,2/7) and general practitioners (4,4/7). Preferred activity to reach all stakeholders is the use of social networks, media, and websites, while particularly for policymakers, academics and general practitioners, the conduction of atlases and scientific articles stand out.

Conclusions: The evaluation of the situation of palliative care for advocates and professionals was the best considered ATLANTES activity. Participants suggested adding policymakers and general practitioners as priority stakeholders. A web tool and social networks were proposed to disseminate information.

P 11 - Policy, Including International Developments

P 11.001 Calculating Worldwide Needs for Morphine for Pain in Advanced Cancer and Proportions Feasibly Met by Country Estimates of Requirements: Retrospective, Time-series Analysis (2007-2017)

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Background/aims: The International Narcotics Control Board (INCB) collects *estimates of requirement* for morphine from countries worldwide. To support country *estimates*, INCB states that 80% of people who die from cancer need 6.075g of morphine over 90 days but do not publish countries' *calculated need*. We aimed to describe and explore the proportional gap between *estimate of requirement* and *calculated need* for morphine of people who die from cancer in countries worldwide and baseline variables correlated with development in gaps between the two.

Methods: Retrospective time series-analysis 2008-2017 using publicly available data. We used INCB-recommended methods to *calculate need* using country-reported *estimates* and Global Burden of Disease cancer deaths by country. Gaps between *calculated need* and *total treatable* population using *estimates* were calculated. Adequacy was set at 100%, no comment is made on estimates >100%. Linear mixed-effects model for World Health Organization regions with baseline predictors to explore predictors for gaps.

Results: 10-year data for 186 countries could be extracted. We identified only minor improvements in proportions of *calculated need* feasibly met by *estimates*. Effect size for standardised slope change across years is statistically significant but of small effect size ($\beta = 0.007$, 95% CI: 0.002

to 0.012). 13 countries had a slope change larger than 0.5 (reducing gap to adequate) but 6 countries had slope changes larger than -0.5 (widening gap from adequate). 7/13 countries reducing the gap between *estimates* and *calculated need* are in WHO African Region. Statistically significant predictors of slope change were Gross Domestic Product per capita ($\beta=0.07$, 95% CI: 0.03 to 0.11) and health expenditure ($b=0.006$, 95% CI: 0.001 to 0.01).

Conclusions: We identify slow progress in reducing gaps between total treatable using *estimates* and *calculated need*, in some countries gaps are widening. Publishing *calculated need* alongside *estimates* would help monitor adequacy of morphine availability.

P 11.002 Is Palliative Care Research Biased towards Oncology? Trends in Literature from 2000 to 2021: A Bibliometric Big Data Analysis

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Background/aims: Palliative care (PC) is a multidisciplinary medical speciality focusing on life-threatening diseases of all kinds. In clinical practice however, the integration of PC is mainly established in oncology and limited in other medical fields. To find out if this also accounts for scientific literature, we performed a bibliometric big data analysis of trends in palliative care research.

Methods: We retrieved data on articles about palliative care from 2000 to 2021 from PubMed and Thomson Reuters WoS database. For Pubmed we used the search term: (palliative care[Title] OR end of life care[Title] OR terminal care[Title] OR palliative[Title]). We used Joinpoint regression analysis (JPA) and keyword clustering (KC) to describe the trends and major topics in palliative care research.

Results: In total, we analyzed 27397 articles and their keywords. There was a continuous increase in published articles over the study period. JPA revealed two years with significant trend changes in the number of articles published (2009, 2019), resulting in three trend periods with a positive increase in published articles per year. KC of each period showed no topics that could explain the trend changes, except for the Covid-19 cluster in the last period.

Conclusions: Palliative care is an emerging field with constant growth over the last decades. The research topics included mainly oncology, pediatrics, and terminal care in all periods, but the article counts and special focus of topics changed only marginally. Other life-limiting diseases are still underrepresented in palliative care literature suggesting an oncology-bias within palliative care literature.

Rank	2000-2009	2010-2019	2020-2021
1	Cancer & Symptoms	Pediatrics	Quality of Life & Advance Care Planning
2	Terminal Care & Patient preferences	Terminal Care & ICU	Pediatrics
3	Attitude of health personnel	Cancer & Symptoms	Cancer & Prognosis
4	Referral & Consultation	Attitude of health personnel	Hospice Care for lung neoplasm
5	Pediatrics	Hospice Care	Terminal Care & Communication
6			Covid-19

P 11.003 What Is Community? Understanding Notions of Community in Relation to English Palliative and End of Life Care Ambitions Framework

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Background/aims: The Ambitions for Palliative and End of Life Care: a national framework for local action (2015) was relaunched in England in

2021 for five years. It seeks to provide ambitions and guiding foundations to improve palliative and end of life care across the country. A mapping survey conducted in 2021/2022 showed that Ambition 6 (Each Community is Prepared to Care) was least likely to be focused on. Aim: To further examine how people understand the concept of 'community' and enact Ambition 6. This is part of a larger project examining how people understand, interpret and implement the Ambitions framework.

Methods: We undertook 17 individual online interviews (identified as case studies from previous survey) and four online focus groups.

Focus groups were based on professional role or interest (e.g. commissioners, public, service managers, healthcare staff) and contained between 2-8 participants. We also held one interactive workshop focused on the concept of community using data from previous strands to guide the workshop. All data was transcribed and coded thematically.

Results: Participants felt inclusion of Ambition 6 in the framework legitimised a focus on the public in palliative care. Yet, community was widely understood as difficult to conceptualise in the context of palliative and end of life care. Notions of community ranged from organisations, the general public, geographical areas, groups of people (including those less likely to be provided specialist services), and frequently referred to 'others'. There were disagreements about who was responsible for enacting Ambition 6. A lack of awareness of the Ambitions Framework outside of palliative care can impact the extent to which this Ambition is realised or recognised.

Conclusions: Difficulties in understanding and communicating about 'community' makes it difficult to realise an ambition that each community is prepared to care. Discussions about 'community' can facilitate shared learning and innovation within and beyond palliative care providers.

P 11.004 Global Indicators for Quality Palliative Care Services across Six WHO Regions: A Mixed Methods Longitudinal Study

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Background/aims: Governments must meet the requirements of Universal Health Coverage to provide palliative care as an essential health service. It is important to ensure that measurable quality indicators underpin diverse models across international health systems, and that outcomes are demonstrated for patients and families. The study aim is to describe and evaluate models and quality indicators of palliative care across all 6 WHO regions, in terms of structure, process, and outcomes.

Methods: Design: Mixed methods longitudinal study of newly referred palliative care adult patients and their families with embedded qualitative interviews. Convenience sampling was applied.

Setting: Belarus, Jamaica, Oman, Thailand, Vietnam, and Zimbabwe.

Methods: Phase of illness was measured and monthly Integrated Palliative Care Outcome Scale (IPOS) and Client Services Receipt Inventory.

Analysis: Comparative tabulation of service proforma; assessment of psychometric properties of outcome tool; descriptive analysis of service use; thematic analysis of qualitative interview data.

Results: N=741 patients, mean 58.6 years old, majority digestive organs cancer. Internal consistency of IPOS (Cronbach $\alpha=0.78$) and test-retest reliability (canonical correlation=0.76) were confirmed. Patterns of health service use differed by country due to variation in healthcare resources and systems. From 54 qualitative interviews, 4 care domains (good physical symptom management, adequate psychological support, respecting social norm, and trusting relationship) and 5 system indicators (information provision, friendly environment, adequate funding, communication and continuous care, and shared decision-making) were identified for quality palliative care.

Conclusions: Despite vast heterogeneity in service models and samples, it is possible to identify core outcomes and measure these, and define quality cross-nationally. We support locally-led additional quality indicators to ensure contextual relevance.

P 11.005 How Is Palliative and End of Life Care Included in Policies that Aim to Improve Care Integration? A Documentary Analysis

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Background/aims: Integrated Care Boards in England aim to improve the integration of care across services. Palliative and end of life care has been shown to improve integration and outcomes for patients. Despite this, palliative and end of life care is rarely a policy priority.

Aim: To explore if and how palliative and end of life care is included in Integrated Care Board strategies.

Methods: Web searches were completed on 30th November 2021 to identify Integrated Care Board strategies. Where identified, strategies were searched using the following key terms: palliat*, end of*, terminal, hospice, bereave*, death, die, and dying, EoL and 'of life'. Content analysis was used. Relevant content was extracted and mapped onto an adapted Social Care Institute for Excellence logic model for integrated care.

Results: 23 of 42 Integrated Care Board strategies were identified. Two did not mention any of the key terms. Six recognised palliative and end of life care as a priority.

Content from 19 strategies were mapped onto the adapted logic model. Eight strategies referred to enablers of integrated care, including partnerships with hospices, voluntary services, patients and the public. 18 included components of care, including advance care planning and care coordination. Nine related to structures of care, focusing on sharing care records between services. Nine referenced processes of integrated care, focusing on meeting standards of care. 11 mentioned outcomes, including preferred place of death and reducing emergency department attendances. Five described the impact their plans would have, such as equal access to care. The connections between enablers, components, structure, process, outcomes, and impact were often missing.

Conclusions: Commissioners can use our adapted logic model to develop their strategies and ensure they include information on how they plan to deliver palliative and end of life care, the impact this will have, and how outcomes will be measured.

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P 11.006 Advance Care Planning and Advance Directives in Latin America: How Far Have We Travelled? Results from a Survey of Key Informants from National Palliative Care Associations

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Background/aims: Advance Care Planning (ACP) and Advance Directives (AD) were developed in high-income countries and are considered important means to achieve goal-concordant end-of-life care. However, it is unclear how low- and middle-income countries have incorporated (or not) ACP/AD. We aimed to map and compare the current state of ACP/AD in Latin America.

Methods: We contacted all existing national palliative care associations from the 20 Latin American countries and asked them to appoint a key informant regarding the state of ACP/AD in their countries. We conducted online interviews with each informant using a pre-tested questionnaire and asked them to confirm the accuracy of the information that we recorded.

Results: According to the key informants from the 18 participating countries, the highest-ranked barriers for the implementation of ACP/AD are lack of credibility, the dearth of regulatory guidance, and healthcare professionals' expectations that patients should start those conversations. Only 7 countries have some type of ACP/AD regulation; none of the 18 countries provide adequate training for healthcare professionals in that area; in only 5 countries healthcare professionals feel legally secure to honor patients' treatment preferences documented in an AD; in 9 countries, patients react positively to ACP conversations; in 6 countries, patients often allow their families to change their choices documented in AD; the majority of the population from the 18 countries are not aware of the aims of ACP/AD; and in 9 countries, patients' preferences regarding medical treatments at the end of life are usually respected through various means not necessarily involving AD.

Conclusions: The design of future public policies in palliative care in Latin America must take into account challenges with low regulation, mixed attitudes towards ACP/AD, as well as high heterogeneity with regards to honoring patients' care preferences at the end of life that are present in that region.

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P 11.007 Missing Data on Where People Die: A Death Certificate Study by World Region, Age, Gender and Cause of Death

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Background/aims: Improving the quality of data on place of death (PoD) provides better evidence to assess if people's preferences are respected and where palliative care is most needed. We aimed to examine recent trends in the level and type of missing data on PoD, by world region, age, gender and cause of death.

Methods: We sought national PoD data from vital registries of 47 countries varied in United Nations (UN) regions and Quality of Death Index. We describe the distribution of ill-defined PoD categories (unknown, unrecorded, "other") from 2012 to 2021, examining variations by UN region, age, gender and cause of death (ICD-10).

Results: Among 26.1 million deceased (57.2% aged 70y or more) across 22 responding countries (covering 8 UN regions in 4 continents), information on PoD was missing for 7.0%, with a decreasing trend from 2012 (8.0%) to 2021 (6.7%). In 0.7% of cases, PoD was recorded as unknown, in 1.1% it was unrecorded and in 5.1% it was coded as "other". Per UN region, ill-defined PoD data ranged from 1.1% to 9.8%. It was highest in those aged 11-17y (16.2%), and people dying from dementia (5.3%; compared to cancer, and COVID-19 for 2020-21).

Conclusions: Globally, there is a considerable share of people dying in places not captured by current classifications and/or unknown. Since this event is not equally distributed, a more comprehensive global PoD

classification must include categories responsive to groups of deceased for which PoD is comparatively less known.

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P 11.008 Translation and Cross-cultural Adaptation of the Chinese Version of Integrated Palliative Care Outcome Scale:

Expert Reviews and Cognitive Interviews

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Background/aims: Despite the burden of advanced cancer in China, there were no reliable and validated patient-reported outcome measures for use to measure the care needs and outcomes of patients with advanced cancers. The Integrated Palliative care Outcome Scale (IPOS) is a psychometrically sound and multidimensional measure that has been used worldwide for patients with advanced illnesses including cancer. This study aimed to translate and cross-culturally adapt IPOS to the Chinese context in advanced cancer care.

Methods: Chinese versions of IPOS Patient and IPOS Staff were translated and culturally adapted following the Rothrock guidance and the Palliative care Outcome Scale family of measures Manual for cross-cultural adaptation and psychometric validation. Five phases were included:

- (I) Conceptual definition;
- (II) Forward translation (translation from English to Chinese);
- (III) Backward translation (translation from Chinese to English);
- (IV) Expert review;
- (V) Cognitive debriefing.

Results: One new item was developed, and changes were made, agreed upon by the expert review meeting. The comprehension and judgement difficulties identified in the pre-final patient and staff versions were successfully solved during the cognitive interviewing process. IPOS was well accepted by both patients and staff, none of the items in the Simplified Chinese versions of IPOS was inappropriate, and all questions were judged relevant and important.

Conclusions: In this study, we translated and culturally adapted the patient and staff versions of IPOS and demonstrated content validity and acceptability of the scale through expert review and cognitive interviews with patients and staff.

P 11.009 A Person-centred Outcome Measure in Advanced Illness: Psychometric Validation of the Chinese Version of the Integrated Palliative Care Outcome Scale

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Background/aims: Outcome measures amenable for palliative care patients in China have been lacking. The Integrated Palliative care Outcome Scale is a brief and valid PROM that evaluates the most burdensome concerns and has been used with advanced cancer patients and adapted to many cultures. The study aimed to evaluate the psychometric properties (validity, reliability, and responsiveness to change) of the Integrated Palliative care Outcome Scale in China.

Methods: A multi-centre validation study was conducted to test the psychometric properties of the Chinese Integrated Palliative care Outcome Scale - both (1) patient self-report and (2) staff proxy-report versions. We tested construct validity (factor analysis and correlational analysis), reliability (internal consistency, test-retest reliability and inter-rater reliability), and responsiveness (through longitudinal evaluation of change).

Results: Three hundred eight inpatient adults with advanced cancer were consecutively recruited from two medical oncology units in China. We confirm a three-factor structure (Physical Symptoms, Emotional Symptoms/Communication, and Practical Issues). Good convergent validity to hypothesised items and subscales of the Edmonton Symptom Assessment System is demonstrated. The Integrated Palliative care Outcome Scale shows good internal consistency ($\alpha = 0.83$) and acceptable to good test-retest reliability ($\kappa=0.59$) and inter-rater reliability ($\kappa=0.48$). Longitudinal validity in the form of responsiveness to change is good.

Conclusions: The Chinese Integrated Palliative care Outcome Scale is a reliable and valid outcome measure for use in patients with advanced cancer and available in both patient self-report and staff proxy-report versions. It is suitable for assessing needs, symptoms and concerns in advanced cancer, monitoring the change of health status over time, determining the impact of healthcare interventions, and demonstrating the quality of care.

P 11.011 The Risk of Recurrence of Venous Thromboembolism after Discontinuation of Anticoagulant Therapy for a Venous Thromboembolic Event in Patients with Cancer: Systematic Review and Meta-analysis

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Background/aims: The ideal duration of anticoagulant therapy in patients with active cancer and current venous thromboembolism (VTE) is unknown. Current clinical practice guidelines advocate anticoagulant therapy for at least 6 months and possibly for as long as the cancer is active. However, the incidence of recurrent VTE after discontinuation of anticoagulant therapy has scarcely been systematically studied.

Aims: To assess the incidence of recurrent VTE after discontinuation of anticoagulant therapy in patients with cancer who had an episode of VTE and completed an initial course of anticoagulant therapy.

Methods: A systematic literature search was performed in 5 databases (date last searched: April 7, 2022). A random-effects meta-analysis was used to estimate the overall absolute incidence of recurrent VTE for the

pooled studies at different time intervals. Forest plots were provided and the results were summarized by the mean and 95% confidence intervals (CIs).

Results: A total of 13 articles involving 1328 patients were included. The pooled incidence of recurrent VTE after discontinuation of anticoagulant therapy was 3.7% (95% CI 2.3-5.7%) in the first 3 months, up to 9.4% (95% CI 5.3-16.1%) in the period 3-5 years. The final analysis and results will show the incidence of recurrent VTE per 100 person years and cumulative incidence after discontinuation of anticoagulant therapy.

Conclusions: These preliminary results show that the percentage of patients with cancer associated thrombosis developing recurrent VTE after discontinuation of anticoagulant therapy per time interval seems limited. However, even several years after diagnosis of VTE, a clinically significant amount of these patients present with a recurrent VTE. Our estimates can support clinicians in carefully weighing the risks of long and short-term anticoagulant therapy in patients with cancer associated thrombosis, thereby improving the process of shared decision-making. Conflict of interest: Dr. Klok received research support from Bayer, BMS, BSCI, MSD, Leo Pharma, Actelion, The Netherlands Organisation for Health Research and Development, The Dutch Thrombosis Association, The Dutch Heart Foundation and the Horizon Europe Program.

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P 11.012 Digital Health in Cancer and Palliative Care: Policy Implications of the MyPal H2020 Stakeholder Workshop

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Background/aims: MyPal is a Horizon 2020 project developing and testing electronic patient-reported outcome (ePRO) systems in adults with haematological malignancies and children with blood cancers or solid tumours. An interdisciplinary workshop with key stakeholders was held in October 2022, focusing on developing policy and guidance for digital health interventions in cancer and palliative care.

Aim: To support development of policy and guidance for digital health applications in cancer and palliative care contexts.

Methods: The workshop audience heard presentations about the MyPal project, after which they split into three facilitated discussion groups to consider the following questions:

- How can global policy on access to digital health be more equitable?
- How can governments and health services be better prepared for the way in which support is provided via digital platforms?
- What are organisations' and health services' needs in the developing digital health?
- To what extent does digital health care impact on organisations' ability to deliver high quality care?
- What are clinicians' needs in the developing digital health?
- To what extent does digital health care impact on patients' experiences of cancer and palliative care?

The groups reported the key points they identified in a plenary.

Results: 35 researchers, technical innovators, clinicians, patient/professional representatives and policy makers took part in the workshop. Suggestions for improving the impact of digital health applications

included supporting innovation through competitive markets, data protection, co-design with patients and families, developing healthcare professionals' competence in digital health, and ensuring equity in access to essential technological equipment.

Conclusions: The interdisciplinary and international workshop highlighted potential developments, opportunities, and challenges in the use of digital health in cancer and palliative care. A summary report of the workshop will be available by January 2023.

P 12 - Development and Organisation of Services

P 12.001 Effect of Proactive Monitoring Using the Integrated Palliative Care Outcomes Scale (IPOS) on Patient Quality of Life - A Randomized Controlled Trial

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Background/aims: With the objective of identifying patients who have unmet needs and may benefit from early palliative care, we assessed a new outpatient-based palliative care model – ‘Supportive and Palliative care Review Kit in Locations Everywhere’ (SPARKLE) delivered to patients with advanced cancer alongside their usual oncologist-led care. SPARKLE comprises regular symptom monitoring using the Integrated Palliative care Outcomes Scale (IPOS). If any problems were identified, these would be further assessed and managed by a palliative care nurse.

Methods: A total of 240 patients with advanced cancers will be recruited to a randomized controlled trial of SPARKLE. The primary outcome would be quality of life as measured by the Functional Assessment of Cancer Therapy-General (FACT-G) at 4 months after randomization. ClinicalTrials.gov Identifier: NCT04242251

Results: As of 23 August 2022, 202 patients were recruited and FACT-G at 4 months were available for 100 patients. There were no significant differences between SPARKLE intervention and control groups.

Updated results would be presented at the conference.

Conclusions: Preliminary analysis suggests no significant differences in quality of life at 4 months between advanced cancer patients who received proactive monitoring with IPOS and management of problems identified versus those who had usual care. This may be due to patients in both the intervention and control groups being relatively asymptomatic during the study period.

	Intervention (n=57)	Control (n=43)	p-value
Physical wellbeing	22.5	21.9	0.60
Social wellbeing	20.0	20.8	0.54
Emotional wellbeing	18.8	18.5	0.72
Functional wellbeing	18.8	19.3	0.69
FACT-G total	80.1	80.5	0.92

P 12.002 The Care Plus Implementation Study: Evaluating Palliative Care Integration and Organisational Culture at Four Cancer Centres in Australia

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Background/aims: To explore palliative care (PC) integration and the resulting changing organisational culture and practices at four cancer treatment centres in Australia.

Methods: Multi-site stepped wedge implementation trial testing usual care (control) versus Care Plus (practice change involving early PC integration) following the Consolidated Framework for Implementation Research. As part of the trial, qualitative interviews with health professionals, patients and families were conducted to explore the implementation processes of Planning, Engagement, Practice Change and Evaluation across hospital sites. Interview transcripts were thematically analysed by making codes and categories with emerging themes. Consolidated criteria for Reporting Qualitative research guidelines were used to maintain rigour.

Results: Forty-nine semi-structured interviews were held with cancer (n=18), PC clinicians (n=17), administrative staff (n=3), consumers (n=2), Care Plus patients (n=8) and family members (n=1). Key themes included (1) the importance of language, terminology and the stigmatisation of palliative care as it is perceived as end of life; (2) the value of standardising practice with PC positioned as part of high-quality care pathways and (3) the contributions and limitations of communication training, prompts, and scripts.

Conclusions: Integration of palliative care into cancer care is influenced by organisational culture where palliative care is valued as a key component of high-quality cancer care, facilitated by expert communication skills. The application of this standardised practice of PC integration heralds an important step forward in the field.

P 12.004 “An Integral Part of Treatment”: What Oncologists Think about Early Integration of Palliative Care into Oncology Clinics

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Background/aims: The Integrated Symptom Control and Palliative Care “Triggers” service was developed to support oncology outpatients to live as well as possible throughout their cancer journey.

The aim of this survey was to evaluate the views of oncology clinicians about the “Triggers” service in a tertiary referral oncology centre 6 years after the service was initially established.

Methods: A brief anonymous staff feedback questionnaire was developed with PPI input comprised of four questions with structured answers and one free text question.

The survey was carried out in 2018 and repeated in 2022. All oncology staff working in clinics where the “Triggers” service was invited to participate.

Descriptive analysis was carried out on the structured questions and thematic analysis on the free text question.

This service evaluation was approved by the local Committee for Clinical Research.

Results: Feedback forms were received from 42 staff members in 2018 and 52 in 2022.

49/52 (94%) rated the value of the service for patients and families as very positive. (69% in 2018). 50/52 (96%) thought the service had a very positive impact on patients. (69% in 2018). 96% (50/52) felt it had a positive effect on the running of the clinic. (76% in 2018).

Three strong themes were identified from the 2022 free text responses. The “Triggers” service provides urgent and prompt access to the palliative care team for management of patients with complex needs. The oncology teams felt that the “Triggers” service was helpful to the clinics and staff working in them. Finally, they recognised that the “Triggers” service is integrated and routinised into the oncology clinics.

Conclusions: As the “Triggers” early palliative care service has become embedded and integrated into the oncology outpatient clinics over time, oncology clinicians have become increasingly aware of the associated the benefits for patients and staff.

P 12.005 Using Normalization Process Theory to Evaluate the Use of Assessment Tools in Specialist Palliative Home Care - A Qualitative Interview Study

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Background/aims: Although the benefit of patient related outcome assessments has been proven, their use has not yet been uniformly established. Within the research project COMPANION, data was collected using assessment tools with the aim of developing a complexity and casemix classification (CMC). A long-term use of the tools is necessary to enable outcome measurement and the application of the CMC. Normalization Process Theory (NPT) considers the social (inter-)actions of implementation processes operationalised through four constructs: coherence, cognitive participation, collective action and reflexive monitoring.

The aim is to describe necessary structures and processes and to identify inhibiting and facilitating factors to a successful implementation of assessment tools in everyday work in specialist palliative home care (SPHC).

Methods: Qualitative study: Semi-structured interviews with professionals from SPHC teams who participated in the COMPANION project. Data was analysed using Framework Method and contextualised within NPT.

Results: 17 interviews across five teams were conducted. In some teams, coherence to routine assessments already exists based on previous experience, or it develops through the recognition of advantages. Cognitive participation depends on individuals and is decisive for coherence building. The attitude of the management level also plays a major role. Collective action, the integration of the tools (e.g. for structuring conversations) varies and depends on the manifestation of the first two constructs and other already established routines. In context of reflective monitoring, both positive (e.g. increased focus on certain problems, shortened documentation time) and negative (additional burden) aspects were mentioned.

Conclusions: Although benefits are proven and even partly recognised, not all teams maintain routine use of assessment tools. Here, not only the social (inter-)actions are decisive, but also the influence of the context. Future implementation strategies should consider this

P 12.006 Perception of Implementing “IPLAN” - A Structured Approach to Improve Advance Care Planning in a University Hospital: Results of Focus Group Interviews with Professionals

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Background/aims: The necessity of well-discussed and documented advance care planning (ACP) in patients with advanced life-limiting diseases has become evident during the COVID pandemic. The board of

hospital directors identified a hospital-wide lack of integrated ACP processes and assigned the palliative care services to develop and implement a participative and interprofessional pragmatic structure called IPLAN (Prognosis estimation, Life-domain assessment, Actionplan discussion, Network communication) as quality assurance project.

Our aim therefore was to gain deeper insight into the needs of health-care professionals prior to the IPLAN implementation, and their perception of the structure and its components.

Methods: Three focus groups with health care professionals (nurses, physician) were performed on a non-palliative care unit in which IPLAN will be implemented. Verbatim transcriptions were analyzed based on qualitative content analysis (Mayring).

Results: Thorough discussions of ACP are relevant for nurses and physicians. Analysis revealed the following main themes:

Need of more information what ACP entails and stronger support by the palliative care team

Necessity of tools (e.g. to identify patients’ needs for ACP conversations, communication tools) such as developed within IPLAN

Task clarification within the interprofessional team

Identification of the best time point for ACP conversations with patients
 Necessity of time devoted for ACP conversations by health care professionals

Conclusions: Nurses and physicians on a non-palliative care unit consider ACP conversations as essential. Professionals express a need for pragmatic tools, communication strategies and support in daily clinical practice. The structured approach as offered by IPLAN could provide these tools to start ACP conversations. Triggered by IPLAN, the focus of care activities could change from a strong diagnosis-driven care towards a well-discussed anticipatory preparation of future care.

P 12.007 Learning and Developing Together: A Tailored Approach to Transition for Young People with Specialist Paediatric Palliative Care Needs in a Children’s Hospice

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Background/aims: To develop a tailored transition approach for young people (YP) under the care of a specialist paediatric palliative care (SSPC) service.

Methods: Biannual meetings were established with 1 SSPC and 5 local adult palliative care (PC) teams. All identified SSPC patients >14yo were consented and their case discussed. Appropriate adult services were identified and shared with YP and their families. A flexible paced introduction for 17-20yo to adult PC, with joint SSPC working, enabling wider transition to occur, and optimizing support. Transitioned YP outcomes were feedback.

Results: In the past 5 years, 19 YP transitioned with a further 13 YP died during the process. In 2021, of 20 YP in the process: 16 (8 <16yo) cases identified and presented; 2 (18yo) joint working and 2 (19-21yo) transitioned. Transitioned services: pain service (1), adult PC (6), long arm PC model (6), respiratory service (2), GP only (2) and 3 died during transition. Some cases highlighted unpredictable episodes of ill health that required intermittent PC input. A ‘long arm approach’ was trialed, involving an annual PC review and rapid upscaling to support if YP’s health deteriorates. Some cases, SSPC provided complex symptom management that could be supported by non-PC adult services. Virtual meetings ensured clinical leaders attended, enabling review of traditional adult referral criteria and trialing of innovative service models. Regular meetings supported consistent messaging, shared goals and clear planning. Post-transition feedback supported

innovative model. Families valued advance information and flexible pacing of transition.

Conclusions: Not all YP under SPPC transitioned to adult PC due to uncertain prognostication with episodic ill health. Shared learning and case based discussion lead to the development of a new 'long arm' model. Joint meetings enabled shared learning, expertise development and feedback to strengthen learning and model innovation.

P 12.009 Understanding How People with Palliative and End-of-Life Care Needs Living at Home and Informal Carers Access Designated Telephone Support Out-of-Hours

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Background/aims: Since 2011, UK national guidance has recommended that people with palliative and end-of-life care needs should have access to a designated out-of-hours phone line. The availability of such support is unclear.

Aim: To map the availability of UK-designated phone lines out-of-hours for people with palliative and end-of-life care needs living at home.

Methods: Structured interviews with UK professionals with commissioning/leadership responsibilities or knowledge of local palliative care provision, purposively sampled by geographical area. The topic guide was informed by stakeholder priorities, including designated phone line availability, who responds, and access to patient information. Descriptive statistics for closed questions and thematic analysis for open discussion were undertaken.

Results: 71 interviews across 60 UK geographical areas were conducted. 16 (27%) areas did not have a designated phone line and a further 25 (42%) described geographical, temporal, or other limitations. Models of phone support varied (e.g. who answers). Designated phone lines were considered crucial to streamlining access to support. Out-of-hours access to health records was critical for effective advice. Referral to specialist services was often required to access phone support but did not always occur. Without this, people relied on general out-of-hours support lines (not specific to those with palliative needs) which led to delays and difficulties. Patients sometimes had multiple numbers to call, leading to confusion.

Conclusions: Despite national recommendations, designated phone lines for those with palliative and end-of-life care needs are still not widely available or easily accessible. This means they miss out on timely and equitable access to support. Phone lines vary in how they are delivered but generally having the necessary skills and expertise, and access to health records were considered essential. Further research is needed to determine which models are efficacious.

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P 12.010 Trust, Collaboration and the Role of the Advanced Practice Nurse (APN) in Gynaecological Cancer Treatment (TANGO Study)

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Background/aims: The collaboration of providers across different departments represents a major challenge in cancer care. Trust in

interprofessional and -organizational collaboration from the patient's perspective has hardly been studied so far, neither has the role of an advanced practice nurse in gynecological oncology (APN GO) can play in this context.

The study examines trust, interprofessional and -organizational collaboration and the role of the APN GO in the treatment path of women with gynecological cancer.

Methods: The study follows a convergent mixed-methods design. We have been collecting data through repeated qualitative interviews and structured questionnaires with patients as well as digital patient diaries. We used the phenomenological approach according to van Manen for qualitative data analysis. Quantitative data is analyzed using descriptive statistics. We will synthesize the data using joint display tables. Data collection will be completed by the beginning of 2023.

Results: 12 patients with breast cancer were recruited in two Swiss hospitals. We have conducted 40 interviews so far. We found that the APN was particularly involved during chemotherapy as well as before and after a surgical procedure. The continuity of support from health professionals was particularly important to build trust, in addition to influencing factors, such as competence as well as respectful and honest interaction.

Conclusions: By building a relationship in preceding phases of the cancer care continuum, trust can already be established among patients and professionals before palliative care is considered for some patients. The APN was primarily involved during the acute treatment phase, where a relationship of trust was established. We see great potential for this trusting relationship and the APN to continuously support patients, especially during follow-up and palliative care.

This study is funded by the Swiss Cancer Research Foundation.

P 12.011 Rapid Response Service Models in End of Life Care: What Works, for Whom and in Which Circumstances?

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Background/aims: Research has identified a lack of out of hours and community services to support people who are at the end of their lives. Rapid Response Services (RRS), facilitate the patient's choice to die at home; aiming to cut the risk of unplanned hospital admissions and minimise delayed discharges. Yet, there is little evidence about how RRS enhance end of life experiences and outcomes for patients and families, or their economic impact. This presentation draws on an on-going realist economic evaluation of two RRS in England. It will present early findings of how, who, and why RRS work in community end of life care, including the associated economic costs and benefits.

Methods: Realist evaluation is a theory-driven approach which seeks to understand not only whether an intervention works, but what it is about it that works, for whom, in what circumstances, and why. It acknowledges that services (known as 'programmes') take place within complex social systems. Through 3 phases of research, early suppositions were drawn from intensive literature reviewing and information gathering with stakeholders, these were then rigorously tested and revised through iterative data collection and analysis. Semi-structured interviews were undertaken with RRS staff, external Health and Social Care Professionals, carers and patients (n= 'up to' 55), together with data to assess the costs and benefits of the different service models.

Results: With data collection and analysis due to complete Dec-Jan 2023, preliminary findings demonstrate the impact and influence of communication, service values, diagnosis/prognosis, 'being known', staff competencies, and service hours, for access, engagement, and experience. The final quantitative and qualitative data will be combined and

presented as detailed programme theories of what works, for who, how, and why.

Conclusions: Final programme theories, with examples of supportive data will be shared, alongside recommendations and implications for service design and delivery.

P 12.012 Social Services and Palliative Care Providers: Living Labs as Inspiring Examples in The Netherlands

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Background/aims: End of Life (EoL) care aims at multidimensional care and support to improve quality of life of patients and their families. Often EoL care is dominated by medical and homecare professionals, while the needs of patients and family members can also be met by professionals and volunteers from social services, experts in the field of social, emotional and psychosocial support. Patients and their families often face difficulties with work, income, housing, relationships or other social and psychological problems. Local 'Living labs' bring together relevant organizations, including local government, and facilitate cooperation between professionals and volunteers from healthcare organizations, social services, and wider support services.

Methods: Representatives of local organizations are invited to join a living lab. Together they decide what to achieve in one year. Participants build trust and learn to draw on each other's knowledge and competences by discussing cases, problems and solutions. They design small-scale experiments to develop a sustainable cooperation aimed at meeting the needs of individual patients and their families.

Living labs are supported and facilitated, a method for monitoring is designed, and results and lessons learned from local living labs are disseminated on a national level to inspire others to start cooperation across the domains of palliative care and public health.

Results: On three locations living labs were established. Participants state already after one or two sessions that they benefit from meeting other professionals. GP *"As a medical professional I discovered another point of view: social workers find solutions to help patients to stay at home, for example with help from their social network in the community. This prevents a lot of problems and makes my work as a GP less complicated."*

Conclusions: Results show that bringing together local policymakers, professionals and volunteers in health and social care benefits an integrated approach in early EoL care.

P 12.013 Developing a Palliative Care Nurse Led Service, in Collaboration with an External Specialist Consultant Supportive Service, within an Acute University Hospital

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Background/aims: In the interim to appointing a Consultant within the Palliative Care Team at an acute university hospital the decision was made to become a Nurse Led Service. This was enabled by the collaboration with an external specialist consultant service, which provides virtual Consultant support for the Clinical Nurse Specialists. The hybrid model incorporates twice weekly board rounds which are utilised to discuss and advise on patient care, with access to advice calls as required in between. The aim of the study was to evaluate the effectiveness of the Collaborative Nurse Led Service for patients and their families.

Methods: These include case studies/patient stories and patient satisfaction questionnaires.

Results: During the 6 months since the Nurse Led Model has commenced there were 451 patient reviews, 13 of which required advice in addition to that obtained during the allocated board rounds. Patient feedback was very positive as demonstrated within a case study of a patient, referred for complex symptom management and a rapidly deteriorating condition. Team working between the Clinical Nurse Specialists and supporting Consultants resulted in effective symptom management and psychological support for both patient and family, preventing inappropriate transfers to the critical care centre and ultimately facilitating their preferred place of care/ death. The patient and family felt supported and cared for in the last weeks of life which is evidenced in written and verbal feedback.

Conclusions: Although there are some limitations noted, the collaboration with the external consultant support has ensured service provision continues and care remains of a high standard, positively affecting patients, families and the staff caring for them.

P 12.014 Exposing and Understanding the Hidden Work of Getting Prescription Medications Right at Home, in Hospital & Hospice: An Activity Theory Analysis to Improve Patient Safety and Carer Confidence

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Background/aims: The practical work of palliative medications is poorly understood. Much is overlooked in system design and official policies. This study maps work activities of decision-making/prescribing, monitoring/supply, administration, deprescribing/disposal and transitions between care locations.

Aims:

1. Create a practice-based multivoiced model of activities required to get palliative medications right at home, in hospital & hospice.
2. Use the model to identify how to reduce workarounds (mitigating system problems) and improve safety and confidence.

Methods: Following ethical approval and scoping existing literature, observations (120hrs) and interviews (n=70: purposively selected patients, carers, professionals) were conducted in home/community, hospital & hospice settings in London. Activity Theory provided a sensitising framework for a reflexive thematic analysis of detailed fieldnotes and verbatim audio-transcriptions. All forms of work/activity (what happens, who does what, how, when and where) were critically considered.

Results: Getting palliative medications right requires loops and spirals of activities. 'Add-on' system fixes overlook differences between intended/experienced work in uncertain, changing situations. Activities are disrupted by unclear, or contested, distributions of labour across patient/carer and professional roles. Diverse meanings attached to activities, combined with assumptions about how activities should link, compound hidden work. Table 1 summarises patterns of work needing attention to improve safety and confidence.

Table 1: Data-derived themes	Patterns of work
<i>Identity and flexing</i>	Medication management depends on perceived freedom to undertake 'how to get things done around here' work
<i>Sustained investigative work</i>	Patients, carers and professionals are engaged in continuous cycles of chasing and checking activity
<i>Disempowerment by design</i>	Unnecessarily complex rules, regimes, and unclear or contested responsibilities
<i>Transition inadequacy</i>	Hindrances in boundary-crossing, 'assumptions about assumptions' in asynchronous rather than dialogic communication.

Conclusions: Our model reveals hot (debated) and cold (overlooked) activities. Understanding these is essential to design meaningful reductions in the burdens of hidden work for patients/carers and professionals.

P 12.015 Patients' Experiences Using Patient Reported Outcome Measures in Basic Palliative Care

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Background/aims: The need for improvement of basic palliative care for people suffering other life-threatening diseases than cancer has gained considerable focus in Denmark. Patient Reported Outcome Measures (PROM) may be used to identify patients' palliative care needs. A new PROM EORTC QLQ-C15-PAL combined with new items related to lung, heart, and kidney diseases, family, spirituality, intimacy etc. was developed by The Danish Health Data Authority.

Aim: To evaluate patients' experiences with the new PROM in basic palliative care among people with life-threatening cancer, lung, heart, and kidney diseases.

Methods: A feasibility study was conducted at 12 hospitals and municipalities Sept. 2021-Oct. 2022. Patients completing the PROM during usual care were asked to complete an evaluation survey, and a purposeful sub-sample were invited to semi-structured interviews. Survey data are analysed descriptively and recorded interviews are thematically analysed within three topics: 1) experiences of completing the PROM 2) relevance of PROM content 3) PROM as a dialogue support tool.

Results: Data from approx. 270 evaluation surveys and 17 interviews are currently being analysed. Preliminary analyses indicate that approx. 84% found the PROM easy to complete, 88% found the items relevant, and 74% answered that completing the PROM was useful in preparation for dialogue with healthcare professionals. Interview findings suggest that the patients attached great value to the new questions about family, spirituality and intimacy. However, data also indicate that if the PROM was not used in the dialogue, patients experienced it as a burden.

Conclusions: The study suggests that a majority of patients find the new PROM beneficial, and that supplementing the EORTC QLQ-C15-PAL with items regarding family, spirituality and intimacy add important value. However, the perceived value of PROM seems strongly linked to active use of the responses in a dialogue with the healthcare professionals.

P 12.016 Professionals' Experiences Using Patient Reported Outcome Measures in Basic Palliative Care

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Background/aims: The need for improvement of basic palliative care for people with cancer and other life-threatening diseases has gained considerable focus in Denmark. One accentuated solution is Patient Reported Outcome Measures (PROM). A new PROM (based on EORTC-QLQ-C15-PAL added new questions related to lung, heart and kidney diseases, the family, spirituality, intimacy etc.) has been developed by The Danish Health Data Authority.

Aim: From a professional perspective to evaluate the new PROM in basic palliative care for people with life-threatening cancer, lung, heart and kidney diseases.

Methods: A PROM-feasibility study was conducted at 12 hospitals and municipalities from Sept. 2021-Oct. 2022. After each consultation where PROM was filled out by a patient an evaluation survey was completed by the healthcare professionals according to experiences of relevance and value. To explore in more depth group interviews were conducted with professionals in each site. Analyses are in progress: Quantitative data will be analyzed descriptively, and qualitative data will be analyzed thematically into three preliminary themes: 1) a screening tool for palliative care needs 2) a dialogue support tool 3) relevance for initiation of palliative care services.

Results: Data encompass approx. 280 evaluation surveys and 10 audio-recorded group interviews with a total of 36 healthcare professionals. Preliminary analyses indicate that 46% found new needs of the patients, 61% experienced that PROM improved the quality of the dialogue, and 52% initiated services based on the patient's responses. Interview findings suggest that PROM contributed to a more holistic understanding of the patient's current situation. However, some patients with psychological or physical problems were challenged by the PROM.

Conclusions: The preliminary conclusion is that PROM is useful for the group it has been tested. However, PROM seem to be more suitable for some patients than others.

P 12.017 The Needs of Health Personnel Providing Home-based Pediatric Palliative Care: A Systematic Mixed Method Review

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Background/aims: Home-based pediatric palliative care provided by health personnel is often warranted among families. However, little is known about the needs of health personnel to deliver high-quality pediatric palliative care.

To characterize the needs of health personnel providing home-based pediatric palliative care using a systematic mixed-method review.

Methods: The Joanna Briggs Institute methodology for mixed methods systematic review was used and the review is registered in PROSPERO (CRD42021292865). Quantitative and qualitative studies from 2012-2021 reporting on health personnel's needs, experiences, perspectives, coping strategies, and/or challenges of home-based pediatric palliative care were eligible for review. Databases included Medline, Embase, PsycInfo, CINAHL, Web of Science, AMED, and Cochrane Library. The screening was conducted independently in pairs. Quantitative data were transformed into qualitative data and analyzed using thematic synthesis.

Results: Overall, 7559 citations were identified with 17 studies eligible for review. Preliminary findings indicate that health personnel strives to ensure high-quality home-based pediatric palliative care and that their

needs reflect this care goal. Health personnel describes a need to establish early and functioning relationships with children and their families. Health personnel emphasizes the need to be part of a well-organized and coordinated team, which requires leadership to establish a home-based service defined by standardized protocols. The need for ongoing development of expertise and training according to pediatric palliative care is required by all health personnel. The analysis is ongoing per October 2022.

Conclusions: This study provides qualitative findings of home-based palliative care from the perspective of health personnel. It can serve health personnel, executives, and policymakers to better understand and improve home-based pediatric palliative care.

P 12.018 Specialist Palliative Care at the Front Door

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Background/aims: At a time of significant pressure within the NHS, patients with palliative care needs often present to the emergency department in crisis. This makes the ED an important site for specialist palliative care assessment. It is widely recognised that 40 million people a year globally will require palliative care and this need is only expanding. Despite this fast-paced environment caring for those patients nearing the end of their life or have unmet symptom needs can be complex and at times difficult to manage.

Methods: From March 2022 a designated clinical nurse specialist (CNS) from the specialist palliative care team funded by the local CCG worked alongside ED physicians and managers to provide a 5-day a week service, working proactively within ED. The CNS would complete holistic specialist palliative care assessments whilst also providing education throughout the department. Data collected included number of referrals, patient demographics, reason for admission, palliative care diagnosis, time of referral to palliative care, time of palliative care assessment, outcome and length of time spent in ED. Data collected was compared to data from previous year which only included number of referrals.

Results: Prior to this new service specialist palliative care were assessing 11 patients per month in ED. Since this service was implemented 50 patients are being. With this service we have assessed 330 patients in ED. From the data that has been collated there was an even split in gender, 90% of these patients had a pre-existing palliative diagnosis. 100% of all patients referred were assessed on the same day. 31% of patients are assessed in Resus and 54% are assessed in Stretcher Triage signifying those patients are seen on or soon after arrival to ED.

Conclusions: Targeted palliative care input within ED can support patients with symptom control and aim to achieve their preferred place of care. This service is currently a pilot scheme and the aim is to present a business case to the trust.

P 12.019 Review of Perinatal Palliative Care Referrals to a Children's Hospice over an 8-year Period

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Background/aims: Review of perinatal referral to our children's hospice service over an 8-year period and professional survey of Neonatal Intensive Care Unit leads.

Methods: The Hospice catchment area houses six neonatal units; 2 of these provide regional neonatal intensive care (NICUs) at levels 3 and 4. The regional foetal medicine unit (FMU) also resides within this area. Perinatal referrals were reviewed.

Results: Over 8 years, 79 perinatal referrals were made from the NICU and cardiac units: 24 antenatally, 33 at 0-28 days and 22 between 1 and 3 months. Of those who died, 8 died in utero, 4 in the first 24 hours, 32

at 2-28 days and 4 at 60-90 days. 33% referred antenatally died in utero, 42% died in NICU, 17% died in the community and 8% in hospital. Of those referred from NICUs, 43% died on the unit, 53% in the community, and 1 en route. 2 of 4 referred by cardiac units died in NICU. Antenatal referrals were largely made up of chromosomal (54%), cardiac (20%) and structural anomalies (13%). Neonatal referrals were largely hypoxic ischaemic encephalopathies (37%), chromosomal anomalies (27%) and chronic lung disease (18%). The hospice-based specialist paediatric palliative care team supported compassionate extubations: 13 at the hospice, 2 at home, 9 on local units, and 3 died prior to transfer. Timing of many referrals did not allow meaningful hospice-based support.

Conclusions: Referrals are proportionally low; work is needed to provide more in-reaching to support and facilitate death in out-of-hospital settings. Neonatal referrals facilitated more deaths in the community compared to antenatal referrals. A significant proportion of this population died within the first 2 weeks of life with tight referral-to-death timeframes.

Attending FMU meetings and neonatal ward rounds may improve referral rates and referral-to-death timeframes. Unit in-reaching can support NICU staff with complex cases, education, memory-making, symptom management and staff-family relationship-building.

P 12.020 Palliative Care Phases in Specialist Palliative Care - Cross-sectional Analysis of Patient Episodes in Three Settings (Palliative Care Unit, Hospital Advisory Team, Specialist Palliative Home Care)

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Background/aims: Palliative care phases (stable, unstable, deteriorating, terminal, bereavement) are useful to assess the palliative care situation of patients/relatives and to evaluate the effectiveness of care plans. Little is known about the phases and their association with symptom/problem burden and functional status in German specialist palliative care (SPC). The aim is to describe the association of symptom/problem burden and functional status with palliative care phase on admission in German SPC.

Methods: Prospective, cross-sectional, multi-centre study collecting data on symptom/problem burden and functional status. Univariate analysis across 3 settings using palliative care phase, burden of symptoms/problems measured by Integrated Palliative Outcome Scale (IPOS) and functional status by Australian Karnofsky Performance Status (AKPS). A symptom/problem was defined as prevalent if assessed at least as moderate. Complete-case analysis with descriptive statistics and non-parametric tests.

Results: 3115 phases (29% stable, 33% unstable, 31% deteriorating, 7% terminal) from 3 SPC settings were included, average age 72 years (range 19-104), 51% female. Median of each IPOS-item differed significantly by phase. Median of most IPOS items accounting for physical symptoms were highest in terminal phase, except *pain*, which was highest in unstable phase. Such a clear effect was not observed for IPOS items related to psychosocial needs. Prevalence of IPOS items *weakness* (48%-78%), *poor mobility* (45%-77%) and *concerns of family* (48%-67%) were high in all phases. AKPS differed significantly by palliative care phase (df 3, p<0.000). Post-hoc pairwise comparison showed large effects between dying and stable (r=0.7), unstable (r=0.5), and deteriorating phases (r=0.5).

Conclusions: We provide first insights into the interrelationships between phase, symptom/problem burden, and functional status in German SPC. Unstable and terminal phases seem to be characterized by particularly high burden. G-BA Innovation Fund, no. 01VSF18018

P 12.021 Rurality and Specialist Palliative Care Timing Prior to Death in Central Nervous System Cancer Patients

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Background/aims: Evaluate the association of rurality with timing of access to palliative care (PC) in central nervous system (CNS) cancer patients.

Methods: This retrospective cohort study using administrative data identified 470 adults deceased from CNS cancer between 2007 and 2015, residing in either the rural or urban Calgary Zone (CZ) of Alberta Health Services (AHS) in Calgary, Alberta. All PC services were examined those based in hospital (PC consult teams, tertiary PC unit), and community (palliative home care (HC), pain and symptom clinics, hospices). Binary logistic regression analyzed the relationships of rurality (rural and urban) and timing of exposure to PC prior to death (early [≥ 90 days] and late [< 90 days]), adjusting for covariates. The adjusted analysis considered PC received in hospital, PC received in community, sex, age at death, disease duration, year of death, Charlson Comorbidity Index, median household income, long-term care admission, generalist HC utilization, family doctor visits 90-365 days before death (none, low [1-3], medium (4-7), high [≥ 8]), and hospital days 0-90 days before death (none, low [1-14], high [≥ 15]), and 90-365 days before death (none, low [1-14], high [≥ 15]).

Results: Compared to patients residing in the urban CZ, rural CZ patients were not statistically more likely to receive late PC prior to death (odds ratio (OR) 1.41; 95%CI 0.68 to 2.95). However, in the 90-365 days before death, those with high (≥ 15) total days admitted to hospital had decreased odds of receiving late PC prior to death compared to those with zero days in hospital in the last 90-365 days of life (OR 0.04; 95%CI 0.02 to 0.10).

Conclusions: Rurality was not associated with PC timing for patients living with advanced CNS cancer. This is different from what is commonly seen where PC timing tends to be late for patients living in rural areas. CNS cancers are more chronic and less treatment options which might lead to earlier recognition of need for PC supports.

P 12.022 Venous Thromboprophylaxis Discontinuation in Palliative Care – What Role Could the Australia-modified Karnofsky Performance Scale Play?

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Background/aims: Palliative care inpatients represent a heterogeneous group with variable risk factors for venous thromboembolic events. NICE Guidelines advise considering pharmacological VTE prophylaxis and reviewing daily. AKPS scores monitor patient performance daily. Terminal-phase patients have an AKPS of 10. Guidelines contra-indicate VTE prophylaxis in final days of life.

Methods: We conducted a single-centre cross-sectional retrospective chart review of drug charts, VTE assessment forms and PCOC-AKPS charts of patients admitted to a specialised Palliative Care Unit over a 2-month period. We audited VTE prophylaxis prescription and trends in AKPS prior to prophylaxis discontinuation.

Results: 46% had completed VTE thromboprophylaxis risk-assessment forms (n=61). 25% without completed assessment forms were already therapeutically anticoagulated. 96% had underlying malignancy and 30% previous DVT/PE. 36% had a weight recorded.

Venous thromboprophylaxis was commenced in 30% of patients (AKPS \bar{x} =50). 9% declined thromboprophylaxis. 5 patients were not prescribed prophylaxis despite indication (AKPS \bar{x} =60).

Inpatients with an AKPS > 30 were statistically significantly likelier to be on continued form of anticoagulation compared to those with AKPS ≤ 30 (52% versus 18%, $P=0.0016$). Mean AKPS score of anti-coagulation/thromboprophylaxis discontinuation was 30.

Conclusions: There is requirement to improve completion rates of VTE assessment forms. Weight stickers on drug-charts could improve weight recording/correct dosage prescription.

Our audit suggests correlation between lower AKPS scores and anticoagulation/thromboprophylaxis cessation. This suggests a role for considering trends in AKPS scores when reviewing anti-coagulation/thromboprophylaxis requirements. Whilst discontinuing anticoagulation is a multi-factorial decision and there being other pertinent indicators e.g. thrombocytopenia/patient-decision, our research suggests AKPS scores could be a useful adjunct-indicator in this joint patient-physician decision.

P 12.023 The Evaluation of the Methodological Quality of Clinical Practice Guidelines on Palliative Care for Cancer Patients in Japan

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Background/aims: Recently, many societies are actively developing clinical practice guidelines (CPGs) in Japan. However, some variation exists in the process of developing CPGs as well as the quality of product. The Japan Council for Quality Health Care (JQ) manages CPGs in Japan. JQ evaluated the quality of 519 CPGs (87 for cancer, 432 for non-cancer) published from 2011 to 2017 using AGREE II (Advancing guideline development, reporting and evaluation in healthcare II). As a result, the quality of cancer-related CPGs was higher than that of non-cancer CPGs. According to the evaluation of the domain3 (Rigor of Development) of AGREE II, 10 CPGs had a score ≥ 80 points among 87 cancer-related CPGs and five of them were CPGs on palliative care published by the Japanese Society for Palliative Medicine (JSPM). JSPM initiated to develop CPGs in 2002 and currently develop 7 CPGs based on GRADE and revise every 3-5 years.

This study aimed to analyze the development process of JSPM-CPGs based on JQ evaluation and to consider further improvement of the process.

Methods: We compared the scores of 1)-7) of AGREE II for 4 CPGs (cancer pain, respiratory, digestive and urological symptoms) with the scores of cancer-related CPGs by JQ. Then, we performed a self-assessment for each item in domain 3 referring the development process in each CPG and then extracted the items that required improvement.

Results: The scores of each domain (1-7) in CPGs published by JSPM were higher than the mean score of cancer-related CPGs, but the difference was small in domain5 (53-61 vs 48). In domain3, items 7-9,11,14 had higher scores and items 10,12,13 had lower scores.

Conclusions: We confirmed the high quality of each CPG developed by JSPM based on GRADE. Involving patients/families in the process of scope and clinical question formulation will improve the quality of the applicability. It is expected that improving the quality of the items extracted in domain3 and domain5 will make the quality of CPGs on palliative care published by JSPM higher.

P 12.024 Care Plus-integrating Early Palliative Care with Multiple Myeloma

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Background/aims: Background: Patients with haematological malignancy frequently do not access palliative care (PC), moreover, for those who do, access is frequently late in the illness.

Aims: To understand the implementation of early PC integration for people with multiple myeloma (MM) across four cancer treatment centres in Australia.

Methods: Multi-site stepped wedge implementation trial testing usual care (control) versus Care Plus (early PC integration as practice change) following the Consolidated Framework of Implementation Research. Care Plus (early PC) was introduced at a standardised point(s) in the illness, either at the time of diagnosis or the time of first relapse of multiple myeloma. Qualitative interviews with health professionals, patients, and families were conducted to explore the implementation processes of Planning, Engagement, Practice Change, and Evaluation across hospital sites. Interview transcripts were thematically analysed by making codes and categories with emerging themes. Consolidated criteria for Reporting Qualitative research (COREQ) guidelines were used to maintain rigour.

Results: Nineteen semi-structured interviews via zoom with haematologists (n=4), PC physicians (n=8), clinical nurses (n=3) and patients (n=4). Patients and clinicians reported satisfaction with the implementation of Care Plus. Major themes included (1) the benefits of standardised points for referral to early PC, (2) the development of strategies for introducing early PC to patients and carers; (3) enhanced collaborative practice between haematology and PC teams; and (4) the time and value of exploring goals and planning for the future available with early PC including asymptomatic patients.

Conclusions: Care Plus facilitated enhanced access to PC for patients with multiple myeloma including at the time of diagnosis. For haematology clinicians, this Care Plus model appeared to provide an opportunity to 're-imagine' how PC may be delivered and the role it plays in patient care.

P 12.025 Consensus on Characteristics of Timely Integration of Palliative Care into Standard Oncology Hospital Care for People with Advanced Cancer: A Delphi Study

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Background/aims: Integrating palliative care (PC) into standard oncology care for patients with advanced cancer improves quality of life and reduces symptom burden. Recommendations for integrating PC in oncology care exist, yet daily clinical practice shows a variety of best practices. This study aims to assess the level of consensus among oncology- and PC specialists and patient-relative representatives on characteristics of timely integration of PC in hospital settings.

Methods: A three round modified Delphi study was conducted. The expert panel consisted of 83 hospital healthcare professionals (43 doctors, 40 nurses), 6 patient- and 2 relative representatives. The first round regarded four elements of integrated PC: (1) identifying PC needs (2) advance care planning (ACP) (3) routine symptom monitoring (4) the

palliative care consultation team (PCCT). Experts were asked how they embed these elements in daily clinical practice: for which patient groups, at which moment in the disease trajectory and who is responsible for introducing an element. In subsequent rounds, experts assessed which of these characteristics should be thresholds for introducing an element. Consensus was set a priori at $\geq 70\%$.

Results: The response rate ranged from 78% (first round) to 59% (third round). Experts agreed that in all patients with advanced cancer: PC needs should be assessed (97%), ACP should be introduced (86%) and symptoms monitored (82%). The PCCT should be involved at patients' request (86%) or when patients suffer from multidimensional symptoms (76%). Patients having a life expectancy of < 3 months should be informed about the PCCT (74%) and offered a consultation (71%).

Conclusions: Experts agreed that patient characteristics or moments in the disease trajectory should be triggers for introducing one or more elements of PC. This study provides starting points for the further implementation of timely integration of PC for patients with advanced cancer.

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P 12.026 PalMaGiC – A Lifeline for Patients with Incurable Gastrointestinal Cancer. Evaluation of a Palliative Case-management Intervention in a General Hospital Department

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Background/aims: Generalist palliative care in hospital departments lack overall organization to fully manage the symptom burden and support needs of patients with incurable gastrointestinal cancer. Palliative case management-interventions show promising results in reducing healthcare utilization and enhancing quality of life. Less is known about these interventions and their potential to improve the quality of generalist palliative care in hospital departments.

Aim: To explore patients' experience of a palliative case management-intervention in a general hospital department (PalMaGiC) to obtain knowledge of advantages and disadvantages and ultimately adjust the intervention if needed.

Methods: Design: A Qualitative explorative study.

Data collection: Interviews of 14 patients with incurable gastrointestinal cancers of the esophagus, pancreas, colon, or rectum were performed. Patients' were affiliated with PalMaGiC, an intervention established in a gastroenterology department and based on symptom assessment, care-planning, care-coordination, and need-based follow-up. Data were analyzed by content analysis.

Results: The PalMaGiC-Intervention was perceived an asset when living with incurable gastrointestinal cancer by delivering a need-based approach and altering focus from disease to quality of life. Participants described the intervention as filling in a gap and being a lifeline in the healthcare system by providing 24/7 safety, a consistent specialist-nurse, and a patient-healthcare alliance. Participants requested additional open dialog within complementary and alternative medicine, attention to the promotion of hope and a different use of health-related quality of life-questionnaires in connection with assessment of symptoms and problems.

Conclusions: The PalMaGiC-intervention has the potential to meet the needs of patients requiring palliative care in general hospital departments, but there is a need to further develop the content and personalized approach.

P 12.027 Spatial Accessibility of Palliative and Hospice Care in Germany

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Background/aims: Spatial accessibility is an important factor for service use and health care justice. In a palliative care situation, accessibility for relatives to spend time with the patient is especially important.

Aim: To assess spatial accessibility of hospices, palliative care units (PCUs) and specialist palliative home care teams (SPHCTs) for adult patients in Germany.

Methods: Institutions were first identified via a national database, data was complemented with lists from state associations, if available. Geocoded locations were used to identify accessibility regarding distance, travel time by car, and travel time weighted with population. Service areas were calculated with network analyst tool in ArcGis Pro.

Results: 384 PCUs, 295 hospices and 466 SPHCTs were identified. All types of services had high accessibility, especially when time to service was population weighted. 65.1% of the population can reach a PCU in 15 minutes or less, 94.3% in 30 minutes or less. Less than 1% needs more than 45 minutes. Hospices were accessible in less than 30 minutes by 91.5% of the population (61.1% less than 15 minutes, <1% more than 45 minutes). SPHCTs can reach 93.3% of the population in less than 30 minutes (58.4% less than 15 minutes, <1% more than 45 minutes). Accessibility is lower when distance is used as indicator (e.g. PCUs are more than 45 km away from 7.4% of the area, hospices for 11.4%, SPHCT for 5.3%). Accessibility differed between federal states, and some regions services appear to be less accessible.

Conclusions: Overall, palliative and hospice care institutions are easily accessible, ensuring service provision close to the place of residence. With rising prices for fuel, distance may become more important for accessibility, especially in rural areas. While our results can't indicate underprovision of services, areas with low accessibility should be monitored. Further, we will apply a gravity model including socio economic factors.

P 12.028 Identifying Different Patterns of Community Episodes of Palliative Care: A Secondary Analysis of Routinely-collected Phase of Illness and IPOS Data

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Background/aims: Palliative Phase of Illness (Phase) is a measure based on the urgency and degree of palliative care needs. This study aims to identify the impact of community palliative care over episodes of care and whether there are different patterns of community palliative care episodes, according to the end Phase.

Methods: Secondary analysis of routine clinical and outcomes data collected from all patients cared for by one large urban community specialist palliative care service in the UK between April 2020 – March 2022. Variables included: patient demographics, episodes of care details,

Phase, and symptoms/concerns using the Integrated Palliative care Outcome Scale (IPOS). We compared community patients based on their Phase at episode end and the impact of community palliative care over episodes of care.

Results: 2,546 patients received 3,319 episodes of community-based palliative care. 1,752 episodes ended with a stable Phase of Illness (Stable group), and 1,567 episodes ended with unstable or deteriorating Phase (Unstable/Deteriorating group). In the Stable group, median age was 81 years; 59% female; 41% had cancer. In the Unstable/Deteriorating group, median age was 72 years; 48% female; 79% had cancer. In the Stable group, mean 'pain' score reduced from 1.1 to 0.5 by episode end; mean 'breathlessness' score reduced from 1.0 to 0.5; mean 'anxiety' score reduced from 1.1 to 0.7; and mean 'feeling depressed' score reduced from 0.9 to 0.5. In the Unstable/Deteriorating group, mean 'pain' score increased from 1.5 to 1.7 by episode end; mean 'breathlessness' score increased from 1.0 to 1.1; mean 'anxiety' score increased from 1.5 to 1.6; and mean 'feeling depressed' score increased from 1.2 to 1.3.

Conclusions: This analysis demonstrates different patterns of change in Phase of Illness, symptoms and other concerns, in community palliative care episodes, according to age, sex and diagnosis. More detailed analysis of this data to understand predictors of Phase at end of episode is ongoing.

Conflict of interest: Funding: Supported by Yorkshire Cancer Research (L412)

P 12.029 Experience of Declarants Who Designate Health Care Agents in Advance Decision at a Taiwanese Medical Center

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Background/aims: Taiwan's Patient Right to Autonomy Act has been in effect as of January 2019. Individuals with full capacity can sign an Advance Decision (AD) after completing consultation for Advance Care Planning (ACP). Declarants can assert their decisions about life-sustaining treatment (LST) and artificial nutrition and hydration (ANH) (no acceptance/time-limited acceptance/by Health Care Agents' decision/acceptance) under five specific clinical conditions, and choose to designate an HCA. From 2019 to 2021, Taipei Veterans General Hospital ACP Team assisted 2,020 declarants in completing ADs and found HCAs are rare. Thus, this study further investigated declarants' thinking in designating an HCA.

Methods: Retrospective analysis of aggregated data on declarants who designated HCA (n=69). Descriptive analysis, Chi-square and Cochran's Q tests were conducted.

Results: The average declarant was 55±19.1 years old, 62.3% were female; 85.5% of declarants had at least one relative within the second degree by consanguinity or affinity present while ACP. Overall, medical decisions do not differ by the type of medical measures. Except for the terminally ill condition, the number of declarants choosing no acceptance was significantly higher than other medical options for all clinical conditions. Post-hoc examination revealed that under the terminally ill condition: (1) the number of declarants choosing no acceptance is significantly lower than for other clinical conditions; (2) the number of declarants choosing time-limited acceptance was significantly higher than the number who chose it in the third, fourth, and fifth clinical conditions.

Conclusions: For declarants with an HCA, clinical condition is essential for their medical decision-making, and the terminally ill condition has a distinct association with their decisions. Many of those who designate an HCA had an apparent medical decision. The ACP consultation team should proactively provide the practical details of the clinical conditions and HCA for declarants.

P 12.030 What Impact Does the Implementation of the AMBER Care Bundle Have in a Regional Cancer Centre?

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Background/aims: The AMBER Care Bundle (ACB) is a tool to enhance communication and support for patients with uncertain recovery. It facilitates early discussions with patients and those important to them about what their preferences may be if their condition does not improve. Little is known about its utility in a tertiary cancer setting.

Aim: To audit the effectiveness of the ACB and support its implementation at a tertiary cancer centre

Methods: The ACB was launched in May 2021 supported by a war based education programme. Prospective audit was undertaken from October 21 to April 22 measuring recognition and communication of uncertain recovery in acutely unwell patients. The presence of treatment escalation plans was also recorded. These data were compared to retrospective data from 2015 and 2020.

Results: 40 patients with acute deterioration were audited in the 6 months post launch. 50% were supported by the ACB. In a further 45%, deterioration was recognised with principles of the ACB followed. 100% of patients had an escalation decision documented compared to 47.5% in 2020. 95% of patients in 2022 had a preferred place of care documented compared to 32% in 2020, preferred place of death was also documented in 95% of patients compared to 60% in 2020. 92.5% of patients had discussions about advance care planning documented compared to 0% documented in 2020. Preferred place of care was met in 70% of patients in 2022 compared to 7.5% in 2020. 100% of patients and their families had been involved in discussions about care compared to 62.5% in 2020.

Conclusions: There is a role for the ACB within our centre in guiding discussions when patients deteriorate acutely. Whilst willingness to communicate with patients and families about uncertain recovery is generally good, the presence of the tool has served as a useful prompt in ensuring conversations cover patient and family priorities.

P 12.031 Identifying Enablers and Barriers in the Provision of Community-based Palliative Care Out-of-Hours

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Background/aims: Patients and their families receiving palliative care in the community rely on 'out-of-hours' services over 70% of the time. Although distressing symptoms may persist, and new problems arise, at any time out-of-hours provision varies widely across the UK. This project aims to explore enablers and barriers in the provision of out-of-hours community-based palliative care.

Methods: Semi-structured qualitative interviews with healthcare professionals across the UK providing out-of-hours community palliative care. Reflexive thematic analysis was used to explore enablers and barriers in the provision of out-of-hours care.

Results: 28 interviews were conducted in 20 localities with 39 participants, including: GPs, community nursing teams, and palliative care medical consultants and specialist nurses. Four overarching models of out-of-hours care were identified with variable and inequitable service provision. Variability was based on levels of integration between generalist and specialist palliative care out-of-hours, and the care provided (hands-on care and/or advisory care). Across the models, enablers and barriers were constructed as four themes: 1. coordination of care, including challenges accessing medicines for symptom control. 2. timely

management of distressing symptoms, with services developing responsive teams for care out of hours. 3. plugging the gaps in care, with healthcare staff using innovations to fill these gaps, 4. moral distress for staff struggling with limited resources to provide care that was coordinated, timely and met care needs.

Conclusions: Out-of-hours palliative care in the UK is variable and inequitable. Key to optimal provision is care coordination and integration between generalist and specialist services, and sufficient workforce, expertise, and resources to prevent suffering. Ensuring timely access to medicines out-of-hours is a priority. The findings inform strategic planning by policy makers and service providers for optimal community palliative care.

P 12.032 Does Racism Occur in Palliative Care Settings? A Survey of UK Specialist Palliative Care Services

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Background/aims: Racism is an underlying cause of the causes of ethnic inequality, driving socioeconomic deprivation, poor housing and ultimately poor health and well-being from birth to death. Little is known about whether and how racism is experienced within specialist palliative care services.

Methods: An online survey was designed and disseminated by the Association of Palliative Medicine Race Equity Committee with national peer review and ethics committee review.

Results: As of 12/10/22, there are 769 responses (closing date:31/10/2022) from individuals working across a range of roles and service types. 66% of respondents selected they were White British (dominant ethnicity).

42% of all respondents had experienced or witnessed racism in their palliative care role—19% had personally experienced racism. Racism witnessed towards patients/visitors was mostly from other staff members. For over half of the respondents who had experienced/witnessed racism, these incidents had occurred within the last year. 44% did not report the racist incidents and the reason for over half of these was because they did not feel comfortable doing so or did not think it would be acted on.

58% of all respondents thought their organisation/team provided equitable access, quality of care and outcomes for people from minority ethnic backgrounds. 45% felt their organisation/team represented the diversity of the community it served, but only 35% felt the senior leaders were representative. 49% thought minority ethnic staff were equally likely to be appointed to senior positions—but this differed according to respondent ethnicity. Qualitative findings expose the different forms and degrees of racism experienced.

Conclusions: This survey, the first of its type, found evidence of interpersonal and structural racial prejudice and discrimination in UK palliative care settings. Palliative care services cannot see themselves as exceptions to contributing to racism in structurally racist societies. Work to address this must be prioritised.

P 12.033 An Analysis of Weekend Telephone Support of Palliative Care Team at National Oncological Center

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Background/aims: Institute of Oncology, main cancer center in the country, provides specialised palliative care unit for palliative oncological

patients, involving hospital care, outpatient clinic, mobile palliative care unit and telephone support. For better consultation accessibility for patients, caregivers and medical staff in last year we broaden phone support from 8 hours during week days to 24 hours 7 days per week.

Aim: To analyse the use of extended phone service among patients, relatives and medical staff.

Methods: We analysed the data of phone calls during weekends and public holidays in one year period, from September 2021 to the end of August 2022. As one phone call we considered all phone calls per patient in that day. We observed the main reason for calling, who was the caller and what were the taken measures.

Results: In observed period there were 372 phone calls during weekends and public holidays, on average 3.3 calls per day (range 0 to 10). The most common reasons for calling were pain (17%), followed by administrative questions (14%), decline of patient general condition (12%), report about patient death (10%), dyspnea (8%), nausea and vomiting (5%), constipation (3%), anxiety (3%), confusion (2%), bleeding (2%) and epileptic seizure (1%). In 18% there were miscellaneous reasons for calling, in 5% we have no data. In 78% called the caregiver, in 11% medical staff and in 9% the patient. In 73% cases we provided advice, in 9% prescription for medication, in 8% we organized admission to palliative care department and in 6% patient was sent to emergency department.

Conclusions: Extension of phone support from weekdays to weekends and public holidays was well accepted by patients and especially by their caregivers providing them sense of security and more confidence in taking care of their beloved ones. By good phone support admission to hospital care and emergency department during weekends and public holidays is infrequent.

P 12.034 Referral Time of Mobile Palliative Care Unit

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Background/aims: Mobile palliative care unit (MPCU) was implemented in our cancer center on top of all specialized palliative care services (SPC) - hospital, outpatient clinic, consultation, phone support - in September 2021. At our hospital we regularly monitor the referral time of SPC, subdivided into three groups: very late (less than 30 days before death), late (31–90 days before death) and early (more than 90 days before death). Throughout the existence of our SPC services we have observed a lengthening of time between referral and death, as well as an increase in the proportion of patients with an early referral to SPC. The aim of the study was to analyze referral times of MPCU activation during its first year of service.

Methods: We gathered general data of observed group from September 2021 to August 2022, most common symptoms at MPCU activation and referral time. Referral time was calculated from the date of the first visit of MPCU and death.

Results: During observed period MPCU performed 574 home visits for 346 patients. At the time of this analysis 294 (85%) were death. At MPCU visits main symptoms were: pain in 55%, fatigue and tiredness in 43%, and dyspnea in 27% cases. 14% patients were evaluated as actively dying. Overall referral time was 35,7 days (range 0 – 365). MPCU was activated more than 90 days before death in 11%, 31–90 days before death in 25% and in 64% less than 30 days before death. 87 (25%) patients were seen by MPCU in last 7 days of life, among them 40 patients in last 3 days.

Conclusions: MPCU referral times are shorter than previous observed referral times in our SPC without MPCU before. We can easily explain the results with the role of the mobile palliative care unit in SPC network in our country. MPCU represents a service that support people at dying at home and main indications for its activation are: difficult patient mobility,

patients in late palliative care with complex and difficult-to-control symptoms and patients in last weeks of life who wish to die at home.

P 12.035 An Early Integrated Palliative Care Support Service for Adult Intensive Care Patients on ECMO and their Families during the COVID-19 Pandemic

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Background/aims: Extracorporeal membrane oxygenation (ECMO), a supportive therapy for severe acute respiratory/cardiac failure, is associated with high morbidity and mortality. COVID-19 added further complexity: young patient cohort, little time to adjust to psychosocial burden of sudden critical illness, uncertainty around treatments/timelines, limited hospital visitation/ communication. An early Specialist Palliative Care (SPC) support service was established for all ECMO patients/families in the Adult Intensive Care Unit (AICU) in a Specialist Heart/ Lung Hospital. This service was closely integrated within the AICU multi-disciplinary team. Our aim was to evaluate the feasibility of delivering this novel service and to assess the impact on families and AICU staff.

Methods: Baseline data were collected through retrospective note review of all ECMO patients over a 3-month period. Prospective data were collected over the initial 4 months of the new SPC service. Descriptive statistics were used to describe the feasibility of the service, defined as the proportion of patients referred to SPC team and time to SPC referral. Anonymous family/AICU staff feedback was collected.

Results: 28 ECMO patients with were included in the prospective evaluation and results compared with baseline data from 24 ECMO patients. Referrals to SPC increased from 30% to 100%. Average time between starting ECMO and SPC referral decreased to 0.8 days (28 days at baseline). Average duration of SPC contact for those who died was 45 days (18 days at baseline). Feedback: 10/10 families and 15/20 AICU staff found service beneficial 'Your regular phone calls throughout the time my son was seriously ill on ECMO were incredibly supportive, reassuring and compassionate'.

Conclusions: Preliminary data suggests early integration of SPC within AICU facilitates effective communication and supports both the intensive care team and families to alleviate distress and burden, including in the context of ECMO withdrawal when there is no chance of recovery.

P 12.036 Implementation Lessons Trialling Palliative Care Interventions in the Intensive Care Unit: Relationships between Determinants, Implementation Strategies and Models of Delivery - A Systematic Review

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Background/aims: In view of high symptom burden and mortality, palliative care is an essential part of intensive care. Heterogeneity amongst intensive care units (ICUs) and how they deliver palliative care has hindered translation of evidence into practice, and evidence on implementation is unclear. Using a logic model as a framework for synthesis, this review aims to identify and synthesise knowledge on how models of

integrating palliative care into the ICU have been implemented and provide critical recommendations for successful future development and implementation of complex interventions in the field.

Methods: Standard systematic review methods, following PRISMA reporting guidelines. Search strategy combined terms related to palliative care, intensive care, and implementation. Components of the Implementation Research Logic Model were used to develop themes for reporting intervention characteristics, determinants, implementation strategies and outcomes, and to synthesise relationships between these components.

Results: Searching in Feb 2022 of MEDLINE, Embase, Cochrane, CINAHL, and PsycINFO identified seventy-six articles: 10 process evaluations and 66 effectiveness studies. Most studies were conducted in the USA. Consolidated Framework for Implementation Research headings organised determinants into themes: intervention characteristics, inner setting, outer setting, characteristics of individuals, and process. Implementation strategies addressing determinants were presented as subthemes using Expert Recommendations for Implementing Change compilation headings, mechanisms of change impacting outcomes highlighted. Intervention domains e.g communication, were presented as a second theme set with Consolidated Framework for Implementation Research heading subthemes.

Conclusions: Common determinants and strategies have been found in studies targeting palliative care in the ICU. Individual ICUs can use these lessons and strategies when assessing their own needs and developing tailored interventions addressing them.

P 12.037 Face Validity of Case-mix Classes in a Community Palliative Care Setting: A Cross-sectional Study

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Background/aims: Case-mix classes have been developed to represent the level of complexity and costs for episodes of community palliative care, to better characterise palliative populations, plan/distribute resources, and adjust for outcomes. Our aim is to assess face validity of these case-mix classes in a large population receiving community palliative care.

Methods: Secondary analysis of clinical and outcomes data routinely collected from all community-based patients cared for by one hospice between April 2020 – March 2022. Community case-mix classes are based on: palliative Phase of Illness, functional status (Australia-modified Karnofsky Performance Scale ≤ 20 , or ≥ 30), and symptoms/concerns using the Integrated Palliative care Outcome Scale (IPOS). We applied these case-mix classes [I: lowest cost weight of 1.0 to VI: highest cost weight of 2.8], and report prevalence and characteristics in each class.

Results: 3,497 episodes of community-based palliative care were included. Class distribution was I (n=376, 10.8%), II (n=126, 3.6%), III (n=905, 25.9%), IV (n=403, 11.5%), V (n=315, 9.0%), and VI (n=1,372, 39.2%). Age, gender, and diagnosis distinguished the classes as follows: Class VI had the highest mean age (84 years), the highest female proportion (63.4%), and lowest proportion with cancer (23.3%) compared to other classes mean age (73 – 76 years), female (46 – 55%), and cancer (50 – 70%). Class II had higher proportion of non-cancer (50.0%) compares to Classes I, III, IV, and V (28.7% - 33.8%). The median professional contacts per week by healthcare staff were the lowest among Classes I – III (0.7 – 0.9 per week), 1.5 per week for Classes IV & V, and highest for Class VI (3.5 per week).

Conclusions: The previously developed case-mix classes for community palliative care have good content validity. Classes I (lowest cost weight)

to VI (highest cost weight) demonstrated increasing frequency of staff contacts, and representing the expected increase in resource use across Classes.

P 12.038 Development and Modelling of a Supportive Palliative Care Intervention for Non-western Migrants with Palliative Care Needs and their Families Using the Medical Research Council Framework in Denmark

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Background/aims: Opportunities for use of palliative care are missed among non-western migrants living in Denmark, despite existing equal and free access to health care. This study aims to develop a theoretically informed, evidence-based intervention to increase palliative care utilization among non-western migrants with a life-threatening disease and their families.

Methods: Following the Medical Research Council's framework for developing and testing complex interventions, stakeholders (public, patients, family caregivers, healthcare professionals, and academics) were involved at different stages of the intervention development process to increase acceptance and ownership. The intervention was developed iteratively by synthesizing evidence from 1) a systematic review, 2) semi-structured interviews and group discussions with patients (n=8), family caregivers (n=11), and healthcare professionals (n=10), and 3) three workshops with migrants (n=5), and healthcare professionals (n=6). Participants from six different settings across two regions of Denmark participated in the study.

Results: The final intervention components included the following three components:

- 1) skill-based training for palliative care professionals,
- 2) health consultations with the respective healthcare professional in the healthcare setting or at home, and
- 3) coordination of care between general practitioners, palliative care professionals at the hospital, and/or the municipality.

The mixed-methods design proved to be a suitable approach to identifying multiple intervention components targeting different stakeholders to achieve the desired outcomes.

Conclusions: The comprehensive description of the development process of this intervention aims to increase transferability to other countries with similar healthcare systems as Denmark. The research team will further test the intervention to assess acceptability, feasibility, and potential effect.

The main source of funding for the study is the Danish Cancer Society.

P 12.039 So What? - Piloting the Feasibility and Effect of Screening for Palliative Care Needs in Haemato-oncology Inpatients

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Background/aims: High unmet needs occur in haemato-oncology patients across their disease trajectory, yet few gain access to palliative care. Prognostic uncertainty is one of the main perceived barriers.

To assess the feasibility of using the Integrated Palliative Outcome Scale (IPOS) and the Myeloma Patient Outcome Scale (MyPOS) in routine haemato-oncology care to screen for specialist palliative care (SPC) needs irrespective of prognosis.

Methods: Cross-sectional, routine data pilot implementation of the IPOS and MyPOS in a consecutive sample of haemato-oncology inpatients (all disease stages, confirmed diagnosis) of a German University hospital. A preliminary cutoff of 3 severe or 2 overwhelming concerns indicated SPC need. We used participatory observation, qualitative interviewing, thematic analysis, and chart review to determine feasibility.

Results: Of 118 consecutive inpatients (pts) between June 11–Oct 10, 2022, 15 pts (13%) did not want to return a questionnaire, 53 pts did not receive it due to transfer before assessment (20; 17%), cognitive or language barriers (10; 8%), or staff shortages during the pandemic (23; 19%), response rate 42%. Most pts preferred paper/pencil rather than the e-version (tablet). Prognosis was curative in 17/50 pts (34%), uncertain in 2 (4%), and incurable in 31 (62%). Of the 13 pts (26%) screened as SPC need, 6 pts were treated in curative intent; 2/13 pts were referred to SPC nurses, 1 declined, 1 was missed, and 9 pts were provided generalist PC by their haemato-oncology team. None of the pts screened negatively were referred to SPC. The haemato-oncology team perceived IPOS and MyPOS useful for quickly focusing on the most important general palliative and supportive needs of their pts.

Conclusions: Screening for palliative concerns in haemato-oncology pts irrespective of prognosis is feasible and may help promote generalist and specialist PC approaches. Screening cutoffs need further exploration.

P 12.040 Self-assessment Tool Palliative Care Creates Insight into the Organisation of Palliative Care on an Organisational Level as Well as on a National Level

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Background/aims: The Netherlands Quality Framework for Palliative Care is a guiding model for the quality of Palliative Care (PC). Based on this framework, a self-assessment tool for healthcare organisations (HCOs) has been developed. The tool gives HCOs insights into the organisation of PC and indicates which domains can be improved. This study describes the outcomes of how PC is organised in 121 HCOs that have completed the self-assessment tool for PC.

Methods: 121 HCOs completed the self-assessment tool and used at least 10 patient records of the last expected deceased patients. Domains of this tool address for example identification of the palliative phase, advance care planning, organisation of PC and collaboration with other HCOs.

Results: The outcomes of the tool show possible improvements of the PC in HCOs but also indicate nationwide trends in PC. For example, identification of patients who need PC needs further attention (only 34% of all HCOs reported using tools for identification). The patient records showed among other things that advance care planning is not common (reported in 68% of all investigated patient records).

Conclusions: The self-assessment tool for PC gives HCOs insight into the quality of the PC they provide. With an increasing number of HCOs that use the tool, a better overview of the organisation of PC in the Netherlands is created. Trends can be seen over time. Areas of improvement encompass all domains of the quality framework. Although the tool can under- or overestimate the results due to self-assessment, the effect will be reduced by the use of the 10 patient records.

P 12.041 Could Emergency Department Visits in Patients with Advanced Cancer Have Been Avoided? A Prospective Study from the Perspective of the Attending Hospital Physician

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Background/aims: Many patients with advanced cancer and their families are confronted with unplanned emergency department (ED) visits. To improve patient care, we investigate whether ED visits could have been foreseen / avoided, and the factors associated with these concepts.

Methods: A prospective cohort study from May 2013 – June 2014 including all adult patients with advanced cancer visiting our tertiary hospital's ED. When attending physicians answered the Surprise Question ('Would you be surprised if this patient dies within a year?') with 'no', they filled out an online survey about foreseeability and avoidability of the ED visit (5-point Likert scale, 1= surely no to 5= surely yes) and the estimated life expectancy. Disease, visit and referral characteristics were collected retrospectively from patient records. Frequencies and proportions of foreseen and avoidable ED visits were calculated. Associated factors were assessed using a full multivariable logistic regression model.

Results: We included 210 patients, median age 62 years, 46% male and 31% with a gastro-intestinal primary tumor. Main symptoms were pain (19%), fever and dyspnea (both 18%). Attending physicians considered 138 ED visits as foreseen (66%), due to disease progression or social reasons (living alone). Fifty ED visits were considered avoidable (24%), if e.g. home care or proactive care planning would have been available. For patients with pain as main symptom, it was more likely that the ED visit was considered avoidable (OR 2.98, 95% CI 1.18–7.51, $p=0.02$). In patients with a life expectancy < 7 days, the ED visits were less likely to be foreseen (OR 0.18, 95%CI 0.04–0.83, $p=0.03$) and more likely to be avoidable (OR 5.14, 95% CI 1.11–23.7, $p=0.04$)

Conclusions: Most ED visits of patients with advanced cancer are not avoidable according to the attending physician. ED visits of patients with a life expectancy of < 7 days or with pain as a main symptom, were more often considered avoidable.

P 12.042 Assessing the Quality of Care for People Dying of Cancer in Hospital – Development of the "QualDeath" Framework

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Background/aims: High quality end of life care involves addressing a patient's physical, psychosocial, and spiritual needs and also responding to family carer needs. Measuring the quality of care associated with dying and death is an important component of health care and helps shape how care is delivered. Currently, it appears there is a lack of evidence-based, systematic processes to examine the quality of dying and death of patients expected to die from cancer in hospital settings.

Aim: Develop a systematic appraisal framework (QualDeath) for reviewing the quality of dying and death for patients with advanced cancer in the hospital.

Methods: (1) Explore the published evidence with regard to existing tools and processes related to appraisal of end of life care via a rapid literature review; (2) Scope current practice in several major hospitals in Melbourne, Australia with regard to existing processes related to appraisal of quality of dying/death via semi structured interviews and focus groups with key stakeholders; (3) co-design QualDeath based on the aforementioned and workshop and focus group with key stakeholders (hospital administrators, clinicians and consumers) to foster acceptability and feasibility and reach consensus.

Results: We developed "QualDeath": a framework to assist hospital administrators and clinicians to systematically review the quality of

dying and death for patients with an expected death from advanced cancer in hospital settings. It offers four levels of potential implementation for hospitals to select from and incorporates medical record review, multidisciplinary meetings, quality of end of life care surveys and bereavement interviews with family carers.

Conclusions: The QualDeath framework provides relevant hospitals with recommendations to formalise processes to evaluate end of life care. Although QualDeath was underpinned by several research methods we advocate further research is conducted to rigorously explore its impact and test feasibility.

P 12.043 From Vision to Outcomes: Developing a Strategic Plan for the Next Five Years of an All-Ireland Palliative Care Research Network

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Background/aims: In 2012, the All Ireland Institute of Hospice and Palliative Care (AIHPC) established a Palliative Care Research Network (PCRN) to address the need for collaborative multidisciplinary palliative care research on the island of Ireland. The PCRN is governed by a Strategic Scientific Committee (SSC) whose membership includes researchers, people with life limiting conditions and their family/carers, expert collaborators, hospice/palliative care providers, and national funding bodies.

Aim: To collaboratively develop a Strategic Plan setting out priorities, actions and outcomes required over the next five years to deliver the network's vision of undertaking research which improves the quality of life/death for people with life-limiting conditions on the island of Ireland and internationally.

Methods: Three phases:

- 1) Identification of strategic priorities/actions at workshop with 30 stakeholders - people with life limiting conditions and family/carers, researchers, hospice/palliative care providers, and health agencies from across Ireland. Results shared for email review by participants/PCRN members
- 2) refinement of plan by SSC/AIHPC, in consultation with wider PCRN, early career researchers, AIHPC members, people with life limiting conditions and family/carers, and funding bodies
- 3) final review/sign-off with AIHPC Member organisations.

Results: Five strategic priorities agreed:

- 1) strengthen/expand collaboration
- 2) develop palliative care researchers/influence career paths
- 3) involve service users/carers/communities across the research cycle
- 4) create academic-clinical environment for innovation
- 5) maximise research impact on practice/policy; aligned to 15 actions and 10 measurable outcomes.

Conclusions: The PCRN Strategic Plan 2023-27 details how the network will deliver their vision for palliative care research on the island of Ireland. The collaborative approach aimed to include perspectives from diverse stakeholders, and build the consensus needed for the plan's implementation.

P 12.044 Symptom Burden of Patients in Specialist Palliative Home Care in Germany

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Background/aims: Specialist palliative home care (SPHC) teams aim to maintain and improve patients' quality of life in the community setting, regardless of diagnosis. Symptom burden may differ between oncological and non-oncological patients. However, little is known about diagnosis-related differences in symptom prevalence and burden of SPHC patients. We aim to describe main symptoms and symptom burden of adult patients in SPHC regarding the differences of patients with oncological and non-oncological diagnoses.

Methods: Prospective, cross-sectional, multi-centre study collecting data reflecting the complexity of patients' situations. Descriptive and comparative statistics on physical symptom burden assessed by Integrated Palliative Outcome Scale at the beginning of a care episode.

Results: 785 care episodes from 9 SPHC teams were included, average age was 78 years, mean duration of care episode 18.4 days (SD 19.3), 566/785 (71.3%) had an oncological diagnosis. In 464/566 (82%) episodes, patients with oncological and in 190/219 (86.8%) with non-oncological diagnoses suffered severely or overwhelmingly from ≥ 1 symptom, 66 (11.7%) and 35 (16%) from ≥ 5 symptoms. Main burden (severe/overwhelming) in oncological episodes was weakness (365/565; 64.6%) and in non-oncological limited mobility (169/218; 77.5%). There are differences in the prevalence of symptom burden (severe/overwhelming), some were not significant, e.g. episodes with patients affected by pain (oncological: 46; 21.9% vs. 38; 17.4%) ($\chi^2(1)=2.002$, $p=.157$). Some other symptoms showed significant differences, e.g. episodes with patients affected by dyspnoea (oncological: 56; 9.9% vs. 35; 16.1%) ($\chi^2(1)=5.94$, $p=.015$).

Conclusions: First results showed differences between patient groups regarding symptoms. Overall, episodes of non-oncological patients showed a higher symptom burden. Prospectively, to better understand existing differences, symptom clusters and trajectories will be calculated.

Funding: G-BA Innovation Fund, no. 01VSF18018

P 12.045 Development of Cooperation between Cancer Care and Specialized Palliative Care

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Background/aims: Clinical studies regarding earlier integration of cancer care and palliative care point to health benefits in the form of eg. improved symptom control, quality of life and survival, and can promote person-centered care.

Our aim was to investigate how personnel who meet cancer patients cooperate and wish to cooperate with specialized palliative care in order to find working models for earlier intergration of palliative care.

Methods: A digital survey with open- and closed-ended questions. Recipients were members of process groups within a regional cancer centre, the majority being physicians and nurses in surgery, medicine and oncology.

Results: Out of 563 questionnaires sent, 221 responses (52% physicians) were received.

Only 22% had a structured way to discuss patient's need of palliative care.

A patient assessed to be at the absolute end of life was a decisive factor for contact with specialized palliative care for more than half of the respondents.

36% of the physicians could refrain from contacting specialists in palliative care despite assessed need for the patient. This was often due to

patient refusal, deterred by the name and the supposed connection to death. Health care staff's could also find themselves unable to introduce the word palliative.

The majority had access to counseling from a specialist palliative care team and 1/3 also wanted extended counseling.

Continuing education in palliative care was available to over 40% and close to 60% wanted more.

Conclusions: The results indicate that a large part of staff in cancer care, as well as many patients, still believe that palliative care is mainly relevant in the final stage of life.

The high percentage of respondents wanting extended education in palliative care highlights the necessity for specialists in palliative care to take an educational responsibility and thereby provide the opportunity to inform about the benefits of early palliative care and the necessity of a structured team-based discussion to enable early integration.

P 12.046 Transmural Collaboration in Palliative Care: A Feasibility Study about the Implementation of a Care Pathway to Improve Care Transitions of Acutely Hospitalized Patients

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Background/aims: Personal values, needs and wishes are essential to provide appropriate palliative care for patients with a life limiting illness.

Intervention: The transmural palliative care pathway support for unplanned admissions: 1) a telephonic intervention within 24 hours after admission to exchange information about the patient's physical, psychological, spiritual and social needs and preferences, and 2) multidisciplinary consultation with the GP before discharge aiming to improve communication, decision making, continuity of care and prevent rapid readmissions.

Aim: Study feasibility of the care pathway support.

Methods: A prospective feasibility study using quantitative and qualitative methods was conducted from July - October 2022. Data were collected via surveys, semi-structured interviews and focus group interviews. Data were qualitatively analyzed.

Results: Preliminary results of the use of the care pathway for 17 patients (N=17) in one academic hospital in the Netherlands showed that all GPs were contacted by hospital physicians. Information was exchanged about life expectancy, treatment limitations, end-of-life preferences like preferred place of death, quality of life priorities and involved healthcare professionals. Although most GPs were invited (N=13) to participate in multidisciplinary consultation, only 2 (N=2) participated.

Overall, GPs appreciate the effort made to involve them in the caring process. The pathway improved communication and exchange about the patient's values, needs and wishes for GPs and hospital physicians. Online participation of GPs in multidisciplinary consultation was considered valuable but is difficult to achieve due to a lack of time and high work pressure. Telephonic consultation after the MC was performed to optimize continuity of care after discharge.

Conclusions: After the first positive experiences, the pathway support will be extended to two other hospitals in the region. Continuous evaluation will be performed to optimize the pathway support in the upcoming months.

P 12.047 A Clinical Audit Demonstrating the Benefit of Multimodal Approach to Improving Advance Care Planning and Resuscitation Plans in a Tertiary Hospital

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Background/aims: Advanced care planning (ACP) is the process of documenting a person's preference for medical treatment in the event of future deterioration. Previous literature suggests that the rates of appropriate and clearly documented ACP discussions is poor in the inpatient hospital setting.

To improve discussion and documentation of ACP and resuscitation plans in patients who die during a hospital admission.

Methods: We performed a clinical audit of inpatients to evaluate the benefit of several multimodal interventions implemented to improve ACP. These interventions included both educational initiatives and systems-based improvements. This audit was performed following implementation of the above interventions and compared to previous audits conducted in 2016 and 2011.

The audit cycle was conducted at Concord Hospital, a 750-bed tertiary hospital located in Sydney, Australia. Inclusion criteria included inpatients who died during admission under any team, excluding the palliative care team. Patients who died: outside of the hospital or in the palliative care inpatient unit were excluded.

Results: In 2021, 97% of audited patients had a documented ACP prior to death compared to 80% in the 2016 audit. While 67% of ACPs were completed in the first 24-48 hours of admission in 2021, in 2016 only 32% of ACPs were documented on admission, with 17% made less than a day prior to death.

In 2016, 72% of ACP orders were discussed with the next of kin and 39% with the patient. Of these patients, 48% had their ACP correctly documented. In 2021 94% of patients had a paper resuscitation form filled; however, identification stickers, which are associated with risk of error, were used in 64%; and 25% of forms were only partially completed (front page only).

Conclusions: Improvement in the prevalence and timing of ACP prior to death is seen in the post-intervention audit in 2021. A repeat audit in five years will be conducted, with interventions focused on improving documentation of advanced care planning.

P 12.048 Demonstrating the Impact of Palliative Care during the COVID-19 Pandemic among Hospice Inpatients: A Secondary Analysis of Routinely-collected Person-centred Outcomes Data

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Background/aims: Use of patient-level outcome measures can support patient-centred care and improve quality of care for patients and their families, particularly during the context of the COVID-19 pandemic.

To demonstrate, during COVID-19, patients' symptom burden using patient outcome care measures; and estimate changes in symptom scores over the duration of palliative care episodes.

Methods: We undertook secondary analysis of longitudinal clinical data routinely collected by specialist palliative staff between April 2020 – March 2022. We described the characteristics of patients, their episodes of care, and their Phase of Illness at first contact. We determined the burden of symptoms using the Integrated Palliative care Outcome Scale (IPOS), and changes in mean IPOS scores during episode of care. We also compared changes in year 1 (April 2020 – March 2021), and year 2 (April 2021 – March 2022) of the pandemic.

Results: 656 patients received 728 episodes of palliative care during year 1, and 441 patients received 492 episodes during year 2. For these episodes, during year 1 and 2 respectively, median ages were 73 years (IQR: 62 – 82) vs 72 years (IQR: 61 – 81), 49% vs 45% females, and 79% vs 83% had cancer. Palliative Phases of Illness were stable (1% vs 1%), unstable

(33% vs 59%), deteriorating (55% vs 26%), and dying (10% vs 14%) at start of episode of care.

By end of episode of care in year 1, mean 'pain' score reduced from 2.4 to 0.9; mean 'breathlessness' score reduced from 1.6 to 0.9; mean 'anxiety' score reduced from 2.2 to 1.0; and mean 'feeling depressed' score reduced from 1.7 to 0.8.

By end of episode of care in year 2, mean 'pain' score reduced from 2.2 to 1.1; mean 'breathlessness' score reduced from 1.7 to 0.9; mean 'anxiety' score reduced from 2.1 to 0.9; and mean 'feeling depressed' score reduced from 1.4 to 0.7.

Conclusions: Despite the COVID pandemic pressures, palliative care services continued to deliver positive benefits for hospice inpatient and their families.

Conflict of interest: Funding: Yorkshire Cancer Research (L412)

P 12.049 Access to Specialist Palliative Care: Insights from Designation Data of 28 of 30 UK Brain Tumour Centres

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Background/aims: This paper reports on findings of the Tessa Jowell Brain Cancer Mission (TJBCM) designation committee, in determining the scope of hospital specialist palliative care services available to people living with brain tumours in the UK. This data provides a snapshot of variation and access to palliative care within one disease group.

Methods: The TJBCM is delivering a transformative national programme, including designating centres providing high quality brain tumour care as a "Tessa Jowell Centre of Excellence". The designation process involves a comprehensive application form, site visit and interviews, based on international best practice guidance. All centres were asked to explain their palliative care services and to provide patient/carer feedback and outcome data. Data were then grouped by themes and analysed.

Results: Data reflect substantial variation in design, quality and extent of services. Variation exists in the patient pathway, services available, links with community care, and access to research. Examples of best practice included access to enhanced supportive care (13 centres), access to comprehensive support for complex decision making (1 centre) and neuro-specialisation within the SPC team (3 centres). Contrary to NICE guidance, many centres did not include palliative care as part of their "core" neuro-oncology MDT with only 9 centres (32%) having palliative care specialists listed. 14 centres (50%) stated that palliative care consultant(s) were a core part of their neuro-oncology team. Neuro-specialisation of palliative care services appeared uncommon. Variation in community services available was often due to a high proportion of third sector investment in this setting. Centres which failed to provide evidence of palliative care involvement did not achieve designation status.

Conclusions: Specialist palliative care as part of the treatment pathway for brain cancer shows significant variation across the UK, which is likely to result in inequity of access and variation in outcomes.

Conflict of interest: Nicky Huskens is Chief Executive of the Tessa Jowell Brain Cancer Mission (not for profit/charitable organisation).

P 12.050 Proactive and Systematic Multidimensional Needs Assessment in Palliative Care (MAP) during the First Encounter: A Delphi Consensus Study

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Background/aims: A systematic needs assessment in palliative care (PC) in the first encounter may guarantee a comprehensive patient-centred care by addressing all dimensions of need and allowing a meaningful initial encounter with the patient and their family. However, there is limited consensus on how to comprehensively capture all relevant needs.

Aim: To provide an expert panel-endorsed systematic, standardised and proactive Multidimensional Needs Assessment in Palliative care (MAP) for patients with advanced cancer as a semi-structured interview.

Methods: MAP was drafted based on the literature review, semistructured interviews with patients, family carers, and PC professionals and a modified nominal group process with PC experts. A consensus process was carried out by an expert panel from Spain using the Delphi technique for 3 rounds to reach a minimum agreement of 80% on each item.

Results: The expert panel agreed on 46 needs of the proposed 55 needs related to 6 assessment areas which should be considered in MAP (Table).

Conclusions: MAP is a consensed semi-structured clinical interview that may bring equity to PC care by systematically assessing multiple domains while adjusting to the needs of each patient and their family.

Funding: Instituto de Salud Carlos III, Fondo Europeo de Desarrollo Regional (FEDER) "Una manera de hacer Europa", reference PI19/01901.

Invited	Responses round 1 N(%)	Responses round 2 N(%)	Responses round 3 N(%)
136	67 (49.3%)	53 (79.1%)	52 (98.1%)
Assessment areas	Needs agreed by the end of the 3 rounds		
Clinical History	8		
Physical symptoms	17		
Functional and cognitive status	4		
Psychological symptoms	5		
Social issues	8		
Spiritual and existential concerns	4		

P 12.051 Palliative Home Care and Admission to Hospital: A Retrospective Study of Older Cancer Patients

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Background/aims: We evaluate the association of specialist palliative home care (HC) with days spent admitted to hospital in the 30 and 90 days prior to death.

Methods: This retrospective cohort study using administrative data identified adults ≥ 65 years of age, deceased from cancer between 2008 and 2015, living ≥ 180 days after diagnosis of cancer, and residing in the urban Calgary Zone of Alberta Health Services. All palliative HC and generalist HC services were examined. Regression analyses determined the

relationship of palliative HC, generalist HC, and no HC with days in hospital in the last 30 or 90 days of life.

Results: There were 4633 adults in the sample. In the last 30 days of life, compared to patients receiving no HC, patients receiving palliative HC and generalist HC spent fewer total days in hospital (Regression Coefficient (B)_{palliative-HC} -3.91; 95%CI -4.78 to -3.04; B_{generalist-HC} -1.60; 95%CI -2.45 to -0.75). In the last 90 days of life, compared to patients receiving no HC, only those receiving palliative HC (B -4.99; 95%CI -6.68 to -3.29) spent fewer days hospitalized. The results for those receiving generalist HC in the last 90 days of life were not significant in comparison to patients receiving no HC (B -0.67; 95%CI -2.33 to 0.98).

Conclusions: Receiving palliative HC was associated with fewer total days in hospital in the last 30 days of life, as was receiving generalist HC, compared to patients receiving no HC. Receiving specialized only palliative HC in the last 90 days of life was associated with fewer days admitted to hospital, compared to patients receiving no HC. Improving access to palliative HC for older cancer patients at high risk of hospitalization may reduce acute care costs in the last 30 to 90 days of life.

P 12.052 Collaboration and Early Palliative Care after Immune Therapy Revolution in Metastatic Melanoma: A Focus Group Study *C. Prod'Homme*¹

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Background/aims: While the benefits for early and integrated palliative care (PC) are clear, it remains to be determined just how to go about doing so. We questioned the impact of the emergence of new treatments in oncology such as immunotherapy on the practical conditions of a real collaboration between specialized PC and onco-dermatology (OD). The purpose of the study was to explore the perception of PC and OD healthcare professionals regarding interdisciplinary collaboration in early PC for patients with progressing metastatic melanoma (MM) under continued immune therapies.

Methods: The data were generated through four focus groups held over a period of 1 year, for a total duration of 13 hours. 13 Participants included OD and PC Physicians, Nurses and a Psychologist. They discussed clinical cases in which both teams had collaborated and that were considered to display clinical and ethical complexities. Focus groups were facilitated by researchers in humanities and social sciences.

Results: This study clarifies what was at stake in the various forms of collaboration between the OD and PC teams. The OD team expressed the fact that from their point of view, PC team endorsed the roles of experts, third party, support group and instructors. Healthcare professionals were led to discuss the differences between "PC" and "early PC" and how responsibility could be shared over the course of longer patient trajectories. Early PC consultations in OD often begin by deconstructing patient representations of PC and offering a different and perhaps more gratifying representation of PC.

Conclusions: Our results highlight the way PC can be integrated in OD after immune therapy revolution.

P 12.054 The Effect of Specialized Palliative Telemedicine for Patients with Advanced Cancer at Home: Study Protocol

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Background/aims: Specialized palliative care (SPC) plays an important role in providing patient-centered care and support to caregivers, besides intensifying/coordinating collaboration among different health care sectors. This study proposes a SPC intervention enriched with a dyadic psychological intervention for patients with advanced cancer and their caregivers delivered by telemedicine at home. The primary aim is to investigate the intervention effects on the patients' health-related quality of life. Secondary outcomes include sleep, anxiety/depression, health system use, survival, dyadic coping patient-caregiver, and caregiver burden.

Methods: A randomized controlled trial will be conducted at the Dept. Oncology, Rigshospitalet-DK. Patients' inclusion criteria: ≥ 18 years, solid organ cancer, no longer receives curative treatment, able to speak/understand Danish, cognitively able to participate, ≥ 1 symptom/problem with score ≥ 3 at EORTC QLQ-C30. Patients will indicate closest informal caregiver (≥ 18 years), who will be invited to participate in the study. Sample size=174 patients. The intervention group will have the first SPC appointment within 5 days from randomization and regular video appointments according to the SPC team's assessment, as well as 2-5 dyadic psychological intervention sessions. Monthly multidisciplinary conferences composed by oncology team, SPC team, general practitioner, and district nurse will be organized to discuss the patient's therapeutic plan. The control group will continue receiving standard care. Recruitment period estimation=14 months. Assessments are planned at inclusion and after 2 weeks, 4 weeks, 8 weeks, and 6 months. A pilot study supported by the Danish Cancer Society will be conducted in 2022-2023.

Results: Results are expected in jan 2023

Conclusions: Video consultations and the cooperation/integration model can inspire a new thinking regarding the organization of the future of palliative care for patients with cancer and their closest relatives in Denmark and abroad.

P 12.055 Models of Outpatient Palliative Care Clinics - A Narrative Review

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Background/aims: There are very few independent or integrated outpatient palliative care clinics (OPC) in Romania, although they are the best setting for providing early palliative care (PC), require relatively few resources and can serve a large number of patients.

Aim: To identify the types of functional models of PC in independent or integrated outpatient clinics in countries with health systems similar to Romania.

Methods: A narrative review was conducted between June - December 2020. PubMed was searched and also guidelines, reports and analyses published online with free access, combining palliative care, outpatient or ambulatory and model.

Results: Twenty-nine articles were included, describing 5 models of OPC-independent, embedded, collocated, telehealth and enhanced primary PC. In describing the models, the following aspects were considered essential: a) beneficiaries-who they are, what are their care needs, how they are selected and prioritized? b) providers-what disciplines will be involved? what will be the roles of the different providers? what skills and experience do they need to have? what interventions will apply? c) necessary facilitating structures with particular attention to documentation and standardized tools, funding methods and other support services needed? d) what monitoring is in place and how is the quality of care ensured? Currently, much of the available evidence supports independent ambulatory provided by a specialized interdisciplinary PC team.

Conclusions: Although the independent interdisciplinary model represents the gold standard for outpatient PC delivery, given the heterogeneity of health systems, patient populations, resource availability, clinician training, and attitudes and beliefs toward PC worldwide, it is important to emphasize that none of the models presented will provide a generally valid solution. OPC clinics need to be designed to meet the unique needs of all stakeholders - patients, families, referral healthcare providers and institutions.

P 12.056 Introducing Early Palliative Care to an Integrated Specialist Palliative Care Model in Ireland

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Background/aims: Palliative care focuses on quality of life in the context of life limiting illness. Literature supports its early outpatient integration with oncology teams in advanced cancer and demonstrates significant benefits for patients and families. Organisational benefits include reduced costs, emergency department attendances and hospitalisations. Current Irish model consists mainly of hospital consult, inpatient and community palliative care. Despite inclusion in national service planning, there is no systematic approach to integrated outpatient care. Literature describes models of early palliative care and encourages clinicians to implement as local resources allow, progressing towards aligning with the evidence base. The covid pandemic caused increased waiting times for community services, creating a lever for change. The aim was to introduce early ambulatory palliative care into and integrated model of care.

Methods: A change project implemented using the Define Design Deliver framework. This resource neutral change consisted of: education, redirection of community ambulatory patients to consultant lead outpatients and a standard operating procedure. Evaluation models utilised were Kirkpatrick's model, Before and After, model and Plan-Do-Study-Act cycles

Results: Immediate reduction in waiting times for community palliative care team were achieved. The educational intervention was disrupted by covid pandemic restrictions. A standard operating procedure was formulated and revised, incorporating a clinical nurse specialist lead clinic.

Conclusions: This project demonstrates that it is feasible to commence implementation of this model but challenges prevent full alignment with evidence. Resources are required for expansion. This project provides data and evidence to support applications for further resources. Further information in the form of a service user survey would assist in service planning in the local context and shape this for the future to meet the needs of patient and ultimately improve care.

P 12.057 What Value Does a Specialist Palliative Care Pharmacist Outpatient Clinic Add?

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Background/aims: A multidisciplinary (MDT) palliative care outpatient clinic in a large metropolitan hospital was struggling to meet the demand of referral numbers. The initiation and titration of high-risk medications was limited due to safety concerns about the inability to review patients in timely manner, resulting in compromised symptom management. In 2020 to improve medication safety, a specialist palliative care pharmacist (SPCP) review was scheduled prior to each MDT appointment for medication reconciliation and education. A SPCP clinic was also established to monitor medication changes, titrate doses or cease medications depending upon assessment and provide advice regarding ongoing medical review.

Aim: Assess the impact of a SPCP clinic.

Methods: Retrospective review of patient medical notes to determine demographic information and interventions conducted in the SPCP clinic. Surveys of patients and staff to assess impact.

Results: Between Jan-June 2020, 19 patients were seen (33 appointments), and 36 (94) and 34 (100) for the same period in 2021 and 2022 respectively. For each year 39%, 38% and 45% of reviews were to monitor medication changes. Analgesia was the most common medication monitored and adjusted. The SPCP liaised with medical specialists, GPs, pharmacists, and community and rural services to facilitate continuity and safety of medication regimens. Feedback from the 5 (26%) 2020 and 10 (28%) 2021 patients surveyed, was overwhelmingly positive about their increased medication understanding and confidence. Consultants reported confidence in initiating medication changes knowing an experienced clinician would review. The clinic had a A\$58,900 gross gain in the 2021/22 financial year.

Conclusions: Introducing a SPCP to conduct medication reconciliation, education and monitoring has improved symptom management and medication safety. Medication titration in a timely manner has been enabled, while MDT appointments have been freed up for new patients.

P 12.058 Evaluation of Patient Profile in Palliative Care of a Private Hospital in South of Brazil

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Background/aims: To determine the profile of patients and care provided by the Palliative Care Center, as well as to evaluate and structure the indicators to improve care for patients with palliative care (PC) indication admitted to a private hospital in Brazil.

Methods: Creation of a Business Intelligence report with the Palliative Performance Scale (PPS), time between hospitalization and first evaluation, time between evaluation and discharge and other data of interest. Creation of a group for its indicators and protocols, permanent meetings was also established.

Results: With structured data, it is possible to keep the knowledge of the profile of those in PC, as well as the behaviour to request assessment and action of the team for the patient. In 2021, the hospital obtained 407 patients in a PC protocol. The mean time between the hospitalization and first assessment was 10.1 days and between assessment and discharge was 9.8 days. In 2022, 385 entries were registered in CP. Time proves to be more resolute, with an average of 5,8 days for the first, and 7.9 days on average until discharge. The mean age of the patients was 80 years and the PPS was 30-40%, being around 81% of the patients with PPS less than or equal to 50%. Among the patients followed up, the mortality rate was 22%.

Conclusions: The results show a better direction of the teams in face of the proposals of the protocol of earlier CP service assessment. Through the data obtained, we noticed an increasing number of patients included, shorter time to ask for CP assessment and shorter time to outcome. Identifying hospitalized patients who need PC allows for a better quality of care, as well as allowing the entire team involved to have greater knowledge of the proposed therapeutic plan, developing individualized and safer care. Collect and gather this data is important to encourage the patient referrals for CP assessment by healthcare providers, since the CP is still incipient in Brazil and have need to grow.

P 12.059 Finding a Virtual Solution to a Very Real Problem: The Introduction of Virtual Clinical Nurse Specialists to One Hospice Team

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Background/aims: Nationally, the death rate and need for palliative care is increasing annually, with predictions that this will increase by up to 40% by 2040. In a time when national shortages of experienced nurses, able to work at specialist level, is having an impact on clinical services, hospices are unable to fill vacant Clinical Nurse Specialist (CNS) roles, with suitable candidates. The vacancies left the clinical teams in this hospice struggling to fulfill commissioned service expectations and meet clinical demand. During the pandemic response, some CNSs worked remotely, but were still able to support the clinical team, which produced the idea of creating a 'Virtual' (VCNS) role.

Aim: To address the shortage of Clinical Nurse Specialists in one hospice team, by creating a new role of VCNS.

Methods: A scoping exercise was performed to establish the extent of the shortfall in service. Adverts were placed to determine whether the opportunity to work remotely, from a more distant area, would attract nurses already working at specialist level. Seven very experienced nurses applied and were interviewed, and all met stringent criterion. Five were appointed across three locality teams, and two joined the bank, to support all three teams. Problems of managing induction and equipment had to be resolved, and a network of education, support and supervision developed.

Results: Over the first six months of the one-year pilot, referrals increased by over 50%, and caseload numbers by over 25%. Although there has been no increase in face-to-face visits from the existing CNS team, which was one hope of the project, the appointment of VCNSs to support the workforce has allowed us to double (6677 from 3206) our telephone support, and to manage the increase in referrals and case-loads. The proven benefit of the VCNS role, means that we will be extending the one-year pilot.

Conclusions: The role of VCNS has been successful in bridging the gap in service and creating an original solution to cope with increased future pressures.

P 12.060 Experiences with Palliative Care for Head and Neck Cancer Patients at the Outpatient Clinic and Remote

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Background/aims: The Erasmus MC set up an Expert Center to give structured attention to patients with head and neck cancer (HNC) in the palliative phase. After their palliative diagnosis patients can choose to remain visiting their physician at the outpatient clinic or to be monitored remotely in their home situation. This unique approach entails that each patient is assigned to an oncological nurse. Besides, these oncological nurses have regular contact with patients general practitioner and monitor symptoms with help of an electronic patient reported outcome structure ("Healthcare Monitor"). In this study we evaluate the experiences of patients and next of kin with this unique approach of care.

Methods: 60 patients with HNC in the palliative phase and 52 next of kin of deceased HNC patients were included. We evaluated their experiences with the palliative care through a specially developed patient reported experience questionnaire.

Results: The majority of patients and next of kin experienced the consultation with the physician and the following consult with the oncology nurse as pleasant. The physician and the oncology nurse communicated in an understandable way and there was enough room for questions. One third of patients and next of kin reported to have missed a topic during the consults, such as discussing life expectancy. Another 34% of the patients stated that it was not discussed in what situation they wanted to refrain from treatment. During the remote care the majority of patients and next of kin felt safe with remote monitoring, they were able to sufficiently clarify their problems and if necessary action was

taken in time. However, 35% of patients and 46% of next of kin reported that the provided psychosocial support was not sufficient.

Conclusions: HNC patients and next of kin were satisfied with the palliative care. They felt safe with the remote care and symptoms or problems were adequately monitored. However, there is room for more attention to discuss life expectancy and psychosocial support.

P 12.061 The Comprehensiveness and Correspondence of Place of Death Classifications: An International Comparative Analysis

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Background/aims: Respecting preferences for place of death (PoD) is important. The first step is to classify PoD in a way that captures the full spectrum of places that are meaningful for individuals. We aimed to describe the comprehensiveness and correspondence of PoD classifications globally.

Methods: We sought information on PoD classifications from vital registries of 47 countries varied in UN Regions and Quality of Death Index. We describe the structure of PoD classifications (2020-21), cross-linking the categories and wording used in the countries. We focus attention on the entity "home" as it is the most common preference for PoD.

Results: Of 22 responding countries (16 EU), 21 use a single PoD classification structure and only Portugal uses a hierarchical classification (in 3 levels, with sub-categories within health institutions and specific services within hospitals, such as ICU and emergency department). Categories range 3 to 21, the most common (present in all countries) were: home (however the wording varies), hospital, health care or medical institution/health establishment (however differences limit comparability), and other/elsewhere. Home is captured in 1-3 categories per country, with wide-ranged wording: home, courtyard, domicile, home/non-institution, home of family members, home of friend, private house, private home, private residence and residential house. Cyprus and Luxembourg use the most comprehensive classifications (21 and 18 categories, respectively). Final findings from all countries will be presented at the conference.

Conclusions: There is scope to improve the comprehensiveness of PoD classifications and category correspondence. Although all countries capture "home," there are critical variations in wording. An exhaustive international PoD classification will allow better cross-country data and studies mapping preferred and actual PoD, critical to help provide choice on where people die across world regions.

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P 12.062 First Year of Implementation of Mobile Palliative Care Unit at National Oncological Center

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Background/aims: At our oncological center we provide specialised palliative care (SPO) for oncological patients. Apart from hospital care, outpatient clinic and telephone support, one year ago we implemented mobile palliative care unit to support patients and their caregivers at home.

Aims: To analyse mobile palliative care service provided in the first year of implementation.

Methods: We analysed one year data of patients supported by mobile palliative care unit from the beginning of September 2021 to end of August 2022. We observed patient characteristics, number of home visits, hospitalisations, outpatient visits and phone calls from first home visit on.

Results: During observed period mobile palliative care unit performed 574 home visits for 346 patients (on average 1.7 per patient, range 1-8). The average age of a group was 70.8 years, gender distribution was 50:50% male: female. Most common diagnosis were: lung (25%), gastrointestinal (25%) and gynaecological (11%) cancer. After first home visit some patients used also other SPO services: 80 patients (23%) needed hospitalisation at acute palliative care department (1.2 admission per patient, range 1-5), 21 patients (6%) visited outpatient clinic. Most common service used was 24/7 phone support line where we registered 683 calls (1.9 call/patient). At the time of analysis 280 patient (80%) of observed group were dead. 224 (80%) of them died at home, 33 (12%) at hospital, 14 (5%) in hospice, others in various long-term care institutions.

Conclusions: Our data clearly shows that palliative patients need broad palliative care network (inpatient and outpatient department, telephone support and mobile unit). Support by mobile palliative care unit enables more patients to die at home.

P 12.063 Palliative Care Phases (PCP) in Cancer Patients Receiving Specialised Palliative Home Care (SPHC): A Mixed Methods Study

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Background/aims: The Palliative Care Phases (PCP) have been proven to be an important component in the assessment of complex needs of patients and are effective in determining resources necessary to meet these needs. In Switzerland, no data are yet available on the PCP of patients with advanced cancer receiving specialised palliative home care (SPHC). The present study aims to contribute to needs-based care, quality improvement and efficiency promotion in SPHC by determining PCP-specific symptoms and needs of patients and family caregivers as well as corresponding resources provided by health professionals and family caregivers.

Methods: We are conducting a convergent mixed-methods study among adults with cancer, who are being cared for by one of three participating SPHC services. We collected quantitative data through questionnaires filled in by patients, family caregivers and nurses to assess symptoms and needs, caregiver burden and resource consumption. Focus group interviews with the nursing staff as well as semi-structured interviews with patients and family caregivers were conducted for further exploration of the PCP. Data are being analysed by applying multinomial regression, repeated measures ANOVA and qualitative content analysis.

Results: Three focus group interviews and 20 individual interviews were conducted. Initial findings from qualitative data show PCP-specific characteristics and needs that were consistently mentioned among patients, family caregivers and nurses. 91 patients were recruited for quantitative data collection. Most of them were in the stable (n=38) or deteriorating phase (n=22). The merging process by joint display tables is under way and results will be presented at the conference.

Conclusions: Our study results reveal important insights concerning the PCP among patients in SPHC. Gaining multi-perspective information on PCP-specific symptom burden, needs and resource consumption can promote tailored care for patients and their relatives.

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P 12.064 Documentation of Triggers for Referral to Specialist Palliative Care from NCEC Guidelines in COPD Patients

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Background/aims: The National Clinical Effectiveness Committee (NCEC) guideline 27 on COPD includes triggers for consideration of referral to specialist palliative care (SPC); FEV1<30%, long-term oxygen, mMRC grade 4, more than 3 hospitalizations in last year, more than 6 weeks of steroids in previous 6 months, poor functional status.

Aim: To review the documentation of NCEC COPD triggers in patients referred to a SPC.

Methods: Charts of all patients with primary diagnosis of COPD referred to palliative care service from January to June 2022 were reviewed. Demographic data, referral source, clinical triggers were collected.

Results: 23 patients (11 females, median age 78.4 years) were included. Most (17/23) were referred by a hospital team; the remainder by their general practitioner. FEV1 was not documented in 65% of referrals; 26% (6) had a FEV1 <30%. 78% of patients were on long term oxygen. 74% of patients[NASA1] has breathlessness at rest or minimal exertion between exacerbations. The modified Medical Research Council-Dyspnoea scale (mMRC) grade 4 was documented for two patients. Seven patients (30%) had symptoms of heart failure. The ECOG (Eastern Cooperative Oncology Group) score of 3 or 4 was used a substitute marker for poor functional status. 74% of patients has ECOG grade 3. It was not possible to gather information about number of hospital admissions, or use of steroids from the referral information.

Conclusions: It is important that primary and hospital teams understand when SPC should be considered, and that SPC understand what may be considered poor prognostic indicators for illness other than cancer. A single national referral form simplifies the process of referral, but consideration should be given to modifying the form which is currently cancer focused (mentions radiotherapy and chemotherapy) and considering other functional scales such as the Clinical Frailty Score or RUG ADL, which may be more commonly used.

P 12.065 Training Implications for Generalist Palliative Care Settings When Using the Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem) – A Secondary Qualitative Analysis

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Background/aims: The IPOS-Dem is a person-centred outcome measure to elicit palliative care needs in people with dementia. Implementing the IPOS-Dem into routine clinical practice in a new non-specialist setting raises implementation challenges. The aim is to explore how IPOS-Dem could best be implemented in community and acute care setting.

Methods: Secondary analysis of cognitive interviews, using think-aloud and probing techniques. Quotes implying a training need in relation to palliative care, dementia care, or the completion of IPOS-Dem were synthesised into emerging themes. Themes were refined according to the three domains from Michie et al's COM-B model (capability, opportunity, and motivation framework for behaviour change) to identify potential elements for a tailored implementation strategy.

Results: Ten cognitive interviews (4 district, 4 acute care nurses, 2 relatives) were conducted. Nurses from the community care setting have different training needs to those working in acute care. COM-B model results: Capability: Nurses from both settings need training on the construct validity of the IPOS-Dem which measures how much the person with dementia is affected by a symptom rather than by its

symptom severity. Also, specific items in the IPOS-Dem (e.g., weakness or lack of energy, being able to connect with others) may provide explicit palliative care related training opportunities in both settings.

Opportunity: Acute care nurses need more training on how to evaluate dementia-specific symptoms, implying wider training needs for providing person-centred care to the fast-rising dementia population. Motivation: The IPOS-Dem is a motivator in and of itself for further person-centred assessment activities (e.g., actively seeking information with family).

Conclusions: Our results highlight multidisciplinary training needs extending across two domains of the COM-B model for nurses in using patient-centred outcome measures as the first step towards a tailored implementation strategy.

P 12.066 Improving Decision Making around the End of Life for the People of North Wales

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Background/aims: Treatment and care towards the end of life (EoL) often involve decisions that are clinically complex and emotionally distressing. Patients' decision-making needs to be supported by appropriate, individual, timely discussions with clinicians and those important to them. In North Wales, the support for end of life decision-making (EoLDM) is fragmented and uncoordinated. We undertook a detailed exploration of EoLDM in North Wales to inform a quality improvement (QI) strategy.

Methods: We mapped components of EoLDM and examined those via individual and group interviews with stakeholders based on normalisation process theory constructs. We checked alignment with local and national guidance, contextualised findings utilising previous regional work, and prioritised QI topics.

Results: Examination of EoLDM components (discussions, documentation, acting on decisions and governance) revealed well-known barriers (e.g. time constraints, lack of universal health care record) and key themes (e.g. need for clinician education & communication skills, executive leadership and dedicated people & systems resource). A targeted QI strategy includes coordinated communication 'do not attempt resuscitate' pathways between care settings, dedicated training resource for rolling clinician education, fit-for-purpose documentation of treatment escalation considerations and a public awareness campaign.

Conclusions: The detailed exploration of EoLDM across the region has resulted in a targeted QI strategy. It acts as a springboard for future work to normalise EoLDM. Our vision is that everyone in North Wales has fair opportunity to have discussions to support their individualised EoL decision-making at the right time supported by skilled clinicians. Fit-for-purpose pathways and documentation should ensure decisions and preferences are acted upon, within a robust governance framework. The work is funded by Betsi Cadwaladr University Health Board, via Welsh Government End of Life Board monies.

P 12.067 Introduction of a Hybrid Project Management Tool for a Palliative Care Team "Getting the Almost Done - Done" - A Qualitative Action Research Study

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Background/aims: Dealing with changing situations is an integral part of palliative care (PC). This requires an adaptive approach for a) the patient

(treatment plan) and b) the team (project management (PM)). Three types of PM exist:

- 1) traditional (step wise, little flexibility, focus on the final product);
- 2) agile (flexible-iterative approach, focus on continuous improvement); and
- 3) hybrid (combination of traditional and agile). To respond creatively to changing situations, PC projects have to be adaptive and timely.

Finalization of these projects is important to avoid a backlog. However, the ideal PM tool for PC is unknown. Our aim was to develop a PM tool for PC projects.

Methods: Participatory action research:

- 1) planning phase: thematic analysis of semi-structured interviews (PM experience/perception);
- 2) action phase: adaptation (written feedback) of a purpose-built PM tool (Excel sheet); and
- 3) observation/reflection phase: team meetings and adaptation of tool. Setting: core team (n = 9) of a tertiary interprofessional PC service.

Results: Interviews of phase 1 revealed two topics:

- A) "agile management" with six themes: importance of a team; importance of effective communication; clear leadership; adaptation to reality; getting the work done; human behind the project;
- B) "tool" with three themes: effective-transparent communication; flexible-practical; clear-simple structure. In phases 2) and 3), the draft of the tool was simplified, resulting in a hybrid PM tool (excel sheet) with the following items: idea catalog feeding a project list with a deadline, progress report, and role of team member. The PM tool serves as a framework for quality control meetings and covers the following domains: clinical, quality, faculty development.

Conclusions: Participatory development, simplicity, and transparency are key to the feasibility of a project management tool for a PC team and important to account for team diversity. In practice, such a tool seems helpful to finalize projects timely.

P 12.068 The Role of the Unregulated Healthcare Assistant in Out-of-Hours Community-hospice Care: Organisational Qualitative Case Studies

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Background/aims: Community-based palliative out-of-hours services that operate outside of normal working hours is considered a key priority area. Unregistered healthcare assistants play a pivotal role in the delivery of community hospice palliative care, yet little is known about their role in the out of hour period.

Methods: Six organisational qualitative cases approach was adopted. In each hospice out-of-hour service the case was defined as the health care assistant. Case studies comprised: collection of secondary contextual data; semi-structured interviews (n=59). Framework Analysis was used to facilitate within and across case analysis.

Results: Three broad themes were identified relating to the level of preparation of the healthcare assistant role, complexity of the service provision and impact of the role on the patient and caregivers out of hour care experience. HCAs undertake a complex role, with sole responsibility for the assessment, management and escalation of patient deterioration in the OOH period. However, the complexities of lone working

and the lack of formal standardized preparation are lacking questioning the vulnerability of the patient, family but also the HCA in the delivery of their role.

Conclusions: Evidence in the current study would suggest that despite a lack of standardized preparation, HCAs provide complex roles which influence patient and carer outcomes in out-of-hours community palliative care. Further studies exploring HCAs effectiveness are warranted given the limited evidence base

P 12.069 Developing and Implementing a Policy for End-of-Life Diabetes Management in a Public Hospital in Ireland

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Background/aims: Diabetes mellitus is a chronic disease which can cause organ damage during a person's life due to high blood glucose levels. Its management aims to avoid short- and long-term complications, however, at the end of life these aims change, and the comfort of a patient takes priority.

Problem situation: While ample guidance exists for the management of many aspects of diabetes, there is currently no guidance specifically for end-of-life diabetes management in this acute, tertiary, public hospital.

Aim: The project aims to improve the management of diabetes at the end of life by developing and implementing a policy to guide its management in the hospital, using a HSE change model.

Methods: A literature review was performed to ensure the policy is evidence-based. The HSE's *People's Needs Defining Change* model has been used throughout to guide the change project. A staff survey and retrospective chart review were completed to determine current local practices, identify areas for improvement, determine staff readiness to change and obtain baseline measures.

Results: The literature revealed a paucity of high-quality data on the subject, but key themes emerged: blood glucose targets, frequency of blood glucose monitoring, medication use and communication. The staff survey and chart review showed variability in the approach to end-of-life diabetes management within the organisation and a readiness to change. In collaboration with local experts, a policy was developed and using the key principles of the change model, was implemented. Several evaluation methods have been used to ensure the success of the project and promote sustainability.

Conclusions: This project provides a template for the implementation of a Palliative Care policy in an acute hospital setting using a HSE model for change and has the potential to be replicated in other settings.

P 12.070 Integration of Palliative Care during Fatal Hospitalization in Patients with Heart Failure Compared to Patients with Cancer

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Background/aims: The difficulty of the prognosis has been described as a barrier to the delivery of PC to people with HF. During fatal hospitalizations, the task of identifying the near-death stage or poor prognosis is often easier, allowing, at least at that time, referral for PC. Therefore, we aimed to compare the proportion of patients with HF with that of patients with cancer who were seen by the PC group during the fatal hospitalization, as well as its change over five years.

Methods: Retrospective cohort using administrative data of patients who died in a tertiary hospital between the years 2016 and 2020. We conducted a logistic regression analysis with PC as the outcome, HF as the main exposure, and age, sex, and length of stay (LOS) as covariables.

Results: Data were available for 3,196 patients. Of them, 966 (28%) had a code of cancer and 114 (3.6%) had a code of HF as the main diagnosis during the fatal hospitalization. Of those with cancer, 48% received PC during the hospitalization, at a median of 2 days after admission. Of those with HF, 6% received PC during the hospitalization, at a median of 8 days after admission. This means that patients with HF received PC in the last quintile of their hospitalization compared to the first quintile for patients with cancer. In the multivariable logistic regression, having HF was not a significant predictor of receiving PC, while patients with cancer had 11.5 times the odds of receiving PC than those without cancer (OR 11.5, 95% CI 9.2-14.4). In patients with HF as the main diagnosis and cancer as comorbidity (n=34), only 1 (3%) received PC.

Conclusions: In our hospital, PC practice is integrated into the care delivered to patients with cancer, which is seen not only in the proportion of patients receiving PC but also in the stable trajectory showing a consistent practice. Meanwhile, patients hospitalized in the cardiology ward, even when having cancer, have a very low probability of receiving support from PC and are receiving it late in the hospitalization.

P 12.071 Symptom Management at Home and in Nursing Homes Integrating and Implementing Two 'Good Examples', a Participatory Action Research Study

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Background/aims: Development of an integrated symptom management working method, consisting of two good examples in Dutch palliative care.

RQ: How can signaling and decision making be integrated and implemented in palliative care for patients at home and nursing homes?

Methods: A *Participatory Action Research design* (PAR) with three action cycles to develop an integrated working method in symptom management was performed from Oct 2020 – June 2022. In total, 17 nursing homes wards and 3 home care teams were enrolled. Each cycle consisted of three steps. During the planning phase education was provided, healthcare professionals (HCP) were trained, and agreements for the execution were documented. After three months execution was evaluated and the new cycle planned. During this period the contact persons per team were coached by PC specialized nurse practitioners. Data were gathered during the evaluation phase to optimize the integrated working method and supportive implementation materials.

Results: In total 306 HCP participated in the project. Supportive materials were developed to integrate palliative reasoning in daily practice, information for patients and families, instruction, and support materials for multidisciplinary team members with different NLQF levels and the management. To enable incorporating supporting structures in electronic health records an information standard was developed. HCP perceived a value of working with palliative reasoning (PR) on their own knowledge and that of colleagues, consciousness, collaboration, and individual PC provided. Implementation success depends on: leadership of contact persons, supportive structures, educational levels and multiprofessional collaboration.

Conclusions: The implementation of palliative reasoning as a working method for symptom management requires a phased approach, including a tailored multifaceted implementation strategy. Leadership and a diversity of competences and educational levels in the nursing team are essential for a successful implementation.

P 12.072 A Nationwide Survey of Rehabilitation Practices in Hospice and Palliative Care Units in Japan

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Background/aims: Cancer rehabilitation is also essential for terminal cancer patients, whose functional decline is inevitable. In Japan, since the 1980s, when Hospice/Palliative Care Units (PCUs) began operating, rehabilitation has been provided to inpatients of PCUs by rehabilitation therapists, and the needs is recognized by medical staffs and patients and families. A previous survey of rehabilitation in PCUs was reported in 2007, there is no recent data.

The aim is to clarify the recent status of rehabilitation provided by therapists in PCUs in Japan.

Methods: This was a nationwide questionnaire survey. We sent to certified 452 PCUs between August and October 2022. We asked about the practice of rehabilitation by therapists in PCUs of 2019 to exclude the impact of the COVID-19 pandemic.

Results: Data were obtained from 125 units (response rate: 27.7%). The mean bed was 20.0 (SD, 6.3) and mean stay of PCUs was 28.3 (SD, 12.0) days. Of these, 111 (88.8%) of the units provided rehabilitation by therapists, while 14 (11.2%) did not.

The following rehabilitation practices were reported: i) the frequency per week was more than 4 times, 78 (71.6%); 2-3 times, 27 (24.8%); and once, 4 (3.7%); ii) the length per day was less than 20 minutes, 34 (31.2%); 21-40 minutes, 60 (55.0%); and more than 41 minutes, 15 (13.8%).

Several respondents stated that the degree of rehabilitation provision in PCUs was restricted due to the shortage of therapists and the inability to add rehabilitation fees to inpatient charges of PCUs.

Conclusions: In comparison with the previous report (Inoue et al., 2007: i) the frequency was more than 4 times, 62.5%; 2-3 times, 33.3%; once, 4.2%; ii) the length was less than 20 minutes, 45.8%; 21-40 minutes, 54.2%; more than 41 minutes, 0%), the proportion of PCUs providing rehabilitation and the frequency and length of rehabilitation have increased.

While, this survey showed several problems exist on the side of health-care providers, such as staff shortages and the medical fee system.

P 12.073 Review of Admissions to a Specialist Palliative Care Inpatient Unit with Gynaecological Malignancy

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Background/aims: Palliative and supportive care needs of women with gynaecological cancer are many and varied. With advances in cancer therapies, our role in supporting patients who may be on treatment or planned to receive treatment, is increasing and nuanced. Our role is expanding into the remit of mutually supporting patients for whom there is a hope and expectation of oncological treatment improving outcome.

Aims: To examine referrals with a gynaecological malignancy from the affiliated acute hospital cancer centre to the SPCU.

To identify the patient profile, indication for admission, admission length and discharge destination for this cohort.

To determine average time to symptom control and time to stable phase of illness using Palliative Care Outcome Collaboration (PCOC) data.

Methods: A chart review was undertaken of all patients with a gynaecological malignancy admitted to SPCU from 1st September 2022 to 31st September 2022. Data collected included baseline demographic information, diagnosis, reason for admission, admission length, if the patient died or was discharged, PCOC scores. Data was input to Microsoft Excel. Basic statistics were used. Further review is ongoing at time of writing.

Results: There were 570 admissions to the inpatient unit over this time period. 55 of these were patients with a gynaecological malignancy equating to approximately 9.6% of the total number of admissions. Of these 55, 10 patients were admitted on 2 or 3 separate occasions. 44 patients with a gynaecological malignancy were admitted to the unit over the course of the 13 months. 16% had a diagnosis of cervical carcinoma, 27% had a diagnosis of endometrial carcinoma and 57 % had a diagnosis of ovarian carcinoma.

Conclusions: With advances in cancer therapies for gynaecological malignancy, the trajectory of illness for this cohort may be uncertain. Integrated Palliative and Oncological Care is vital for these patients.

P 12.074 Impact of Coordinated Network of Specialized Palliative Care on Place of Death

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Background/aims: To address fluctuating palliative patients' needs a flexible network of palliative care services and good coordination must be established. In our country we are structuring palliative care on two levels: basic and specialized. Basic palliative care is provided by all health professionals, specialized palliative care (SPC) can be included for patients with complex needs. Network of SPO represent: a hospital department (HD) as an acute palliative care setting, an outpatient clinic for early palliative care (OCEPC), a counselling service (CS) for all other hospital departments and since September 2021 also a 24/7 palliative care phone support line (PCPSL) and mobile palliative care unit (MPCU) for home support. The aim of the study was to provide additional evidence that coordinated network of SPC enables more patients to die at home.

Methods: We analyzed the data of all patients involved in all services of SPC throughout the year, from the beginning of the implementation of the PCPSL and MPCU, until the end of August 2022. We observed patients' age, gender, diagnosis and place of death.

Results: During observed period there were 6182 specialized palliative care services provided to 1,086 patients (54% female, 46% male) with an average age of 69 years. Most common diagnosis were gastrointestinal cancer 27%, lung cancer 20% and gynecological cancer 12%. Frequency of SPO services used were: PCPSL in 3949 (63,9 %), CS in 782 (12,6 %), MPCU in 576 (9,3 %), OCEPC in 532 (8,6 %) and HD in 343 (5,5 %) cases. At the time of analysis 754 (70 %) patients have died. A comparison of groups according to support of MPCU clearly showed a higher proportion of those who died at home when supported by MPCU home visits comparing to a group without (80% vs 62%).

Conclusions: Flexible and coordinated palliative care network must be structured to ensure palliative care adapted to the individual patient needs. The MPCU represents an important element of the palliative care network that can ensure more dying at home.

P 12.075 Changing the Image of Palliative Care Provision in Lithuania

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Background/aims: Palliative care accessibility plays an enormous role for people with life-threatening palliative diseases, enabling them to

access services that help to overcome physical symptoms, loss of dignity, and social and psychological and social burdens while supporting family caregivers. A growing demand for palliative care intensity and quality in Lithuania is observed for persons at the end of their lives. This study aims to identify the extent of Lithuania's access to palliative care services.

Methods: The National Health Insurance Fund database was assessed to retrieve up-to-date figures reflecting the palliative care prevalence of services. Data collection criteria were selected to determine persons who received palliative care at home, day centers, and stationery. Followed by the number of services to identified persons.

Results: A total of 1 493 persons received palliative care in the year's first quarter. Respectfully, 632 persons with the identified end-of-life care need receiving services at home, 87 at the day centers, and 774 in stationary care. Data collection also revealed that 29 396 services were provided for those receiving care at home, followed by 1 557 services at day centers, and 34 774 bed-days were registered at nursing homes, hospices, and hospitals.

Conclusions: Each year there is a growing number of persons with identified life-threatening diseases in Lithuania. Recent changes in Lithuanian legislation of palliative care were that ICD criteria for entering services were withdrawn, enabling wider accessibility for persons needing end-of-life care. Further investigation is required to identify how changes in palliative care regulation will address the increasing demand for care provision.

P 12.076 Development of the Palliative Care Referral System.

Proposal of a Tool for the Referral of Cancer Patients to Specialized Palliative Care

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Background/aims: Early palliative care (PC) has shown beneficial effects for advanced cancer patients. However, it is still debated what criteria to use to identify patients for PC referral.

Aim: To document of the development of the Palliative Care Referral System (PCRS), a tool to be used by oncologists in clinical practice.

Methods: A multiprofessional working group developed the PCRS based on the results of a scoping literature review on PC referral criteria. PCRS criteria were evaluated by experts via a nominal group technique (NGT). Descriptive statistics were used to summarize expert scores on relevance, appropriateness and perceived feasibility of the criteria proposed.

Results: The PCRS proposed included nine major criteria and nine assessment methods for their assessment: severe physical symptoms, psycho-social problems, poor performance status, comorbidities, decision making/communication issues, patient/caregiver request, prognosis as well as other clinically relevant conditions; a scoring procedure was also proposed. Answers to the questionnaire during the NGT showed that five criteria reached full agreement on all items, while four did not, and were then discussed within the group. Participants agreed on the relevance of all criteria and on the appropriateness of methods proposed to assess most of them, while issues were raised about potential feasibility of the overall assessment of the PCRS in clinical practice.

Conclusions: The PCRS has been developed as an help for oncologists to timely identify patients for specialized PC referral. Since feasibility emerged as the main concern, implementation strategies will be tested in subsequent studies.

P 12.077 Comprehensive Education on Palliative Care for Multidisciplinary Medical Professionals to "Disseminate", "Enhance", "Deepen" and "Collaborate" in a Remote-islands Prefecture in Japan

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Background/aims: There are several issues in palliative care in Japan that need to be solved, such as correcting regional disparities in opportunities to learn "basic palliative care," providing opportunities for step-up training, and establishing a system for integrating oncology and palliative care (IOP).

The project aimed to comprehensively develop palliative care in Okinawa prefecture; remote islands prefecture based on the four pillars of "Disseminate", "Enhance", "Deepen" and "Collaborate", and also to expand such efforts nationwide.

Methods: The concrete measures of four pillars are as follows:

- 1) "Disseminate": To hold web-based seminars for learning basic palliative care systematically at 11 areas/facilities including remote islands in the prefecture.
- 2) "Enhance": To hold seminars on clinical practice guidelines for medical professionals who were mainly involved in palliative care in the community and at their facilities.
- 3) "Deepen": To develop a program to implement IOP for practicing "early palliative care".
- 4) "Collaborate": To establish palliative care study group consisting of multidisciplinary professionals.

Results:

- 1) Continuous learning opportunities on basic palliative care were provided throughout the prefecture.
- 2) Evidence-based palliative has been disseminated to core staff on palliative care in the prefecture.
- 3) Our hospital was accredited as a facility of ESMO-Designated Center, which was a practical program of IOP, and we started to develop a made in Japan IOP model.
- 4) Inter-professional and inter-regional collaboration have been matured.

Conclusions: The above efforts were expected to enhance the comprehensive palliative care education and collaboration system, promoted the equalization of palliative care, and improved the quality of palliative care. It was also expected that this project would serve as a reference for the dissemination and development of palliative care in areas connected by land, as COVID-19 continues to be widespread and face-to-face relations remain difficult.

P 12.078 The "Magic Ambulance" Project – Wish Fulfilment for Palliative Patients

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Background/aims: Wish fulfilment is an intervention carried out in palliative care (PC), promoting the meaning of life and maintaining positive memories.

The "Magic Ambulance" Project aims to provide adults with neurodegenerative diagnosis, accompanied by PC, the fulfilment of an essential wish for their current life situation through a multidisciplinary team that will allow them to have specialized ambulance transportation.

Aims: Identify and characterize the "Magic Ambulance" Project.

Methods: A retrospective observational study included 23 professionals, two patients and six family members.

Intentional samples were collected from January to September 2022. Clinical and demographic data were from anonymized integrated clinical records. Data collection was an online questionnaire, with demographic characterization, with open and end questions. Data analysis was done with descriptive statistics software.

This study complies with ethical procedures and authorization granted by the sample.

Results: Two wishes were granted to patients with Amyotrophic Lateral Sclerosis, proposed by the community palliative team. Six family members were involved, making it a very emotional moment with positive memories.

Of the 23 professionals, 15 are female, aged between 30 and 50. Most do not have professional experience in PC. Seven volunteers already had training in PC before the project, and eight received training to integrate the project. Fourteen volunteers participated in the different project phases.

In preparing the wishes, nine elements collaborated from the community team (volunteers, ambulance crew and project team). In the execution phase, seven elements participated.

Conclusions: Myths about PC by the general population and health professionals are a barrier to patient referral, making it difficult to experience the disease in a dignified, involved way and with the necessary family support.

We believe this project promotes literacy in PC and trains professionals for interventions aimed at well-being and quality of life.

Conflict of interest: This project is funded by "La Caixa Foundation".

P 12.079 Challenges in Palliative Care and the Role of Oral Health Professionals: A Literature Review

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Background/aims: Oral health problems are a common cause of distress in Palliative Care (PC) patients and their families/caregivers. However, oral health professionals (OHP) are most often absent from PC teams. The aim of this study is to review the role of OHP in PC teams.

Methods: A narrative review of the literature. Data was collected from electronic databases and reference lists were hand searched. Eligible papers were those reporting the activity of OHP in PC.

Results: Oral health problems are frequent in PC (namely dry mouth, taste disturbance and coating of tongue), causing great impact in patients and their families/caregivers. Nevertheless, oral health problems are often under diagnosed and neglected, even in PC. Although the importance of OHP in PC is acknowledged, currently they are usually absent from PC teams. There is very little evidence of collaborative models between OHP and the core PC teams.

Conclusions: Oral problems are highly prevalent in PC patients, affecting their quality of life. However, OHP are most often absent of PC teams. This literature review showed the importance of incorporating these professionals in interdisciplinary teams to improve the well-being of PC patients. Further investigation about the collaboration of OHP in PC teams is needed.

P 12.080 Insights into a Long-term Cross-sectoral Care and Case Management for Persons with Severe or Highly Active Multiple Sclerosis and their Caregivers

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Background/aims: The ongoing COCOS-MS (Communication, Coordination and Security for Persons with Multiple Sclerosis) study (funded by GBA Innovationsfonds FKZ 01VSF19029) is a randomized controlled phase II clinical trial. Herein, we evaluate the impact of a long-term (12 months) patient advocacy Care and Case Management (CCM) for persons with severe Multiple Sclerosis (PwsMS) and their caregivers.

In the qualitative part of the mixed-method design, we assess the stakeholders' in-depth view about their experiences with the CCM intervention. This knowledge in combination with the quantitative data and an expert hearing at the end of the study will help to evaluate the CCM intervention.

Methods: As part of the COCOS-MS study, qualitative semi-structured interviews are conducted with the following stakeholders: persons with severe MS and their caregivers randomized to the intervention group as well as health care specialists (HCSs) being in contact with the CCM. Data are analyzed using content analysis with MAXQDA 22.

Results: A total of 12 PwsMS, 12 caregivers and ten HCSs complete the interviews. Preliminary results suggest that PwsMS and caregivers highly value having a reliable contact person with a superordinate advocating view opening up new habitats outside of the disease. HCSs especially appreciate the comprehensive and longitudinal documentation of and appropriate actions meeting the severely affected PwsMS changing needs, problems and resources with respect to their physical, psychological, social and legal concerns.

Conclusions: This qualitative sub-study of the COCOS MS trial serves as integral part of the evaluation of the CCM intervention. This will help to optimize the CCM intervention and apply it in a phase III study for long-term neurological conditions with similarly challenging complex symptoms and concerns.

P 12.081 Intensive Care Perceptions and Understanding of Palliative Care in a Tertiary Teaching Hospital in the UK

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Background/aims: Palliative and Intensive Care might seem like very unlikely co-operators in providing the best patient care, however, they are not as far apart as some think. Symptom burdens are high, not least because of the medical interventions, and these impact on the patient's care and sometimes outcomes. Psychological distress is high among both patients and relatives/carers. The burden is not only on patients (and relatives), but also on the staff of the ICU, not least because "palliative" or end of life care may not be "what they came into ICU for".

Methods: We carried out an online questionnaire of ICU staff within our hospital. We wanted to get results from all employee groups, not just doctors. The questionnaire was a mixture of multiple-choice options and free text boxes. We plan to follow up on at least one of the groups identified with a more in-depth interview to ascertain their perceptions of palliative care.

Results: Responses came from Cardiac, Neuro and General ICU as well as Surgical high dependency and were from a variety of staff: nurses (40%), doctors (20%), however also included HCAs, Physiotherapists, Ward Clerks and Pharmacists. The majority (83%) had experience of working with palliative care and had referred patients. The experiences of palliative care were overwhelmingly positive and highlighted the support to patients, relatives

and also staff. 82% of responders felt that palliative care was well integrated into ICU. There was a wide range of views about who the palliative care team should see ranging from "any patient that has a diagnosis of progressive illness and requires support", to "nurses and relatives" to "those with symptom control issues". Themes arising showed that the staff recognised the need for more relative and staff support.

Conclusions: Palliative Care and ICU are well integrated in our tertiary hospital however there still remains more we could do and more the ICU teams would like in terms of support for the patients but also for relatives, and themselves as staff.

P 12.082 Can Specialized Palliative Care in a Hospital Setting Change the Basic Palliative Care Skills among Staff? - A Quality Development Project (PDSA)

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Background/aims: Danish palliative database annual report from 2020 shows, that only 10% of patients referred to specialized palliative care have other diagnoses than cancer.

The Region of Southern Denmark have focus on strengthening palliative care for patients with life-threatening diagnoses other than cancer. Therefore, extra resources (doctor and nurse) have been added to Palliative Team Vejle to be able to start a palliative in-house service at Lillebaelt Hospital.

Aims: The purpose of the intervention is to create equality in access to the palliative care services for all patients with life-threatening diseases regardless of diagnosis, as well as to raise the quality of the effort, in relation to the basic palliative care in our hospital setting.

Methods: Prior to start, meetings were held with each department, and individual intervention plans were developed.

- The staff are trained in SPICT, EORTC-QLQ 15 Pal, advance care planning, communication skills regarding treatment ceiling, sector transitions, etc.
- A hot-line phone has been established 9:00-15:00, which can be used by doctors and nurses.
- Weekly presence of doctor and nurses on ward.
- Bedside learning.
- Daily supervision as needed.

All initiatives taking is in alignment with the needs and possibilities of the individual department.

Results: Hot-line phone with increasing number of calls.

- The first results indicate, that education and presence must be an ongoing process.
- Staff members indicate, that our presence is meaningful to their work.
- The intervention impact other professional groups, e.g. physiotherapists.

Conclusions: Importance of flexibility in the approach.

- It has been necessary to extend the planned period in the individual departments from six months to a year, because of the flow of staff and only one day's presence weekly at each ward.
- Importance of regular follow up after ended intervention.

P 12.083 Enhancing the Theory-based Model of Co-creation in Palliative Care - A Theoretical Perspective

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Background/aims: The aim of the study was to develop a theory-based model of co-creation to use in palliative care despite context where palliative care is given. In palliative care it can be a challenge for health care professionals (HCPs) to provide person-centered care that helps people achieve vital end-of-life goals and promote quality of life. To support dying persons to reach vital goals, the theory-based co-creation model can be seen as a tool for HCPs. It can give HCPs a deeper knowledge of the complexity of palliative care and help them support patients to prioritize activities together with their relatives.

Methods: A theoretical design was used. The co-creation model was tested against theories of person-centered care, health and dignity. Concepts were theoretically analyzed and examined on their philosophical basis. Similarities and differences were analyzed based on if these concepts could be integrated to the new theory-based model of co-creation. If concepts overlapped, the philosophical underpinnings of each added theory were analyzed to reach a deeper level of the co-creation process. An overview of the result was created showing the developed theory-based model.

Results: The new theory-based co-creation model put the light on the person with palliative care needs and her goals at the center of life in end of life. The theory-based model shows that dignity-conserving care actions are essential to reach patients' important goals. These care actions must be related to one or more of the dimensions of palliative care (existential, physiological, psychological, and social), and to the cornerstones of palliative care: symptom relief, relation and communication, teamwork, and support for relatives.

Conclusions: With a developed theory-based co-creation model, HCPs can help avoid unnecessary suffering for their patients and increase the maintenance of patients' quality of life.

P 13 - Primary and Integrated Care

P 13.001 Palliative Care Research Priorities in the West Midlands, UK: A Modified Delphi Study

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Background/aims: National policy makers in England advise a transformative approach to the provision of palliative and end-of-life care that is sustainable, responsive and personalised for all.¹ Research plays an important role in achieving these ambitions. Although new knowledge is needed to inform palliative care provision, the evidence produced must be appropriate to the priorities of the communities we serve, and responsive to local challenges and needs.

Our aim was to elicit consensus on palliative care research priorities for the West Midlands region of United Kingdom (UK).

Methods: Rapid interviews were conducted with stakeholders (staff, patients, carers, and citizens) to identify priorities. Subsequently, a two-round online Delphi study was conducted to reach consensus on the highest priorities (rated as 'high or essential priority' by ≥80% of participants) and rank them.

Results: 158 items under 15 broad themes were identified as priorities through rapid interviews with 56 stakeholders. In the 1st Delphi round with 30 participants, seven items reached consensus, focusing on barriers in communication, equity and access, crises' prevention, social care, and upskilling healthcare staff to provide basic palliative care. The seven items were then ranked by 41 participants in the 2nd Delphi round. The item 'barriers in communicating end-of-life' was ranked first by 30% of

the participants. However, taking into account the overall ranking scores for each item, 'integrated care systems to prevent crises' was ranked higher by most participants.

Conclusions: Identifying priorities for regional palliative and end-of-life care research is a valuable approach to understanding and informing service provision for local communities. The prevention of palliative care crises has been reported as a challenge in the literature and an identified priority for future research in the West Midlands, UK region.

¹www.england.nhs.uk/eolc/what-nhs-england-doing-to-improve-end-of-life-care/

P 13.002 Cost-effectiveness of the Integrated Community Palliative Care Partnership: Scenario Analysis Using Markov Modelling

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Background/aims: Integrated Palliative Care is a proposed model of care to optimise quality of life for older people in care homes nearing the end of life. Aim: to examine the theoretical cost-effectiveness of the integrated community palliative care partnership (ICPP) model in London.

Methods: Scenario analysis using a Markov model for older adults in care homes was developed for 4 statuses: care home, hospital, hospice and death. Health care costs, transition probabilities, mortality, and quality adjusted life (QALY) were extracted from relevant sources and literature. We assume that with ICPP, care home residents feel more assured and better managed, and that they have one less hospital spell or/and fewer old adults are cared for in hospital. Incremental cost-effectiveness ratio (ICER) over 5 years was calculated comparing scenarios from an English National Health Service perspective. Discount rate was 3.5% and prices are inflated to pounds in 2020/21.

Results: Health care costs and care home fees over 5 years were £74,537 and QALYs were 1.62 years per person for the base case scenario (QALYs: care home 0.4; hospice 0.5; hospital 0.3 and Costs: average £7,398; care home £1,871↓; hospice £936↓). In the best possible scenario where quality of life was better (QALYs: care home and hospice 0.5; hospital 0.3) fewer people transitioned to hospital (base case 30% to best scenario 20%) and hospital inpatient care use decreased (£3,377↓), resulted in lower costs (£71,161) and larger QALYs (2.04) over 5 years. The ICER is -£8,038, a negative value, below the guided threshold for cost-effectiveness.

Conclusions: Scenario analyses found that a model of ICPP improves quality of life while reducing health service costs of older adults living in care homes. The modelling is constrained by a limited evidence base but suggests that the ICPP is a high value model of care for a growing number of care home residents nearing the end of life.

Funding: Dunhill Medical Trust and the Cicely Saunders International (RPGF1906\177).

P 13.003 Evaluation of a Complex Advance Care Planning Intervention for Patients with a Chronic, Life-limiting Illness in the General Practice Setting (ACP-GP): A Cluster-randomized Controlled Trial

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Background/aims: Advance care planning (ACP) is an iterative communication process between patients, family, and health providers, about patients' values and preferences for (end-of-life) care. The general

practice setting can provide opportunities for ACP, but deficits remain in its initiation due to barriers at the patient, general practitioner (GP), or health care system level. A complex intervention may be necessary to address barriers.

Aims: To evaluate the effects of a complex ACP intervention for patients with chronic, life-limiting illness in general practice (ACP-GP).

Methods: Cluster-randomized controlled trial with randomization at the GP level. The intervention consists of a patient workbook, GP training, ACP conversations, and a documentation template. Outcomes were measured with the 15-item ACP Engagement Survey for patients and the ACP Self-Efficacy Scale for GPs. Linear mixed models evaluated outcomes at 3 months (T1, primary outcome) and 6 months (T2, secondary outcome) post-baseline.

Results: 35 GPs and 95 patients consented; 18 GPs and 53 patients were assigned to the intervention. We found no difference in the increase in patient ACP engagement at T1 (baseline-adjusted mean difference, 0.34; 95% CI, -0.02 to 0.69; $p=0.062$) or T2 (baseline-adjusted mean difference, 0.20; 95% CI, -0.17 to 0.57; $p=0.28$). For GP ACP self-efficacy, there were no significant differences at T1 (baseline-adjusted mean difference, 0.16; 95% CI, -0.04 to 0.35; $p=0.11$) or at T2 (baseline-adjusted mean difference, 0.11; 95% CI, -0.09 to 0.31; $p=0.27$).

Conclusions: The ACP-GP intervention did not improve patient ACP engagement or GP ACP self-efficacy more than usual care. Trial procedures may have created awareness about ACP in both groups, leading to a stronger activation effect than expected. The COVID-19 pandemic may also have increased awareness of ACP. It may be necessary to also look further at what patients and surrogate decision makers want and need from the ACP process.

P 13.004 Facilitators of and Barriers to Continuity with GPs in Primary Palliative Cancer Care: A Mixed-methods Systematic Review

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Background/aims: General practitioners (GPs) have a key role in palliative care provision for patients with advanced cancer. Continuity is valued by patients with such needs, but is limited within current primary care systems. Exploration of the facilitators of and barriers to continuity in this complex context is required.

Aim: To identify facilitators of and barriers to continuity with GPs in primary palliative care among people with advanced cancer and/or their close persons.

Methods: Mixed-methods systematic review with content and thematic analyses. Keyword searches were carried out in five databases (Ovid MEDLINE(R), Ovid EMBASE(R), CINAHL, Web of Science, and Cochrane), policy documents and grey literature search engines in December 2020. Evidence was reviewed using relevant quality appraisal tools; data were extracted and tabulated. Findings were reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement and the review was prospectively registered on PROSPERO.

Results: Seventeen studies were included. Six studies originated from the UK; six from Europe; three from Canada; and two from Australia. Two studies were mixed-methods, four presented quantitative data, and eleven papers reported on qualitative studies. Four themes were developed: [1] the role of GPs in facilitating continuity; [2] the role of patients and/or close persons in facilitating continuity; [3] changing needs throughout the disease trajectory; and [4] the organisational context in primary care.

Conclusions: Facilitators of and barriers to continuity in primary palliative care are outlined. Further research is required to explore how patients and/or their close persons experience continuity in primary palliative care. Specifically, the work required of them to achieve their

desired level of continuity, and their capacity for action in this context, needs further attention.

P 13.005 Early Palliative Care Derivation and its Association with Antitumor Treatment Near the End of Life. A Monocentric Experience

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Background/aims: The administration of antitumor treatments seeks to increase overall survival and to diminish tumor-related symptoms. However, administration of antitumor treatment in the last month of life is considered a marker of poor-quality care. ASCO guidelines recommend concurrent palliative and oncology care, with the objective of improving the quality of life of cancer patients.

The objective of this study is to analyze the relation of early palliative referral and lower administration of antitumor treatment during the last month of life of cancer patients.

Methods: This is a retrospective observational study including solid tumor patients dying in the sanitary area related to our institution from 1st January of 2019 to 31st of December of 2019. Patients were included regardless of site of death (hospital wards, home and hospices associated to our institution). All patients were evaluated at least once by an oncologist.

Two cohorts were established, cohort A including patients with early referral to palliative care (three months or more before death) and cohort B including patients with late referral (less than three months before death) or not referred to palliative care.

Results: A total of 415 cancer patients died in 2019. Of these, 83 patients (20%) were referred early to palliative care (cohort A). Of the 332 patients belonging to cohort B, 51 patients (15,3%) were never referred to a palliative care specialist. No significant differences in sex, and tumor were found between both cohorts. Eleven (13,3%) patients received antitumor treatment in the last month of life in cohort A, compared to 91 patients (27,4%) in cohort B ($p < 0,01$). Table 1 summarizes our main findings.

Conclusions: Early referral to palliative care units significantly diminishes the use of antitumor treatments in cancer patients during the last 30 days of life. These results encourage both oncologists and palliativists to continue to work together to optimize patient care and reduce aggressiveness in the near-end-of-life setting.

	COHORT A (N=83)	COHORT B (n=332)	P value
Age at diagnosis (years)	71,3 (56,5 – 86,1)	67,4 (54 – 80,8)	0,03
Women, n (%)	40 (48,2%)	161 (48,5%)	0,96
Tumor histology, n (%)			0,57
Gastrointestinal	33 (39,8%)	126 (38%)	
Respiratory	20 (24,1%)	65 (19,6%)	
Gynecological-Breast	11 (13,3%)	52 (15,7%)	
Genitourinary	11 (13,3%)	37 (11,1%)	
Other	8 (9,6%)	52 (15,7%)	
Site of death, n (%)			<0,01
Hospital	42 (50,6%)	275 (82,8%)	
Hospice	31 (37,3%)	45 (13,6%)	
Home	10 (12%)	12 (3,6%)	
Antitumor treatment in the last 30 days of life, n (%)	11 (13,3%)	91 (27,4%)	0,007

P 13.007 Developing a Theory of Change for a Person-centred Integrated Primary Palliative Care Intervention for Elderly People with Serious Multimorbid Illness in Sub-Saharan Africa

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Background/aims: By 2050, 80% of older people will live in low- and middle-income countries. With increasing age, older people face complex serious multimorbid conditions that causes distressing symptoms and concerns. This requires person-centred holistic approach through integrating primary palliative care.

We aimed to use a Theory of Change (ToC) workshop to construct a person-centred logic model of primary palliative care.

Methods: Stakeholders attended ToC workshops held in Ghana, Malawi and Zimbabwe. Stakeholders included older patients at least 50 years of age living with multimorbid illness, their families, primary palliative care practitioners, researchers, advocacy organisations and Ministries of Health/Social welfare. The workshops were facilitated by researchers from King's College London. Presentations, group discussions, including key challenges in palliative care for elderly people and priorities to achieve best care, and feedback and consensus from groups were used. Stakeholders used sticky notes to organise their responses into eight deductive themes, including: Buy in, resources, training, awareness, treatment and care, immediate outcomes, long-term outcomes and impact.

Results: Key challenges identified included shortage of medications, clinic long waiting time and travel expense, elderly people not prioritised to receive primary care and lack of involvement in decision making about their care. Pathways to achieve integrated primary palliative care focused on awareness for all stakeholders of suffering and priority for primary palliative care provision, person-centred communication training of healthcare professionals and community health workers to facilitate holistic treatment and home-based care.

Conclusions: ToC is a robust method to gain consensus among stakeholders on a model of integrated primary palliative care for older patients with serious multimorbid illness and their families. This is the first ToC in palliative care to engage stakeholders across three different countries.

P 13.010 The Burden of Kidney Disease Influences the Health-related Quality of Life in Kidney Transplant Recipients over Time

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Background/aims: Kidney transplantation (KT) prolongs survival rates and leads to improved but over time declining health related quality of life (HRQOL). We aimed to quantify the difference in HRQOL of KT recipients (KTR) to standardized norms of HRQOL scores of chronic kidney disease (CKD) patients to assess the potential need for a multidimensional care of KTR.

Methods: Follow-ups of 333 KTR involved into the ITP-NODAT study were carried out at 6, 12, and 24 months after KT using the KDQOL-SF, a validated tool to assess HRQOL of CKD patients. We analyzed changes within the SF-36 composite scores for physical (PCS) and mental (MCS) health and disease specific scores for effect and burden of kidney disease (EOKD/BOKD). We compared the results to standardized scores adjusted for renal function in CKD patients we found in literature. We used ANOVA and oneway t-test for statistical analysis.

Results: The HRQOL increased significantly after KT in all subscores (PCS $p < 0.001$, MCS $p = 0.002$, EOKD $p < 0.001$, BOKD $p < 0.001$; ANOVA). However, the subscores differ from the adjusted normative scores of CKD patients (table). While we found higher scores in PCS, scores were lower in EOKD and BOKD in KTR. Psychological burden was comparable high to CKD patients at all time points.

Conclusions: KT increases the HRQOL of CKD patients significantly. However, our results show a persistent impairment of EOKD and BOKD as compared to the CKD population, requiring a multidimensional care after KT.

P 13.011 Self-reported Symptoms and Concerns among Palliative Care Patients and their Families in Zimbabwe: A Longitudinal Study of Outcomes

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Background/aims: The assessment of outcomes is critical in understanding quality of care, and in ensuring that patients & families are able to identify what matters to them. Measurement of the symptoms and concerns that are relevant to patients with progressive illness is essential.

Aims:

- 1) To identify the most burdensome symptoms and concerns faced by patients with life-limiting conditions and their family carers in Zimbabwe.
- 2) To determine change in burden of symptoms and concerns over time.

Methods: A repeated measures observational study collecting patient and family reported outcomes using the Integrated African Palliative care Outcome Scale (IAPOS). The IAPOS is a multi-item outcome measure where higher scores indicate worse outcomes. Data were collected at four timepoints in both inpatient and outpatient settings. IAPOS has been developed to assess patient and family centred outcomes in the African palliative population.

Results: 176 participants aged 19-98 years (mean=48.6, SD=18.2) completed the IAPOS at baseline. 58% of participants had a HIV diagnosis, 32% cancer, and 8% other conditions. 151 participants completed the IAPOS at all four timepoints. The five most burdensome symptoms and concerns at baseline were patient worry, family worry, pain, poor mobility, and advice for family future planning. Mean total IAPOS score at baseline was 39.8 (SD=12.9), patients with cancer had the highest total scores. Total IAPOS scores decreased at each timepoint, mean IAPOS score at the final timepoint was 27.0 (SD=13.3). The decrease in total score was observed for all diagnostic groups.

Conclusions: Patient outcomes consistently improved over time for all diagnostic groups. The most burdensome symptoms and concerns reflect multidimensional and holistic palliative care needs, and that these are measurable. The high incidence of family worries further highlights the need to address specific concerns of family members caring for patients living with life-limiting illness in sub-Saharan Africa.

	Baseline		6 months		12 months		24 months		CKD patients eGFR 30-60 (effect size d)
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
eGFR	7.93	2.88	57.57	22.16	56.16	20.8	55.29	21.31	
SF-36 PCS	41.05	9.47	45.92*	9.70	47.05*	9.06	47.74*	8.37	43.6 (0.50)
SF-36 MCS	46.41	11.01	50.32	9.7	51.84	8.35	51.52	9.04	50.4 (0.12)
EOKD	62.36	23.14	81.72*	16.28	85.26*	13.94	85.21*	13.59	91.6 (-0.47)
BOKD	51.04	25.46	66.73*	26.85	75.16*	21.45	73.50*	24.45	85.4 (-0.49)

* $p < 0.5$ compared to standardized norm value, t-test.

P 13.012 Congruence between the Place of Referral and the Place of Death among a Sample of Advanced Cancer Patients. Retrospective Study Using the CART Tree Methodology

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Background/aims: Place of death (PoD) in advanced cancer populations is determined by an interplay of factors associated with the illness, the individual, and the environment. The role of an hospital-based specialized palliative care team (HBSPCT) includes not just symptom control but also orientating advanced cancer patients and relatives about the best

place for receiving the most appropriate care in the final stage of the illness. The main objective of this study is to evaluate the congruence between the place of referral (PoR) and the PoD of a sample of advanced cancer patients in a teaching hospital in Catalonia.

Methods: PoR information was collected as part of standard care for all patients attended by a HBSPCT. Case notes were reviewed for 1208 patients who died after being referred to the most suitable place of care during the period 2010-2012. Date of death was retrospectively recorded. Classification and regression tree (CART) methodology was used for model development.

Results: A total of 1179 patients were included in the study (16 patients were not finally included for missing data). Lung cancer (n=296; 25.5%) and colorectal cancer (n=185; 15.7%) were the most frequent diagnosis. Patients were referred for home care (n=574; 48.70%), acute hospital

(n=290;24.59%) and intermediate hospital (n=315; 26.71%). The level of congruence was of 74.6% for home referrals (428/574), 98.3% for acute hospitals referrals (285/290) and 90.2% for intermediate hospitals referrals (284/315). The overall congruence was of 84,56% (997/1179). Kappa value was of 0.764.

Conclusions: The CART tree methodology provided additional information about PoR and PoD. A good congruency between the PoR and the PoD can be achieved when referral decisions are mediated by an HBSPCT.

P 13.013 Factors Influencing the Uptake and Implementation of Technology-mediated Advance Care Planning: A Normalisation Process Theory Approach

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Background/aims: Internationally, the use of digital technology to document and coordinate advance care plans is increasing. Electronic Palliative Care Co-ordination Systems (EPaCCS) are an example of this and are central to end-of-life care policy in England. Despite a proposed national rollout, there are critical gaps in the evidence base regarding how they are being used and implemented in routine care. This study aimed to explore the causal mechanisms affecting the uptake and implementation of EPaCCS into routine practice.

Methods: An exploratory qualitative design guided by Normalisation Process Theory (NPT). Healthcare professionals across London and West Yorkshire were sampled by care setting, region, and roles. Semi-structured interviews were conducted. Data were analysed using thematic framework analysis.

Results: 52 participants across six care settings (hospice, hospital, primary care, ambulance, community, care home) were recruited. NPT informed the construction of four themes which represent key mechanisms needed to support the uptake and implementation of EPaCCs into routine practice. These include (i) healthcare professionals seeing the value of EPaCCs; (ii) embedding EPaCCs into routine care processes with collective contributions to their use across care settings; (iii) having digital infrastructure with adequate interoperability to enable embedment and use; and (iv) champions driving implementation.

Conclusions: By using NPT, we identify key causal mechanisms that underpin the uptake and implementation of EPaCCs, from individual level behaviour to cross organisational contributions and national digital infrastructure. If these preconditions are not in place, implementation will be inequitable with potential unintended consequences for care quality and patient safety. These perspectives must be considered as EPaCCs are refined to maximise patient benefit and optimise sustainable rollout nationally.

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P 13.014 Exploring the Barriers and Facilitators to Interdisciplinary Palliative Care in the Home Setting – A UK Study

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Background/aims: Good interdisciplinary working leads to improved coordination of care for patients. Many people wish to die at home and, in the UK, this care is coordinated by General Practitioners (GPs) and community nurses, supported by Specialist Palliative Care (SPC) teams. However, the Coronavirus pandemic changed the delivery of care, more people are dying at home and the community workforce is under increasing pressure.

Aim: To explore the current factors affecting working relationships between these healthcare professionals.

Methods: A purposive sample of GPs, community nurses and SPC nurses participated in online qualitative semi-structured interviews. The topic guide was informed by the literature regarding interdisciplinary relationships. Transcripts were analysed using a reflexive thematic approach.

Results: 20 healthcare professionals have been recruited to the study (recruitment ongoing): 6 GPs, 8 community nurses and 6 SPC nurses. Interim findings suggest the following factors affect collaboration: the number of professionals involved in the patient's care, the degree of trust between colleagues, the same location of teams, judgements about professional competencies, the hierarchical nature of the team, professionals' ability to meet face-to-face, the ease of interprofessional communication and the ease of access to GPs for prescribing and home visiting.

Participants described reasons for disruption to interprofessional relationships including changing roles due to the pandemic, particularly the loss of GP home visiting, the impact of increased workloads, the separation of teams due to location and fewer opportunities to meet face-to-face. This may have led to a loss of coordination of care for patients in the home setting.

Conclusions: There is a strain to collaborative working due to the changes made after the Coronavirus pandemic. This analysis will inform recommendations on how to improve interdisciplinary palliative care in the community.

P 13.015 Hospice Care Helps Deprescribe Prevention Drugs for Cardiovascular Disease in Advanced Life-limiting Cancer Patients: An Observational Study

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Background/aims: Advanced cancer patients are mostly treated with polypharmacy, leading to the risk of adverse effects, drug interaction and big tablet burden. Some medications are for symptoms relieve, but others are used for disease prevention, which are not necessary in terminal cancer patients with limit life expectancy. The aim of this analysis is to assess whether hospice care helps to modify or discontinue cardiovascular medication in the life-limiting cancer patients.

Methods: In our retrospective study, we included advanced cancer patients dying in a single medical center in Taiwan during 2010-2019. Patients were divided into three groups: hospice ward care, hospice combine care, and no hospice care. We examined their clinical characteristics, number of drugs and cardiovascular pharmacotherapy, including anti-hypertension drugs, anti-platelet drugs, lipid lowering drugs and hypoglycemic drugs, within 28 days of death.

Results: 8719 patients were enrolled, with 2097 (24.05%) patients admitting to hospice ward, 2107 (24.17%) patients taking hospice combine care, and 4515 (51.78%) patients had no hospice care involvement. The patients had admitted to hospice ward had a significantly less medication administration number on the 28th day before death (9.20, vs 9.60 and 10.45 p<0.001). Meanwhile, the medication administration for

	anti-platelet drugs			lipid lowering drugs			hypoglycemic drugs			anti-hypertension drugs		
	OR	(95% CI)	p value	OR	(95% CI)	p value	OR	(95% CI)	p value	OR	(95% CI)	p value
No hospice care	ref.			ref.			ref.			ref.		
Hospice combine care	0.63	(0.43-0.92)	0.016*	0.89	(0.53-1.48)	0.653	0.77	(0.66-0.90)	0.001**	0.34	(0.12-0.99)	0.047*
Hospice ward care	0.33	(0.19-0.56)	<0.001**	0.16	(0.05-0.51)	0.002**	0.37	(0.30-0.45)	<0.001**	0.88	(0.40-1.96)	0.757

prevention of cardiovascular events were also significantly decreased in the hospice care groups within the 28 days before death (table).

Conclusions: Our study showed that hospice care in terminal cancer patients reduced the risks and burden of taking multiple medications; the impact was more notable when getting towards the end of life.

P 13.016 Are Dying Hospital Patients Receiving Optimal and Timely End of Life Care?

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Background/aims: With the United Kingdom having an ageing population, more people are ending up dying in hospital. Hence, it is vital that healthcare professionals are able to identify irreversibly deteriorating patients and provide access to optimal and timely end of life care. This study aimed to identify whether this was currently being achieved in a critical care centre in Wales.

Methods: A retrospective case notes review was carried out focusing on patients who had been reviewed by the Critical Care Outreach team (CCOT) between January-June 2021, who had gone on to die within 21 days. Criteria, including a scoring system, was developed by the project team to determine if end of life care was optimal and timely.

Results: After removing duplicate records, 118 of 376 referrals had died at the time of this review. Of these 73 patients (62%) met the inclusion criteria. The average time from CCOT review to death was 4.69 days. 100% of patients had a DNACPR order completed, 29 (40%) of these were completed within the last 24hrs of life. Documentation of conversations with family members about deterioration was present in the majority of cases (n=70), but ceilings of care were not reviewed for almost a quarter of patients. Furthermore, only 14 patients had an appropriately completed Treatment Escalation Plan (TEP) in their notes. In only 6% of cases, the care decisions guidance for the last days of life (Welsh national guidance) was used to guide care. While 27 patients were referred to palliative care services, the average time from referral until death was 2.66 days.

Conclusions: This study found that despite the advice from CCOT that patients were too unwell for consideration of intensive/high dependency care support, irreversibly deteriorating patients still received sub-optimal care based on the scoring system developed. The CCOT and palliative care team are now developing a targeted education plan and aide memoire to be used in the future with this patient cohort and will assess the effectiveness of this.

P 13.018 Palliative Care Quality Indicators in the Intensive Care:

A Scoping Review

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Background/aims: Background: Intensive Care (IC) for the critically ill can benefit from a Palliative Care (PC) approach. Defining specific PC quality indicators in this setting might facilitate a better integration of care.

Aim: To examine and map PC quality indicators in the IC setting.

Methods: We followed Joanna Briggs Institute Guidance. We considered all studies focusing on adult IC units, regardless of type of disease. All studies addressing PC quality indicators were considered. A three-step search strategy was used: 1) initial limited search of Medline and ClinicalKey; 2) extensive search using all identified keywords and index terms across databases; 3) hand search of reference lists of included articles. We considered studies published in English, Spanish and Portuguese in any year.

Results: Fifteen articles were included (from 2004-2022): 5 expert opinion, 3 non-systematic reviews, 1 retrospective analysis, 6 prospective trials. Eight papers focused exclusively on healthcare professionals, 3 on patients and 4 included a mixed population. Seven papers presented PC quality indicators, 5 End-Of-Life care indicators and 3 presented both types. Quality indicators were diverse and heterogeneous, concerning different areas such as outcome, process, and structure. Decision making, including defining the surrogate decision maker, goals of care, advance directives, appeared in 14 papers (93,3%). Communication with the family emerged in 12 articles, 7 also proposed family meetings. Appropriate symptom control (n=10), patient and family psychosocial (n=10, 66,7%) and spiritual (n=8, 53,3%) support were also frequent. The inclusion of a PC consultant was only noted in 4 articles (26,7%) and professional's support in 5 (33,3%).

Conclusions: Discussion/conclusion: Suggested PC quality indicators were diverse. Greatest consensus was verified in those regarding decision making.

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P 13.019 Advanced Cancer Patients Admitted to Intensive Care Unit, Referred to Palliative Care Consult Team. Comparison Study between Years 2007 and 2018

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Background/aims: Patients with advanced cancer may become critically ill in intensive care units(ICU), there is a growing need for palliative care (PCT) in this setting. Our study's aim was to compare frequency, characteristic, interventions and outcomes between ICU AdCa referred to PCT in years 2007(our first report published) and in 2018.

Methods: We retrospectively reviewed PCT consults for ICU pts seen in 2007 and in 2018. Descriptive statistics obtained. The chi-square test was used to analyze ICU and PCT mortality.

Results: Among 1637 PCT consults in 2007, 88(5.4%) were in ICU, vs 186/3884(4.8%) in 2018. Median age was 60 y(IQR:50, 69), 47% female, 67% White, 14% African American, and 9% Hispanic. Median time(IQR) from ICU admission to PCT referral in 2007 was 6 d(2, 16) vs, 2 d(1, 4) in 2018, p<0.001. For both years, interventions were opioid management, antipsychotics, and counseling, DNR conversion(145/274 pts; 67%), withdrawal of Mechanical Ventilation(16/40 pts; 40%), and withdrawal of BIPAP(32/36 pts; 89%). Improvement after PCT reported in pain[Median:5, IQR(1, 7) vs 2(0, 5), p=0.002], dyspnea[5(1, 7)vs 2(0, 4), p<0.001], anxiety [3(0, 6) vs 2(0, 4), p=0.023]. In 2007, 51/88 ICU/PCT pts(58%) died during admission versus 130 of 1549(8%) non-ICU PCT pts(P<.0001), while in 2018, 97/186 ICU/PCT pts(52%) died during admission versus 333/3,698(9%) non-ICU PCT pts(P<.0001); p=NS in

both years. In 2007, 23/35 pts transferred to the PCU(66%) died there versus 212/629 pts(34%) who were admitted to the PCU from another service($P<.0001$), while in 2018, 40/60(67%) died there versus 249/719 pts(35%) who were admitted to the PCU from another service($P<.0001$); $p=NS$ in both years. In 2007, 37/88 ICU/PCT pts(42%) were discharged alive vs. in 2018, 89/186(48%)($p=NS$).

Conclusions: During these years 10 years, there was increased number of PTC-referrals in the hospital, the percentage of ICU consults remained around 5%, the time of referral improved significantly. ICU/PCT pts have severe symptom distress. More research needed.

P 13.020 The Caregiver Care Model to Support Caregivers in General Practice: An Intervention Development Study

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Background/aims: Caregivers to terminally ill patients are in a demanding situation. Caregivers with the highest levels of grief symptoms have more contacts with health professionals such as their general practitioner (GP). Thus, general practice has a golden opportunity to initiate early interventive support.

We aimed to develop and pilot-test the Caregiver Care model for support in general practice.

Methods: Caregiver Care consists of

- 1) a questionnaire to identify needs for support originally developed in palliative care in Central Denmark Region, and
- 2) a conversation guide based on elements from evidence-based grief therapy.

The model was adapted to general practice in co-producing workshops with health professionals, and pilot-testing among 40 caregivers in five general practice clinics. Data included recorded workshops, written feedback from GPs and staff, and interviews with GPs and caregivers. Data were analysed thematically with a specific focus on key uncertainties for using Caregiver Care in general practice.

Results: In general, Caregiver Care was perceived as supportive, especially when the GP expressed recognition of the difficult situation and facilitated caregivers' self-care and focus on own mental health. One GP from a clinic located in a city found it less useful and preferred referral to psychologists. Furthermore, GPs and staff reported a need for a high degree of flexibility.

Major adaptations included expansion of the target group to include not only caregivers of somatically ill patients, but also mentally ill patients.

Conclusions: The Caregiver Care targeting caregivers with need for support was in general positively evaluated with suggestions for improvement from health professionals and caregivers. The model was adapted to accommodate the workflow in general practice and is ready for feasibility testing.

The project is funded by the Danish Cancer Society and the Central Denmark Region.

P 13.021 What Contributes to Promote Sexual Health in Oncologic Palliative Care? A Realist Review

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Background/aims: Sexuality is an important determinant of the overall health of a population, including at the end of life and in advanced

cancers. Despite an abundant literature, sexuality and intimacy are rarely discussed in oncologic palliative care and very few interventions aim to address this concern.

To identify which factors and mechanisms contribute to promote sexual health in oncologic palliative care.

Methods: Realist review following Realist and Meta-narrative Evidence Synthesis. We searched for articles in four databases from January 2010 to June 2021. Records were screened for their relevancy to a predefined list of CMO hypotheses ('context, mechanism, and outcome'). Abstracts were independently screened and data extracted from included full-text articles. Using abductive and retroductive reasoning, each article was examined for evidence to support, refine or refute CMO, guided by the Integrated Behavioral Model as a theory development and to propose guidelines on the development of interventions aiming to promote sexual health in oncologic palliative care.

Results: Of the 2056 articles identified, 38 articles were included in the synthesis. They supported six CMO hypotheses that identified contexts and mechanisms underpinning improvement of sexual health and included:

- (1) improving communications skills,
- (2) health care professionals training,
- (3) reorganizing the patient's environment in hospices care setting or at home,
- (4) managing sexual symptoms but also general symptoms,
- (5 & 6) patient centered counseling or couple counseling.

Conclusions: These findings highlight various ways to improve sexual health for patients in oncologic palliative care settings. However, the available literature focuses on sexual cancer type, making it hard to extrapolate our results to all cancer types.

P 13.022 Developing Methods for Public and Community Involvement in Palliative Care Research among Elderly People with Serious Multimorbid Illness in sub-Saharan Africa

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Background/aims: Many old people in Africa will live with multimorbidity and face a high burden of physical and psychosocial symptoms. Old people's voice matter in designing interventions to meet increasing needs, but there is little knowledge or infrastructure to involve older people in research in Sub-Saharan Africa (SSA). We aimed to develop public and community involvement methods for older people with multimorbid illness.

Methods: In-depth qualitative interviews with older patients aged over 25 years with multimorbidity and families from Ghana, Malawi and Zimbabwe. The topic guide explored what enables involvement in research, how to involve people, how can their voice be heard and what the training and support is required to enable meaningful involvement in research. Data were audio recorded, transcribed, coded and thematically analysed using NVIVO version 12.

Results: Total 42 patients and 42 family caregivers from Malawi, Zimbabwe and Ghana.

The themes identified participants *Motivation* to be involved in research to voice issues of national importance to help themselves and others.

Opportunities to be *Involved in research* through their links with advocacy organisations and community leaders (traditional chiefs, religious leaders). These structures could enable ways to promote opportunities for involvement in research and build trust and partnership working with communities. These structures also formed a means to *Disseminate research findings*, such as through radio stations. *Support* needed included training on how to communicate research findings, funds for transport and meals when attending meetings.

Conclusions: The findings identify meaningful PPI methods of promoting importance of involvement to impact on national issues, involving people through working with local communities to build trusting partners, and practical support to enable PPI. We have formalised PPI methods in three SSA countries.

P 13.023 Exploring the Views of Palliative Care Network Coordinators on How Social Support is Integrated at Patient's Home

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Background/aims: Recent literature on palliative care suggests that the end of life is not only a medical, but mainly a social event, requiring a social response. However, social needs of palliative care patients at home are as of yet unclear. Additionally, there is little insight in the integration of social support provided by formal health care providers (HCP), statutory social services under the responsibility of the municipal council and informal support.

In this study we explore the concept of 'the social dimension of palliative care', as well as the integration between HCP and social care providers in the community, according to coordinators of regional palliative care networks (PCNs) in the Netherlands.

Methods: Six focus groups were held with PCN-coordinators, across all regions in the Netherlands.

Results: Coordinators recognized the social dimension of care as an important theme, that nonetheless receives too little structural attention. In their view, it is both about the social network of a person, and about topics that are traditionally under the responsibility of social workers, such as finances. In their view, municipal councils have no specific attention for palliative care patients., and integration of HCP and social services support is lacking. Mentioned examples for integration were at micro level: the appointment of palliative care case managers, at meso level: linking up with the programme dementia-friendly communities and adding social care providers to the PCN-steering group, and at macro-level: providing national guidance.

Conclusions: The social dimension of care is recognized by PCN-coordinators as an important theme, that however receives too little attention. Integration of social support for palliative care patients at home and their loved ones is still limited. However, there are promising examples for integration and attention for the social needs of people in the palliative phase.

P 13.025 Experiences of a Multidisciplinary Approach in a European Comprehensive Cancer Center

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Background/aims: Multidisciplinary team working in cancer care has entered common clinical practice with heterogeneous models. Multidisciplinary Cancer Clinics (MDCC), with the presence of different

specialists and the patient, aim at improving care coordination and patient involvement. This study aims at describing the experience of MDCC including PC and oncology specialist, psychologist and nurse case manager, for patients treated for metastatic cancer in a Comprehensive Cancer Center.

Methods: This is a longitudinal prospective study on cancer patients attending metastatic uveal melanoma (MUM) or metastatic breast cancer (MBC) MDCC. Socio-demographic and clinical data were collected before MDCC (T0) and after two weeks (T1); The Distress Thermometer (DT) and an ad hoc developed questionnaire for perceived satisfaction with care were also administered at T0 and T1.

Results: 73 patients were included (33 MUM, 40 MBC) with a mean age of 64.25 years, and most frequently female (78.1%). People attended visits alongside their caregivers (78%), had a mean of 2 sites involved by metastasis and their first diagnosis of metastasis was 26,3 months before. The mean number of problems reported at T0 on the DT was 0.5, 2.6 and 3.3 respectively in social, psychological, and physical dimensions. After two weeks, self perception of psychological distress and quality of life were unchanged. The majority of patients reported being "much"/"very much" satisfied with multiple specialists attending the visit (84.9%), with involvement in care (56.2%), and with care coordination (73.6%).

Conclusions: Patients with cancer have complex needs that require a tailored assessment and a shared treatment plan. Our results shows high for satisfaction the MDCC approach here presented.

P 13.026 From Paper to Practice to Patient: Implementing a Quality Framework for Palliative Care in Primary Care

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Background/aims: Considering the ageing population and the wish of many patients to remain in their own home till the end of their lives, it is important that primary care professionals are able to provide good palliative care in the home setting. The Netherlands Quality framework for palliative care describes the standards for good palliative care. How these standards can be achieved and how, often overloaded, GPs and primary care nurses can be reached, is challenging. Our aim is to entice and to facilitate primary care professionals to implement the palliative care quality framework.

Methods: To reach our aim we provide a structured 'translation' of each standard of the quality framework: first into recognizable practice-based questions, then to quality improvement tools and working forms, that are easy to apply in daily practice or to use in multidisciplinary teams, such as the Dutch Palliative Care@home 'PaTz' groups.

Results: We translated the standards on all domains of the quality framework. An example of such a translation is:

All 'translated' standards are captured in a digital handbook, called 'Pepper for PaTz groups'. It is available online for free (www.patz.nu). Its

Standard	<i>The cultural background of the patient, his family and related community are recognized, acknowledged, explored and respected during the care process</i>
Practice based questions that GPs and nurses can recognize from their own daily work	<i>How can I cope with Turkish or Moroccan families who want to continue intensive treatment ?</i>
Quality improvement tools	<i>Short movies in Turkish and Arabic that can be watched together with patients and their next of kin</i>
Working forms to facilitate interactive dealing with the standard	<i>Pictures that stimulate discussion about attitudes towards different cultures; a short list of differences between views of Dutch healthcare professionals and Turkish or Moroccan families, based on the literature.</i>
Background materials	<i>Literature, websites</i>

use is promoted among GPs and nurses in PaTz groups. Healthcare professionals that participate in PaTz groups report an increase of their knowledge and skills by using it.

Conclusions: The gap between paper and patient can be bridged by a structured 'translation' of quality standards to practice-based questions and tools for multidisciplinary team meetings and patient care.

P 13.027 How to Improve Paramedic Responses for Patients Dying at Home: A Theory of Change-based Approach

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Background/aims: Paramedics are often called out to patients who are dying. However, their reported skills and confidence in responding to these calls varies. Various interventions have been piloted to improve these skills, but without a fully specified underlying theoretical model. Theory of change models can provide theoretical and testable links from intervention activities to impact and indicate the areas for assessment of effectiveness.

Methods: Relevant staff - including specialist community paramedics, ambulance call handlers and palliative care specialists - were recruited to five consecutive online workshops. After the primary impact was decided (workshop 1), short-and long-term outcomes and potential interventions were developed through the remaining workshops. During and between these workshops a theory of change model was created, with each iteration shared with participants.

Results: The overall impact (or what the intervention should achieve) was; to provide consistent, holistic, patient-centred, and effective end-of-life care. Four potential long-term outcomes which could be measured were:

- 1) increased use of anticipatory and regular end-of-life medications;
- 2) reduced medication errors;
- 3) Reduced unnecessary hospitalisations;
- 4) Increased concordance between patient preferred and actual place of death.

Key interventions focussed on providing immediate information on what to do in such situations including: appraising the situation, developing an algorithm for a treatment plan (including whether or not to convey to hospital) and how to identify ongoing support in the community.

Conclusions: The study demonstrated that a theory of change approach can work well in this setting and the detailed discussions in the workshops served to create a model which, through its individually testable components, provides a theoretical account of the mechanisms needed to effect change. The next stage of the project is to develop the resources, retaining the input of the workshop participants.

P 13.028 Primary Palliative Care for Patients with Cardiometabolic Syndrome due to Multimorbidity and Patients with Severe Comorbidity and their Informal Caregivers, in Attica, Greece. A Qualitative Analysis

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Background/aims: Patients with cardiometabolic syndrome due to multimorbidity, as well as those with comorbidity present with complex needs. We hypothesized that implementation of primary palliative care interventions by family health care teams could alleviate their suffering.

We aimed to assess their perspectives, when palliation is provided by those community teams.

Methods: Qualitative methodology was used. The Ethical Committee of the 2nd Health Care District of Attica approved the research. 11 pairs (the patient and the main carer) were purposefully sampled and interviewed, after providing written informed consent. Clinical characteristics were recorded. Participants were asked open questions; thematic saturation was achieved and phenomenological analysis was performed.

Results: Mean patients' age was 67 years, 8 were male. 4 patients had severe comorbidity [1) Myasthenia Gravis and renal insufficiency, 2) thromboangiitis obliterans (Buerger disease) and Chronic Obstructive Lung disease (COPD), 3) COPD and prostate cancer and 4) severe cerebral infarction and renal insufficiency]. Patients with multimorbidity had diabetes mellitus, hypertension, and dyslipidemia, leading to coronary heart disease and heart failure. All informal caregivers were female (mean age 51 years).

Patients presented with multidimensional needs. Female carers were physically, emotionally, and economically exhausted.

5 thematic themes were identified, as the result of family care teams interventions: 1) The family physician's competence to address physical symptoms and recommend medications. 2) The beneficial team work, 3) The adequate care of psychosocial needs, 4) The availability in case of an emergency, 5) The encouragement and practical help provided to the informal carers.

Conclusions: Participants experienced significant benefits. Alleviation of suffering at a generalist level seems to be important for such patient's populations.

P 13.029 Terminal Care for Parkinsonian Residents in French Nursing Homes: A 10-year Longitudinal Retrospective Study

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Background/aims: Parkinson's disease (PD) affects approximately 6.5 million people worldwide. This progressive neurodegenerative disease causes a high institutionalization rate and a significant symptom burden leading to palliative care (PC) needs as high as those of cancer patients. However, PC has not yet become an integral part of the care for these patients.

To increase PC development for parkinsonian residents in nursing homes, there is a need to scrutinize current practices during the terminal phase. Therefore, the present study aimed to describe (1) the clinical profile of the residents, (2) the medical team involved during the terminal care, and (3) the place of death, using data over ten years.

Methods: This retrospective study included all nursing home residents who died between July 2012 and June 2022, suffering from PD or related syndromes in the Besançon area, France.

The following information was extracted from the medical files: gender, date of birth and death, place of death, parkinsonian syndrome, follow-up by a neurologist, general practitioner visits, PC mobile team, and neurologist referral during the terminal phase.

Results: The study included 109 residents from 7 nursing homes. Most patients had PD (94/109), followed by Lewy body dementia (12/109) and progressive supranuclear palsy (2/109). The mean age at death was 87±7 years. Most residents died in their nursing home (84/109), and 24/109 died in the hospital after a transfer occurring six days before death. Only 31/103 residents had regular follow-ups with a neurologist. During the terminal phase, 2/88 residents had a consultation with a neurological specialist, 10/90 had access to a mobile PC team, and 63/100 had a visit from their general practitioner.

Conclusions: Many PD residents die in nursing homes, but neurological and PC referrals are suboptimal. Future studies should investigate how the integration of PD into the care of PD nursing home residents can be improved.

P 13.030 Is SPICT™ Really for All? - Translation and Adaptation of SPICT4-ALL™ in Primary Care

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Background/aims: Early identification of people who require palliative care at the general palliative care level is challenging due to a lack of systematics and identification tools. The Supportive & Palliative Care Indicators Tool (SPICT™) has shown to be a conducive framework for this challenge; however, it is known that all healthcare professionals can not use the tool, especially in primary care. Hence, the question is if the tool SPICT4-ALL™ is really for all.

The aim of this study was to translate and culturally adapt SPICT4-ALL™ in primary care and to explore the understanding and applicability.

Methods: SPICT4-ALL™ was translated and cross-culturally adapted using the TRAPD-model (Translation, Review, adjudication, pretesting, and documentation). SPICT4-ALL™ was translated and pretested by conducting three focus group interviews with 16 healthcare professionals (social and health workers and assistants, nurses, and pedagogues) from primary care. The interviews were analyzed through thematic analysis, and the SPICT4-ALL™ was then revised and documented.

Results: The pretesting of SPICT4-ALL™ revealed that the tool was applicable and understandable in a primary care context, but there remain terms that not everyone understands due to language difficulties. The tool raises awareness of early palliative care and provides a common language with other health professionals. All the participants find SPICT4-ALL™ useful in the work with early identification of palliative care needs.

Conclusions: SPICT4-ALL™ is a valuable supplementary tool to the original SPICT™ when used in primary care, where the competencies vary significantly among healthcare professionals. However, it should be used as an interdisciplinary collaboration tool as some terms may still not be for all!

P 13.031 Integrated Palliative Care Visits in Patients with Incurable Cancer in Tampere University Hospital 2018-2021

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Background/aims: Palliative care should be integrated into oncologic care timely to improve cancer patients' quality of life and symptom control. In the Cancer Center of the Tampere University Hospital, oncologists can refer their patients to palliative care outpatient clinic according to their judgement. Referral recommendations include e.g. poor symptom control, need for paracentesis or need for an advanced care plan. Palliative care integration could enhance the timely shift from life-prolonging care to palliative care.

This study aimed to examine which patients are referred to an integrated palliative care visit, the contents of the visit and the care pathways after the visit.

Methods: This was a retrospective register-based study. Cancer patients who had at least one integrated palliative care visit between 1.1.2018-30.6.2021 were included in the study. The follow-up period continued until 30.6.2022. Data from the patient records were derived for descriptive analyses.

Results: During the study period, 207 patients were referred to an integrated palliative care visit. The median age was 69, and 110 patients (53%) were female. The main reasons for referral were poor symptom control

(n=64; 31%) and need for a paracentesis (n=60; 29%). An advanced care plan was made for 69 (33%) patients. Altogether 130 patients (63%) died during the follow-up period. For 19 patients, their care pathway included a shift from life-prolonging care to palliative care with contact with the palliative unit, 54 patients had this shift but died soon after it without contact with the palliative unit and 57 died under life-prolonging care.

Conclusions: During active oncologic care, the need for palliative consultation due to symptom burden seems to be better identified than the need for an advanced care plan. While only a minority of the deceased patients had a care pathway with contacts with the palliative unit, more emphasis should be put on more systematic referral and timing of the integration.

P 13.032 Multi-professional Perspectives on Partnership Working in Care Homes to Support Older People with Advanced Disease

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Background/aims: Partnership working between health and social care is essential to support the rising number of people with advanced disease and complex needs in care homes but barriers to integration persist. The Covid-19 pandemic highlighted both strengths in partnership working and opportunities for improvement.

Aim: To explore professional perspectives on integration between health and social services in care homes to support older people with advanced disease and identify areas for improvement.

Methods: A qualitative study using semi-structured individual online interviews with professionals involved in service provision in care homes for older people in London. The interviews explored partnership working in care homes, the impact of Covid-19, and potential improvements. Eligible participants were identified and approached via existing academic and professional networks. Interviews were transcribed verbatim and analysed thematically.

Results: Fourteen interviews were conducted with representatives from hospice(n=4), specialist palliative care(n=2), specialist nursing(n=1), care homes(n=1), geriatrics(n=2), general practitioners(n=1), community-based pharmacists(n=2), and commissioning(n=1). We identified three key themes: 1) fragmentation of services and variation in practice; 2) hindered inter-system communication (e.g. digital) affecting care; 3) the importance of residents 'being known' by care home staff and the wider team for early detection of deterioration. We also explore the potential of relationship-centred care as a useful conceptual and practical lens to orient the integration of services.

Conclusions: Partnership working in care homes is challenged by fragmented services and limited interoperability in digital communication systems. Our findings support the regular use of holistic assessment tools measuring residents' symptoms and concerns to deliver personalised care and facilitate communication between stakeholders.

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P 13.033 Scoping Review on How Compassionate Communities Promote Advanced Care Planning for Healthy People

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Background/aims: Thorough understanding of the local community culture, attitude of its members, and fostering a social climate that accepts advanced care planning (ACP) is important in the implementation of ACP. This study aimed to map what compassionate community is and its use in the healthcare domain to foster a local culture that encourages learning about and supporting ACP interventions in the community.

Methods: Databases used were PubMed, CINAHL, Cochran, PsychoInfo, and Medline. The keyword is “compassionate community.” The search of the 10-year period from 2012 to 2022 generated 718 search results. A peer review was conducted using Rayyan, and 58 articles were ultimately included in the analysis.

Results: A compassionate community is defined as “a community organized to help all citizens learning to live together, including citizens living with life-threatening illness, older citizens, citizens with disability, and citizens with responsibilities such as childcare and long-term care for older family members.” This term has been used mainly for palliative and end-of-life care in the health care field. However, these analyzed studies also included studies of people with mental illness, daily living disabilities caused by intractable diseases, those who receive child and parenting support, and LGBTs.

Conclusions: Compassionate community is not only about end-of-life events and issues including those linked to life-threatening illness, aging, grief, and bereavement, but also about a community culture that encompasses diverse ways of life across all generations.

P 13.034 Specialist Palliative Care Consultation for Patients with Non-malignant Pulmonary Diseases: A Retrospective Study

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Background/aims: Few patients with chronic non-malignant pulmonary diseases receive specialist palliative care consultation, despite their high symptom burden in end-of-life. Objectives: To study palliative care decision-making process, survival, and hospital resource usage in patients with non-malignant pulmonary diseases with or without a specialist palliative care consultation.

Methods: A retrospective chart review of all patients with a chronic non-malignant pulmonary disease and palliative care decision (palliative goal of therapy), who were treated in Tampere University Hospital between January 1, 2018, and December 31, 2020.

Results: Altogether 107 patients were included in the study. Of the patients, 62 (58%) had chronic obstructive pulmonary disease (COPD), and 43 (40%) interstitial lung disease (ILD). Median survival time after palliative care decision was shorter in patients with ILD (59 days) than in patients with COPD (213 days, $p=0.004$). Involvement of a palliative specialist in the decision-making was not associated with the survival time. Patients with COPD who received palliative care consultation visited less often emergency room (73 % vs. 100 %, $p=0.019$) and spent fewer days in the hospital (median of 7 vs. 18 days, $p=0.007$) during the last year of life compared to those without consultation. When a palliative specialist attended the decision-making, the presence and opinions of the patients and relatives were recorded more often, and the patients were more frequently referred to a palliative care pathway.

Conclusions: Specialist palliative care consultation seems to enable better end-of-life care and supports shared decision-making for patients with non-malignant pulmonary diseases. Therefore, more frequently, and earlier in the disease trajectory, palliative care consultations in non-malignant pulmonary diseases, especially in ILD, are called for. No funding was applied for this study.

P 13.035 Usage of Subcutaneous Route of Drug Administration in a Community Hospice: A Retrospective Study

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Background/aims: Subcutaneous (SC) route of drug administration is common practice in palliative care to manage distressing symptoms, when other routes are not feasible. There is little known about patients receiving SC medications in the community. We evaluated the practice of SC medications, in a community hospice setting where SC medication is prescribed by the clinical team and family, or informal carers are taught to deliver the medication. We aim to understand the characteristics of patients receiving SC medications in the community, the pattern of SC prescribing and outcomes of treatment.

Methods: We performed a retrospective study of patients receiving SC medications. Data was retrieved via Electronic Health Records, from 1/1/2022 to 30/6/2022. Data analysis was done with Microsoft Excel.

Results: 208 patients were identified. Mean age was 70 years old, 51% male. 85% had cancer. Phase of illness on initiation of SC medications: 44% dying, 34% deteriorating and 22% unstable. Performance status was 87% ECOG 4, 13% ECOG 3. 14% were new cases. 11% of patients received Continuous SC Infusion (CSCI), 89% received SC medications regularly, by acute titration or on as required basis. Morphine was most commonly used (93%), followed by haloperidol (52%) and midazolam (8.6%). Indications for SC medications were pain (69%) dysphagia (41%), delirium (34.6%) and anticipatory prescription (20%). 196 patients died. 87% died at home, 10% in the hospital and 3% in a nursing home. 70% died within 7 days of initiation of SC medications. 4 mild adverse events were reported.

Conclusions: Significant number of patients cared for in the community required SC medications. Many required them on the first visit indicating that patients are referred late and with uncontrolled symptoms. This has implications for the planning of community palliative care services. In most cases, SC medication was delivered by informal carers with few minor adverse events. There is low use of CSCI and further research is needed to understand the reasons.

P 13.036 Master Thesis Cand Cur APN, AU DK Nurse Experience with Conversations of a Palliative Nature during “Temporary Stays” at Municipal Institutions - A Phenomenological – Hermeneutic Pilot Project

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Background/aims: The Danish healthcare system is changing towards faster discharge from hospitals. However, the condition of many patients does not allow for them to go home, and therefore municipalities have set up “temporary stays” (DK: “Midlertidige døgnplasser”) providing 24/365 care, treatment and rehabilitation by interdisciplinary teams – only few have resident doctors.

WHO and the Danish National Board of Health together with local organizations, all express need for introducing palliative care at an early stage during serious or long-term chronic illness – regardless of diagnosis. Towards this, conversations of a palliative nature are essential – and nurses are key.

The topic is largely unexplored, therefore the aim was to openly explore nurse experience of conversations of a palliative nature at “temporary stays” located in municipal institutions.

Methods: A qualitative, phenomenological – hermeneutic pilot study based on the method presented in “Reflective Lifeworld Research” by Dahlberg et al.

Data collected through free search and a systematic, academic search in databases PubMed and Cinahl. Two lifeworld-interviews were conducted for the analysis.

Results: Municipalities lack sufficient definition and framework of palliative care and its documentation.

- 1 Nurses do their personal best to provide palliative care but most lack knowledge of tools (e.g. ACP, EORTC, SPICT), and there is a large variance in competencies and communication skills.
- 2 Nurses often feel inadequate re. offering support of the seriously ill and their relatives.
- 3 Nurses request more education in the field of palliative care.

Conclusions: Constituents show signs of nurses doing their utmost re. palliative care. However, organizational restructuring, education and supervision is prominent for improving palliative care at basic level to include earlier stages, instead of being reduced to care for the terminally ill and dying.

P 13.037 Older Patients' Experiences of Implementing Long-term Outpatient Home Care Services

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Background/aims: In Lithuania, the long-term care network is extremely poorly developed, it essentially relies on institutional and informal care. Healthcare services at home are fragmented provided in the social and healthcare sectors and are inaccessible to majority of the country's population. In 2014 47 percent of older patients did not receive long-term care. The aim is to evaluate the experiences of older patients receiving home care services (HCS).

Methods: Qualitative research was conducted using the semi-structured interview method, the research type – thematic. The study involved 17 patients receiving HCS.

Results: The research data is disclosed through 3 main topics. The first one reveals the challenges older people face in receiving HCS. In this topic, the most relevant problems were the decrease in physical capacity of patients, loneliness, a burden on relatives, fear and suffering regarding the end of life. The second theme analyses the needs of older patients receiving nursing services at home. Paramount needs for patients are spirituality, ensuring socialization, and staying at their own homes. Furthermore, technology innovations in homecare were rated as a helping thing for nursing. The third theme summarizes the changes in patients' everyday life after HCS appeared in healthcare. The highlights of patients' experiences – changed relationships with the relatives, emerging expectations, patient autonomy and the concept of HCS as an example of teamwork.

Conclusions: The results revealed positive experiences in providing long-term home care services. Although the concept of HCS in primary health care is brand new in Lithuania, aspects that could improve these services are already being noticed – such as including a spiritual consultant or psychologist in the team to ensure psychosocial needs.

P 13.038 Differences in Palliative Care Provision by Primary and Specialist Providers Supporting Patients with COVID-19: A Qualitative Study

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Background/aims: Hospitalized patients with COVID-19 were supported by both primary palliative care and specialist palliative care physicians. Our aim was to describe the delivery of palliative care by primary providers and specialists to hospitalized patients with COVID-19.

Methods: Palliative care providers completed semi-structured interviews about their experiences providing palliative care to patients with COVID-19. Results were analysed using thematic analysis.

Results: 21 physicians (11 specialists, 10 primary providers) were interviewed; mean±SD age was 41±11 years and 57% were female. Six thematic categories emerged, with differences among both groups. *Care provision:* Primary providers described their support of care discussions, symptom management, managing end of life, and care withdrawal; Specialists also outlined coordinating follow-up. *Patients provided care:* Primary providers described patients at end of life, with comfort-focused goals; specialists included patients seeking life-prolonging treatments. *Approach to symptom management:* despite similar medication use, specialists described comfort, and primary providers discomfort in providing opioids with survival-focused goals. *Goals of care:* while both groups outlined increased engagement of families in these discussions during the pandemic, specialists felt these conversations were code status-focused. *Supporting family:* both groups indicated difficulties engaging families due to visitor restrictions and described supporting families' information needs; specialists also outlined challenges in managing family grief and coping and need to advocate for family presence at the bedside. *Care coordination:* internist primary providers and specialist described difficulties supporting care-coordination for those leaving the hospital.

Conclusions: Primary and specialist palliative care providers may have a different approach to care during the pandemic, which may affect consistency and quality of care.

P 13.039 Does Specialist Palliative Home Care Influence the Sense of Security at Home? First Results from the PROAKTIV Study

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Background/aims: The Canton of Bern finances specialist palliative home care (SPHC) services in a 3-year test phase. Selecting a meaningful study outcome is challenging in patients whose quality of life often reduces when nearing the end of life. This study used a novel main outcome to study the effect of SPHC, namely sense of security at home. *Aim* To study the influence of the availability of SPHC teams on the sense of security at home, advance directives, and anticipatory care planning of palliative patients and their family caregivers.

Methods: An interventional cohort study comparing home care with and without proactive specialist anticipatory care planning. Surveys were filled out at baseline and two and eight weeks after the baseline by patients and family caregivers and after the patient's death by professionals. The sense of security questionnaire range from one (no security) to six (high security).

Results: Forty-four patients, 27 family caregivers, and 78 health professionals were included in the study. The overall sense of security reported by patients at baseline was high in both arms (C:5.8 vs I:5.4); two weeks after the intervention start sense of security decreased in the control arm (5.40) and increased in the intervention arm (5.47)(p=0.6). Descriptive results showed that after two weeks patients more often had an anticipatory care plan in the intervention arm (29% vs 54%, p=0.4) Professionals reported having better access to an updated version of the care plan in the intervention arm (0% vs 40%).

Conclusions: SPHC teams could be the care service that operates in the area between normal ambulant home care and institutionalization by providing care planning and providing a secure home situation as long as possible. This study could not show a significant increase in the sense of security at home in the intervention group. Nevertheless, the small

study population decreases the robustness of this conclusion. Descriptive analyses indicated care coordination and planning quality improved.

P 13.040 Local Interorganizational Vision and Strategy Building Concerning Primary Palliative Care: The Chronic Care Model Applied to Palliative Care

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Background/aims: During a primary palliative care implementation project in five Belgian areas (2013-2016), local GP circles and palliative care networks were involved. To understand their possible role, a survey was developed, based on the Chronic Care Model's "Assessment of Chronic Illness Care". The "Assessment of Chronic Illness Care – Palliative Care" (ACIC-P) survey aimed to study ideas of representatives of palliative care networks and GP circles on meso-level inhibitors and facilitators for the implementation of palliative care.

Methods: In 2015, the ACIC-P was co-developed with participating palliative care networks, with extra attention for informal care givers, and for a holistic perspective. The order of the ACIC-P themes is from bedside towards abstract. The 0-11 scores changed to four responses. The survey was built as a Qualtrics® online survey in French and was translated to Dutch.

The survey was filled until 5/2016, in French from 10/2015 and in Dutch from 2/2016. The participating GPs were asked to fill the survey. The five palliative care networks were asked to fill the survey; most of which asked the GP of their multidisciplinary home care team to fill it. The survey was mentioned at a French-speaking palliative care conference. The five palliative care networks organized meetings with GP circles' representatives to fill and discuss the ACIC-P.

Results: 39 surveys were filled in French, 27 in Dutch. 14 responses were excluded: eight respondents were not from the studied areas, six responses were incomplete.

Out of 52 included responses, 27 respondents stated that there are no regional plans on palliative care.

Out of 52 respondents, 31 stated that there are no (palliative care) patient lists. GPs working from a population perspective appear to be rare, particularly for palliative care.

Conclusions: This ACIC-P survey suggests that in Belgium palliative care is organised bedside, with little vision and strategy of meso-level partners. However, the ACIC-P promoted joint reflection on this subject.

P 13.042 Oral Health and Palliative Care: A Report of a Collaborative Approach

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Background/aims: The prevalence of oral cavity symptoms in the palliative population is about 86%. Therefore, an active collaboration between home-based palliative care teams (HBPCT) and local oral health teams (OHT) may promote proximity, brevity and effectiveness of oral care and improve the quality of life of palliative care patients.

Methods: A plan of interdisciplinary cooperation for integrated care was elaborated between the local HBPCT and the local OHT. The referral criteria were established and referral was made through the

existing informatic system. The interdisciplinary sharing of clinical data was guaranteed by the patients' electronic medical record. The shared discussion of photographic records was carried out in scheduled interdisciplinary consultations. A joint plan of care (both pharmacological and non-pharmacological) was established and family/caregivers were educated. A pilot study was conducted with patients admitted to the HBPCT.

Results: The collaborative plan focused on the creation of channels of action prioritized by the symptoms of patients. Five dimensions of action were developed: 1 - sensitization and training of the health professionals involved; 2 - information and prevention of oral problems in patients followed by the HBPCT; 3 - evaluation of the photographic record and all lesions and oral conditions diagnosed; 4 - home evaluation by the OHT service; 5 - preparation of individualized therapeutic plan.

Conclusions: The establishment of direct communication channels between the HBPCT and the OHT proved to be relevant in the timely approach of more or less complex oral manifestations in palliative care patients and supporting their families / caregivers. Not being part of the core palliative care team, oral health professionals are important players in the paradigm shift for a transdisciplinary team in palliative care. A longitudinal study of this collaboration would be interesting and continuous quality improvement and monitoring is mandatory.

P 13.043 Palliative Care Evaluation Predictors on High-grade Gliomas

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Background/aims: High-grade gliomas have poor prognosis, with a median survival of 12-14 months. Randomized controlled trials have shown that early systematic integration of palliative care (PC) in oncologic patients improves quality of life. However, a low percentage of patients are referred to PC and these evaluations are late. Main objective: to determine PC evaluation predictors. Secondary objectives: estimate the proportion of patients referred to PC, the time of evaluation and clinical status at the first PC evaluation.

Methods: We performed an observational, retrospective, descriptive study including patients with high-grade gliomas evaluated in the radiation oncology department of our center between January 2016 and December 2019. Sociodemographic and clinical variables, treatment and corticoid need were analyzed as possible evaluation predictors.

Results: 144 patients were included. Median overall survival was 13.4 months. 66.7% patients were evaluated by PC. 59.7% of patients had functional impairment. Median time between PC valuation and exitus was 1,68 months.

Patients with tumors that crossed the midline, in whom surgery cannot be performed or complete macroscopic resection was not achieved, who cannot complete the planned treatment with chemotherapy or who require corticosteroids during chemotherapy, who required 2 or more hospitalizations or who progressed after treatment were evaluated by PC ($p < 0,05$).

Conclusions: Some poor prognostic factors such as tumors that cross the midline, no complete macroscopic resection, who cannot complete the planned treatment or who require corticosteroids during treatment could benefit from early valuation by PC.

Although more than 60% of patients were evaluated to PC, this evaluation was late, and almost 60% of patients had marked functional deterioration. Prospective studies must be performed to determine other early referral factors in this patients.

P 13.044 Triage in Home-based Palliative Care Teams: A Scoping Review

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Background/aims: Home-based palliative care teams (HBPCT) often face the challenge of managing waiting lists in a efficient and fair way, in order to prioritise access of patients in need of palliative care (PC).

Aim: To investigate triage tools for admission in HBPCT.

Methods: A scoping literature review following the methods described by the Joanna Briggs Institute and PRISMA-ScR recommendations was conducted. Data was collected from electronic databases (MEDLINE, PROSPERO, LILACS, Cochrane Library, Scielo and Scopus). Reference lists were hand searched. Eligible papers were those reporting the development or use of triage systems used by HBPCT. A descriptive qualitative content analysis was made.

Results: From 931 potential papers, 3 were included.

One study used the Edmonton Symptom Assessment System in home-based PC, sorting patients in high (ESAS scores ≥ 7 , home visit in 0-3 working days), medium (ESAS scores 4-6, home visit in 0-10 working days) and low (ESAS scores 0-3, home visit in 0-15 working days). Authors concluded that this triage system facilitated early intervention, improved symptom control, and decreased hospital deaths.

Another study used a triage tool for community PC created after retrospective data collection and analysis and semi-structured interviews with PC staff. It was concluded that this tool was an accurate guide to patients needs and effective in assessing the urgency of need.

A third study created a triage tool after a series of qualitative studies, to apply to different PC settings (including HBPCT). International discrete choice experiment involving PC clinicians established the relative importance of seven key attributes of PC triage, later incorporated on the final version of the triage tool.

Conclusions: This review demonstrates the complexity of PC triage, namely for HBPCT, as well as the scarcity and heterogeneity of work in this topic. Although referral criteria and complexity in PC are well documented in the literature, more studies are needed about triage systems.

P 13.045 The Influence of Ethnic and Cultural Background on Perception of the End of Life in Israel

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Background/aims: Notwithstanding the many difficulties the country faces, Israel is a rather successful melting pot of entirely different cultures. The diversity of the population in the Galilee is reflected in our patient population, our hospice staff and greatly influences our work as a hospice team.

Views and attitudes regarding health, illness and especially the end of life differ greatly between these populations. There are Jews from western European descent, Jews from Arab countries, Palestinian Arabic families, Druze, Orthodox Jewish patients and entirely non religious citizens. There are new immigrants from Ukraine, Russia, Ethiopia, India and many other countries.

As a palliative care physician, who has worked in The Netherlands most of his life, this enormous range of views, ideas and sensitivities was one of the most difficult tasks having to adopt to, working in this country, after I immigrated to Israel in 2016.

In this presentation we aim to examine and illustrate the above differences.

Methods: We will present a ten minute attractive movie, consisting of interviews with patients, carers and team members from different parts of Israeli society. A list of questions will be asked to all interviewees. The interviews are focussed on views about end of life decisions. Should one be honest about the diagnosis and the prognosis? Do we have to administer fluids at the end of life? What about artificial feeding when a patient probably has a limited prognosis? Do the different religions allow for administration of sedatives and analgesics even if this could shorten ones lifespan?

Results: We will examine the differing attitudes and opinions about end of life decisions in a hospice care setting and try to form a view about the implications of these differences for our practical day to day work.

Conclusions: Attitudes toward end of life decisions are, influenced by the cultural and religious background of patients and their families. This has implications for how palliative support is being given.

P 14 - Communication

P 14.002 Factors Associated with Recording a Preference for Place of Death. Analysis of Routinely Collected Data from an Electronic Palliative Care Coordination System before and during the COVID-19 Pandemic

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Background/aims: Consideration and documentation of where individual patients want to die is an important component of advance care planning and helps facilitate care aligned with patients' wishes.

Aim: To examine factors associated with recording a preferred place of death in Coordinate My Care, a large Electronic Palliative Care Coordination System in London.

Methods: Adults with a Coordinate My Care Record, between 01/01/2018 and 05/03/2021 were included. Multivariate Logistic regression modelling was used to identify clinical, social and demographic factors associated with documenting preference for place of death, including timing of record creation in relation to the COVID-19 pandemic.

Results: 72,591 records were analysed (52,006 (71.6%) with a recorded preferred place of death and 20,585 (28.4 %) without). Individuals with a recorded preferred place of death were more likely to be older (Aged 80+ compared to <80) OR: 1.19, CI 1.14 – 1.24), less functionally independent (WHO performance status 4 compared to 1, OR: 1.28, CI 1.19 – 1.37), have a "Do Not Attempt Cardio-Pulmonary Resuscitation" status (OR: 1.70, CI 1.60 – 1.80), be from least deprived areas (compared to most deprived, OR: 1.08, CI 1.01 – 1.16), live in a care home (OR:1.42, CI 1.35 – 1.50), create their record in the General Practice setting (compared to hospital OR: 1.42, CI 1.34 – 1.53) and have created their record during the initial wave of the pandemic (compared to pre-pandemic OR: 1.56, CI 1.49 – 1.63).

Conclusions: Health status, socio-economic circumstances, and timing in relation to the COVID-19 pandemic were associated with having a documented preference for place of death. This has implications for professional training and patient empowerment in terms of having conversations about what matters most to patients at the end of life and how to provide patient centred end-of-life care.

P 14.003 First Encounter with the Palliative Care Team from the Perspective of Patients, Family Carers and Professionals

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Background/aims: The first encounter in palliative care (PC) can be understood as the basis for establishing a therapeutic alliance with the patient and their families to deliver quality patient-centred and family-centred care. Further understanding of the factors that lead to a significant first encounter is necessary to address PC goals of care -prevention and relief of suffering from all dimensions of need. To explore the first encounter with the PC team from the perspective of the patient, the family carer and the PC professional and to understand what they expect from the encounter.

Methods: We conducted a qualitative phenomenological descriptive study using content analysis of semi-structured interviews with 20 patients with cancer, 20 family carers and 20 PC professionals (physicians and nurses) from 10 palliative care services in Spain.

Results: The analysis resulted in four main themes:

- (1) Understanding the goals of PC: need to overcome the barriers to PC due to its negative connotation and the first encounter as a strategy for comprehension;
- (2) Patient-centred care as an added value to the care: holistic support and participation in care;
- (3) Building rapport based on trust: network of support and commitment throughout the illness process and
- (4) Being recognized which appeared as an overarching theme related to the need to be understood, accepted, taken into account and consulted.

Conclusions: The first encounter allows to establish a therapeutic relationship based on trust through a greater understanding of PC and a present and future commitment with the patient and his family.

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P 14.005 Development of a Theory-based Intervention to Help People with Cancer with Starting a Conversation about Palliative Care: Combining Intervention Mapping with a Participatory Approach.

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Background/aims: Communication about palliative care is often postponed or avoided by both people with cancer and their physician. Therefore, the purpose of this study was to develop a theory-based intervention aimed at 1) empowering people with cancer to start a conversation about palliative care with their physician and 2) supporting physicians in reacting appropriately.

Methods: We followed the first four steps of the Intervention Mapping Protocol (i.e. needs assessment, defining program aims, selecting theoretical methods and practical applications and program design) and used a participatory approach. The co-creation process with patients and

physicians, other potential stakeholders and experts (n=22) included three semi-structured sessions (two individual and one group session), and six-weekly discussions with a multidisciplinary research team.

Results: The patient behavior was defined as starting to use the words palliative care either verbally or by showing palliative care documentation or alternative words that cannot be interpreted very differently (e.g. comfort care). The physician behavior was defined as taking minimal time to find out how the patient's question or concern raised and how the patient feels about it. Knowledge, attitude, perceived behavioral control and perceived social norm were selected as factors to target. The intervention was named My Care My Voice. To help people with cancer, a movie, poster, flyer, pen and website were developed. To support physicians, a poster, online training and conversation card were developed. These materials cover methods such as advance organizers and tailoring information.

Conclusions: Combining Intervention Mapping and a participatory approach resulted in intervention materials addressing the specific needs of people with cancer and their physicians regarding starting a conversation about palliative care. The materials are currently being tested on acceptability and feasibility.

P 14.006 How Palliative Care Clinicians Learn to Overcome Communication Challenges: A Qualitative Analysis of Survey Responses

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Background/aims: In a large survey of Swiss palliative care (PC) clinicians' comfort and competence with different communication tasks, we aimed to understand their emotional experiences when communicating with patients as well as how much their communication skills had evolved since the beginning of their career.

Methods: Between October and November 2021, Swiss PC clinicians were invited to participate in an online cross-sectional survey. The last four survey questions were open-ended and invited participants to reflect on the development of their communication skills and on their emotional experiences when communicating with patients in PC. Answers to the open-ended questions were analysed thematically.

Results: The survey was completed by 242 clinicians who were 50 years old in average. The majority were women (79%) and had over 11 years of PC experience (50%). While some described a positive evolution of their skills and reactions, others wanted more support. From the different accounts, we identified six aspects which helped clinicians overcome their fears and improve their confidence: 1) connecting with emotions (patient's and one's own), 2) acknowledgement of individuality, 3) sharing experiences with others, 4) taking time, 5) learning by doing, and 6) life experience.

Conclusions: Participants described a gamut of powerful emotional experiences ranging from anger, guilt, powerlessness, loneliness, sadness, and helplessness, to serenity, sense of purpose, and satisfaction. In transforming those reactions, life experience and professional experience improved their familiarity and thus led to a sense of mastery with different tasks and in understanding their reactions. As it takes time to acquire personal and professional experience, formal and informal support from others may be key in processing strong emotions. This study advances our current understandings about the role of emotions and the value of personal experience and peer support in improving clinicians' comfort with end-of-life communication.

P 14.007 How Physicians Consider Nurses' Role in Decision-making about Life-prolonging Treatments: A Qualitative Interview Study

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Background/aims: In hospitals, decisions about starting, continuing, forgoing or withdrawing potentially life-prolonging treatments are often made in dialogue between a patient and their physician. Nurses can have a valuable contribution in this process, since they are often more aware of patient's preferences and context. However, nurses are not always involved in the decision-making process, nor seem invited by physicians to share this information.

Therefore, we aimed to explore physicians' perception on nurses' role in decision-making about potentially life-prolonging treatment in patients with a short life expectancy and physicians' considerations to involve nurses in these decision-making processes.

Methods: We conducted semi-structured interviews between May 2019 and September 2019 with physicians. Data were analyzed following the principles of thematic analysis.

Results: Fifteen physicians, working in different hospitals and medical specialties, were interviewed. Physicians stated that they are responsible for the final decision about potentially life-prolonging treatments. Nurses' role in decision-making was mostly considered by physicians as complementary towards both patients and physicians themselves. For instance, by supporting patients with framing their wishes and by informing the physician about the patient's condition and preferences. Not all physicians found nurses' involvement in decision-making necessary, but they considered nurses' involvement more useful when it concerned a complex patient situation or in cases of doubts about the best treatment options. However, physicians also experienced practical obstacles for involvement of nurses, such as lack of time and shortages in nursing staff.

Conclusions: Physicians recognize a complementary role for nurses in decision-making about potentially life-prolonging treatment, especially in case of doubts or complex situations.

P 14.008 Not Preferred, but Still the Most Common Place of Death: What Factors Influence Dying in Hospital in an Urban Area?

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Background/aims: Hospitals remain the most common place of death - with higher numbers in urban areas - although most patients prefer to be cared for and die at home. Place of death is considered an important indicator for end-of-life care quality. Aim was to explore factors influencing hospital death in an urban area.

Methods: Postbereavement survey using the validated German "Views of Informal Carers' Evaluation of Services – Last Year of Life – Cologne". The sample comprised deaths from all causes except for accidental and suspicious deaths. A multivariable logistic regression analysis was conducted to identify influencing factors.

Results: Response rate varied between recruitment strategies (10.3% for personal distribution, 21.1% for postal distribution and 74.9% for self-selection). The sample included 351 deaths, 42.2% died in hospital, 27.6% at home, 17.7% in an in-patient hospice, 11.7% in a care home, and 0.9% somewhere else. On average, patients who died in hospital were slightly younger (mean age: 74.17 (SD 12.447)) than those who died out of hospital (mean age: 78.15 (SD 13.163)). The gender distribution was nearly even with 50.7% women. Not receiving care from a specialist palliative home care team (OR: 6.169), the number of

hospitalisations in the last year of life (OR: 4.268), not having an advance directive (OR: 2.958) and not expressing a wish for place of death (OR: 2.303) increased the odds of dying in hospital. While a high nursing care level dependency reduced the odds of hospital death (OR: 0.206), being told that the disease was leading to death did not reach significance.

Conclusions: This study identified potentially modifiable factors that may help patients to die at their preferred place of death. The provision of specialist palliative home care appears to have a major impact on place of death. It is of utmost importance to encourage health care professionals and patients to routinely discuss and record preferences for end-of-life care and place of death.

P 14.009 Addressing the Gap in Evidence of Patient and Caregiver Perspectives on Electronic Palliative Care Coordination Systems (EPaCCS) for Documentation and Sharing of Advance Care Plans

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Background/aims: Electronic Palliative Care Coordination Systems (EPaCCS) are designed to document and share information about the care preferences of people living with chronic, progressive illnesses. This is to ensure that any health professional (HP) involved in that person's care has access to the most up-to-date information. The intended benefits of EPaCCS have been framed around organisational structure and process changes, rather than patient outcomes. We sought to address a significant gap in the research literature by exploring the views and experiences of patients and caregivers on the role of EPaCCS in care delivery.

Methods: We conducted separate focus groups for people with progressive, chronic illnesses and caregivers to explore perspectives on EPaCCS. Participants were recruited from four hospices and three patient support groups, in two regions of England. To analyse the data we employed a thematic analysis.

Results: We conducted six focus groups with people with progressive chronic illnesses (n=10) and caregivers (n=13). Three key findings with commonality among participants included: i) uncertainty on the existence of EPaCCS records or its sharing across providers; ii) scepticism and anxiety that support would be realised despite documentation of care preferences, and; iii) a desire for access to and the ability to edit their own EPaCCS records.

Conclusions: Novel patient and caregiver perspectives indicate a lack of awareness of the presence and content of EPaCCS records being used to inform care delivery or their ability to help realise care in line with preferences. This study suggests that whilst EPaCCS seek to facilitate the delivery of personalised care, they are not understood or trusted by those they seek to support. Patient- and caregiver-led adaptations to EPaCCS may be required, such as enabling patient access to view and edit their record. This could, for some, provide a route to acknowledging and validating records ensuring they continue to reflect their wishes.

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P 14.010 Development and Evaluation of an ACP Conversation Tool for Professionals Providing Dementia Care in Primary Healthcare

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Background/aims: Both professionals and dementia patients in primary care are hesitant in initiating advance care planning (ACP) conversations and rarely complete advance directives. In this study we developed and evaluated a conversation tool that supports primary healthcare professionals in engaging in conversations concerning patients' wishes and preferences for future issues.

Methods: We developed a conversation tool, based on (1) relevant literature (2) semi-structured interviews with 9 people with dementia, 9 relatives, and 4 general practitioners (GPs), and (3) 2 focus group interviews with dementia case managers (DC). Secondly, 3 GPs, 3 geriatricians and 18 DCs tested the tool in daily practice while participating in two supervision and peer-to-peer meetings. Semi-structured interviews were conducted with professionals, patients and relatives. We applied qualitative thematic data analysis using Atlas.ti software.

Results: The tool contains six conversation topics: daily enjoyment, daily care, medical treatment, coping with dementia and approaching death, financial and legal issues, and social networks. Users indicate that the conversation tool provides structure and support when planning and starting conversations, and is easily incorporated in daily practice. After piloting and some minor amendments in formulations and lay-out, the conversation tool now has a final format. Since the conversation tool is finalized, professionals puzzle how to implement it on large-scale in daily practice as a way of collaborating in ACP.

Conclusions: The conversation tool has been shown to help facilitate ACP conversations. Future initiatives should focus on large-scale trans-mural implementation and providing digital file formats.

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P 14.011 Connection by Genuine Contact and Play

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Background/aims: An encounter between the hospital clown and a child or person starts with making contact, in which the other person can feel seen and heard. The clown does this by taking in the room, probing who the other person is, how he or she feels at that moment, but also by observing the other people present and then adjusting his play accordingly. The specific skills of the hospital clown can be directly translated to the practice of providing care.

The CliniClowns use play to get the other person moving, physically or mentally. The main key words in play are: making contact offer safety connecting.

In these core values the CliniClowns and the healthcare professional find each other. Both act on the basis of contact. Its sole purpose is to provide distraction, fun and relaxation, often with anxiety and stress reduction as its effect. But also empowerment, feeling seen and heard and or being challenged are effects that can be achieved through play.

Methods: We work in this workshop with interactive exercises and game assignments to really experience the potential of your perceptive abilities.

Results: In this workshop you become aware of (physical and emotional) information present in space even before people address each other with words. This information turns out to be reliable and useful in communication. Furthermore the participants learn about the purpose of play and games.

Conclusions: Participants gain knowledge about the value and impact of play and arts (clowning) interventions in the palliative care. How play, distractions and real connection result in resilience, pain- and stress reduction and a higher emotional well-being.

And: Experience the value of (communication) skills and methods that the healthcare clown uses to connect and align with the other.

Learn and experience to connect with others through play and navigate emotions from fear to trust.

Is able to apply these skills in one's own practice for the benefit of the client and the healthcare professional

P 14.012 Implementation of the Serious Illness Care Program - A Qualitative Study from Physicians' Perspectives

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Background/aims: Having person-centered discussions about goals, values and priorities with patients that are serious ill are associated with improved palliative healthcare. The Serious Illness Care Program is a multi-component program that can facilitate more, better, and earlier discussions between clinicians and seriously ill patients. For successful sustainable implementation of the Serious Illness Care Program it is important to consider how stakeholders perceive the intervention. The aim is to explore physicians' perceptions of implementing the Serious Illness Care Program into practice.

Methods: Data were collected through four focus group discussions with physicians (n=14) when implementing the program at two hospitals in Sweden. A deductive-inductive thematic analysis was used and the Consolidated Framework for Implementation Research was applied during the analysis.

Results: The physicians' perspectives on the implementation included three areas: (1) individual professional level understood as hovering between preparedness and unpreparedness, (2) being impacted or impactful in a system of colleagues, team culture and organization preparedness, and (3) intervention characteristics such as appropriateness, acceptability and perceived feasibility.

Conclusions: This study identifies key aspects at organizational and individual levels that influenced the implementation of Serious Illness Care Program. The understanding of aspects critical to the success of the implementation provides insight and guidance for adjusting implementation strategies to facilitate sustainable integration of Serious Illness Care Program into hospital care.

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P 14.013 Adaptation of the Serious Illness Care Programme in the Czech Republic

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Background/aims: Conversations between clinicians and patients about patients' priorities and values are necessary to achieve goal-concordant care, but leading those conversations is challenging. Using conversational guides, such as the Serious Illness Care Programme (SICP), can be useful to help clinicians navigate through this process. This project's aim was to adapt SICP and its pediatric version for use in the Czech Republic.

Methods: The adaptation was conducted through a multi-stage process. Firstly, the Serious Illness Conversation Guide and the Paediatric Serious Illness Conversation Guide were translated into the Czech language by a professional translator and subsequently revised by the research team. During the second stage, both revised guides were submitted for a revision to expert panel consisting of 17 physicians experienced in palliative care and communication. An agreement regarding the translation was achieved after 2 rounds in the paediatric version of the guide and 3 rounds in the adult version. This stage was followed by cognitive interviews with adult patients, paediatric patients, and parents (4 in each group) to assess the relevance of the questions, its wording and understandability. Findings of the cognitive interviews were discussed within the research team and amendments to the guides were made accordingly.

Results: By using different techniques it was possible to successfully adapt both guides to the local culture. The involvement of patients in the adaptation process was an important aspect, highlighting the need for a trusting relationship with the clinician and right timing of the conversation. Both professionals and patients highlighted the value of such communication guides.

Conclusions: Although the adaptation of SICIP into a different cultural context can be a challenging process it represents an important step towards better communication between clinicians and seriously ill patients. The Czech version of the SICIP is now available to be further tested in clinical practice.

P 14.014 Development of a Programme Theory of Shared Decision-making in Malignant Bowel Obstruction: A Realist Review with Stakeholder Engagement

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Background/aims: Malignant bowel obstruction (MBO) is a distressing complication of cancer and can be a terminal event. Treatment outcomes are difficult to predict, with little guidance for clinicians on how to conduct decision-making in a way which aligns with patients' values.

Methods: Using realist review and synthesis (PROSPERO ID: CRD42022308251) a programme theory of optimal decision-making in MBO was developed through the systematic searching of 8 databases, grey literature and patient information, and stakeholder consultation. Searches focused on clinician and patient experiences of decision-making around MBO treatments (surgery, gastrostomy, medication, parenteral nutrition). Studies were assessed for rigour and relevance following RAMESES guidance for realist reviews.

Results: From 44 key papers, three contexts characterising decision-making in MBO were explored: i) *Ambiguity and uncertainty* around treatment pathways emerging from inconsistent definitions of goals of care across interdisciplinary boundaries. Lack of acknowledgement of the uncertainties contributed to unrealistic expectations of treatment. ii) *Role-based dynamics* created barriers and facilitators to effective multi-disciplinary collaboration and patient (or surrogate) involvement in decision-making. Pre-existing relationships between patients and practitioners can inhibit open communication. iii) *The circumstances of care* involve treatment across multiple settings, each with a unique ethos of care, leading to communication with patients and families which is sometimes experienced as inconsistent or contradictory.

Conclusions: Decision-making in MBO is an iterative process requiring constant renegotiation: involving patients requires a unified understanding of goals of care across interdisciplinary boundaries, consistent communication across multidisciplinary teams, and open acknowledgement of uncertainties around treatment outcomes.

P 14.015 Contextual Factors in the Implementation of Advance Care Planning for Older People in Long-term Care Facilities in China: A Qualitative Study

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Background/aims: Advance care planning (ACP) may improve patient involvement in decision-making processes at the end of life. However, existing evidence is Western-dominated, and contextual factors for ACP implementation within long-term care facilities (LTCFs) in Asian countries remain unknown. We aimed to identify potential contextual

factors (facilitators and barriers) in the implementation of ACP in LTCFs in China.

Methods: We conducted semi-structured interviews with purposive sampling of residents, family members, and healthcare providers in four nursing homes. Using reflexive thematic analysis, data were analysed inductively and deductively based on the Consolidated Framework for Implementation Research.

Results: 12 residents, 10 family members, and 14 healthcare providers participated. Five themes were generated: (1) 'Death-denying culture' - lack of public awareness, information concealment, and negative feedback on end-of-life care conversations were barriers to ACP implementation in LTCFs, whilst seeking painless death was a facilitator; (2) 'Aligning with family interests' - concerns about burdening family, personal and legal risks of "giving up", and the decision-making responsibility shift to the nominated family representative (i.e. guardian) were barriers; (3) 'Living with uncertainty' - uncertain diagnosis and prognosis and living in the moment were barriers; (4) 'Individualised and tailored approach' - identifying conversation triggers, pre-ACP readiness assessments, and informally introducing ACP were facilitators; (5) 'Build a support system' - ACP awareness campaign, legal support, social worker involvement, and providing staff training were facilitators.

Conclusions: In order to promote ACP implementation in LTCFs, the role of the guardian must be acknowledged, and organisational culture should be respected, such as promoting in-the-moment decision-making and initiating ACP in an individualised way. Findings will inform the development of ACP implementation plans in LTCFs in Asian countries.

P 14.016 A Mixed Methods Exploration of Oncology and Palliative Care Healthcare Professionals Experience of Virtual Consultations

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Background/aims: Virtual consultations (VC) were widely used during the Covid-19 pandemic to ensure continuity of care. Prior to this, little was understood regarding healthcare professionals' (HCP) experiences in translating their care to this modality.

Exploration of oncology and palliative care HCP experience of VC, and the future role of VC in patient care.

Methods: A cross sectional mixed methodology observational study of oncology and palliative care HCPs, analysed via an inductive thematic approach.

Results: 87 surveys completed within a one-month period identifying three master themes. Relationships and connection highlighted the influence of VC in empowering patients, the importance of a therapeutic relationship and its perceived loss within VC modalities. Majority of respondents reported considerable challenges having difficult conversations with patients using VC. Many survey respondents emphasized that they preferred to have first time consultations face-to-face, and not virtually. Personal, professional, and familial theme included factors of patient age, severity of illness and VC skill (patient and professional) in influencing HCPs' experience. Within the domain of logistical and practical implications, increased accessibility was seen as a benefit of VC, as well as the environmental benefits of reduced travel and time. Participants raised concerns regarding overlooking clinical signs and an inability to examine patients, necessitating increased follow up requirements, alongside the anxiety faced with occasionally failing technology.

Conclusions: VC benefits were mainly noted when used for patients already known to the professional, during stable treatment reviews. VC for difficult discussions and for unstable patients were felt to be unsatisfactory and a barrier to their use. There was a strong

preference for patient choice in choosing the preferred consultation modality, alongside prior triaging of the appropriateness of VC for individual patients.

P 14.017 Pallicast - Disseminating Education and Knowledge on Palliative Care in Brazil

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Background/aims: The implementation of palliative care in Brazil has encountered several obstacles, some deeply related to lack of education and misinformation on the subject. Podcasts have the potential to facilitate communication and reach a broader audience that includes clinicians, patients and general public. In 2019, the innovation committee of the Brazilian Academy of Palliative care presented a proposal for a palliative care podcast.

Methods: In three years, 46 episodes were recorded and shared in Spotify, Apple podcasts and other major platforms, reaching over sixteen thousand listeners. This study aims to briefly describe the podcast and its content and conduct an analysis of podcast listenership. Data were analysed for frequency of plays and geographical location between October 2019 and September 2022

Results: The initial project was developed by the Innovation Committee of the Brazilian Academy of Palliative Care. To our knowledge it was the first educational palliative care podcast in Portuguese. During the 3-year period this podcast was aired biweekly, 45 episodes were produced and accessed by 16453 listeners. Most listeners use Apple podcasts as a preferred platform. Pallicast reaches people in 4 of the 5 regions in Brazil (Northeast, Center-West, Southeast and South). The presenters have interviewed during this period several specialists, including doctors, nurses, physical therapists, social workers, occupational therapists, lawyers, bioethics specialists and a cancer patient. The most viewed episodes featured: the role of occupational therapy (1076 views), palliative sedation (692 views) and Palliative care: a patient's perspective (685 views).

Conclusions: A palliative care podcast in Portuguese showed the potential to bring education and discussion on palliative care to several regions of a continental country. Future work should focus on the development of impact analysis and strategies to reach a broader audience.

P 14.018 A Long-term Follow-up of the Family Talk Intervention When a Parent with Dependent Children Is Severely Ill

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Background/aims: When a parent with dependent children becomes severely ill the family face many challenges. Talking about illness-related subjects, e.g. poor prognosis, can be one. Poor communication about illness increase the risk for psychosocial distress among family members. Despite the need of family interventions for these families few have been scientifically evaluated. Even fewer have been evaluated long-term. This study therefore aim to describe families' perceptions of participating in "The Family Talk Intervention" (FTI), in the long term, when a parent with dependent children was severely ill.

Methods: This interview-study involved a long-term follow-up with nine families 4 to 5 years after participating in FTI, when one parent

was cared for in specialized palliative homecare. FTI is a manual-based intervention conducted by social workers. The goals are to facilitate family communication about illness-related subjects, support parenting, and making the children's needs visible. The interviews, analyzed with content analysis, focused on perceptions of the support FTI gave and the families support needs over time.

Results: The families expressed that FTI had helped them to talk about difficult topics, e.g. prognosis, and that this dialogue had continued within the family after FTI. Some families perceived the timing of FTI as too late and that some children needed more support during specific time periods. The families reported that FTI helped them to come closer to each other as a family. Bereaved families (5/9 families at time of interview) expressed extensive support needs after loss and suggested that FTI also could be given after bereavement.

Conclusions: FTI was reported to have long-term benefits for families who experiences severe illness or death and may serve as one of several methods to support affected families. More interventions need to be developed and evaluated to better support families during illness and in bereavement with focus on the children's needs.

P 14.019 How Do People Decide to Stop Eating and Drinking to Hasten Death? A Qualitative Interview Study

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Background/aims: Voluntary stopping eating and drinking (VSED) is a frequently-used method to hasten death. Professional and informal caregivers can be taken aback if a patient considers VSED, especially when they are asked to become involved. However, their involvement is recommended to help patients make a well-considered decision and start VSED with sufficient care. To better respond to patients' needs before and during VSED, knowledge on the decision-making process is needed. **Aim:** How do people decide to hasten death by VSED, what role do others play in decision-making, and what do patients expect before starting VSED?

Methods: In this qualitative interview study 29 cases were included. 13 cases were included before or during VSED and 16 afterwards. Participants were 17 patients, 18 informal caregivers and 10 professional caregivers. In 24 cases the patient started VSED and 19 died. Interviews were analysed by inductive thematic analysis.

Results: Three distinct groups were identified. The first were older people who felt life was completed. They prepared VSED well and had no doubts, but could overlook the need for help and the emotional burden this could pose on their close ones. The second group were older care-dependent patients who suffered chronically from physical and existential causes. They could suddenly start VSED, but relied on informal and professional caregivers to arrange it. This laid a heavy burden on informal caregivers. The third group were mostly younger patients with severe psychiatric disorders, who had a long-lasting but fluctuating death wish. They often prepared VSED in secrecy or started VSED unprepared.

Conclusions: Each group calls for a different response by professional caregivers. Patients in the first group should be advised to timely involve close ones. In the second group, informal caregivers need professional support to arrange care well. In the third group, a wish for VSED can be a sign of despair, which needs to be heard to prevent avoidable or unprepared attempts at VSED.

P 14.021 Conspiracy of Silence in Palliative Care; Experience of Nurses

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Background/aims: Conspiracy of Silence is an implicit or explicit agreement between family members and healthcare professionals (HCP) who

withhold full or partial information from the patient, concerning diagnosis, prognosis or severeness of the situation.

This happens in various situations where palliative care is provided.

Due to this agreement patients may experience a higher level of anxiety and confusion, and problems with adapting to their situation.

For nurses Conspiracy of Silence may negatively impact the relation of care and trust, often makes them feel uncomfortable, and leads to avoidance concerning conversation with the patient.

This study aims to get insight into the experiences of nurses with Conspiracy of Silence in palliative care, on the influence on the care provided and what it means to them both on a professional and personal level.

Methods: We performed a qualitative study with semi-structured interviews, using a topic guide.

Ten nurses, from different work settings where palliative care frequently occurs, participated.

The interviews were audio recorded, and transcribed verbatim.

Content analysis was used to analyse the data.

Results: Four themes emerged describing nurses' experiences with Conspiracy of Silence in palliative care. Conspiracy of Silence:

- has a negative effect on advance care planning (ACP);
- occurs less in the terminal phase;
- causes conflicts with nurses' own values and beliefs;

varies with the work setting where palliative care is provided.

Conclusions: Conspiracy of Silence negatively impacts the quality of life for patients and causes discomfort for HCP. This study, although small, shows that it has a negative effect on ACP, varies with the phase of palliative care and work setting.

To improve the quality of life for patients, as well as the quality of care provided by HCP, further studies are needed to explore this problem and its causes in more depth. Also, ways to overcome Conspiracy of Silence and to tailor care and communication to individual needs are important.

P 14.022 Illness-related Information and Communication When a Parent with Dependent Children Has a Life-threatening Illness: A Parental Perspective

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Background/aims: Communication about illness-related topics, e.g. prognosis, are often perceived as challenging. Poor illness-related communication increase the risk for psycho social distress among family members, therefore it is of importance that the illness-related communication is well-functioning. Few studies from the perspective of parents within this important area exists.

Aim: To describe parents' perceptions of illness-related information and communication within and outside the family when a parent living with dependent children has a life-threatening illness.

Methods: This survey study, which is based on baseline data from a larger intervention study, included 30 ill parents and 29 co-parents recruited from four specialized palliative home care services in Sweden. Data about illness-related information and communication were analyzed with descriptive statistics and differences between the ill parents and the co-parents regarding perceived communication was examined with Mann Whitney U-test.

Results: Between 27 and 57% of the parents reported receiving sufficient information regarding illness-related subjects. Twenty-seven percent of the ill and one of the co-parents reported receiving too much information.

A majority reported satisfaction about illness-related communication within the family, although 15-37% of the parental couples had different perceptions of family communication. About one third of the parents reported having feelings and/or thoughts they didn't want to share with the rest of the family. More co-parents reported that they could talk to others outside the family (p 0.05), while more ill parents reported wanting to show more emotions outside the family (p 0.04).

Conclusions: Communication with parents needs improvement, and it needs to be individualized. Psycho social interventions with the goal to facilitate communication within and outside the family is needed.

P 14.023 Establishing a Trusting Relation – Interdisciplinary Strategies

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Background/aims: In Sweden, palliative care, is an interdisciplinary approach including e.g. doctors, nurses, hospital social workers, physiotherapists and occupational therapists, having knowledge about the patient's physical and medical status. Communication about existential issues as life and death, and meaning, contribute to relieve symptoms for patients and support their next-of-kin. Today, these conversations are not provided on equal terms to all patients in palliative care. Therefore, there is a need for deeper knowledge about healthcare professionals' experiences of existential conversations with patients and their next-of-kin in palliative care, and investigate their main concerns to initiate and implement these conversations.

Aim: To deepen the understanding of healthcare professionals' communication strategies and main concerns in conversations with patients having palliative care needs and their next-of kin.

Methods: Design: A qualitative approach using grounded theory method for data collection and analysis with a focus on communication processes in the participants' natural settings. Seven focus group interviews with assistant and registered nurses, physiotherapists and occupational therapists were conducted. The analysis is in progress and final results will be presented at the conference.

Results: Preliminary results: Professionals' main concerns involved "Establishing a trusting relationship" which they solved by "Maintaining presence" despite challenges. These challenges affected how they handled their main concern and are represented in the categories "Talking about death" "Capturing wishes and needs" and "Guiding the patient and next-of-kin".

Conclusions: A theory based on the professional's main concerns and challenges will be developed when all data have been analyzed.

P 14.024 A Co-designed Training Programme for Palliative Care Nurses and Palliative Care Professionals to Help Patients Who Are Dying Communicate with and Support their Dependent Children: Pilot Evaluation

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Background/aims: There is currently no dedicated training available for palliative care nurses or professionals to help patients and families support their dependent children when a parent is dying. Parents need and want support, yet pre-bereavement provision is not consistent across services, and many nurses and care professionals lack the confidence and experience to support parents.

This study evaluated a pilot, co-designed, training course aimed at palliative nurse specialists and other palliative care professionals.

Methods: Pre-post, mixed methods. The one-day training ran three times. All but one of the 36 delegates participated in the research. The Kirkpatrick Model of training evaluation was followed. Experiences, needs, and expectations were assessed pre-training, and reactions and learning post-training. Logs captured subsequent reflective practice. Thematic analysis and descriptive and non-parametric statistics were used. Self-efficacy and Outcome Expectancies were measured with tools used previously in palliative care training.

Results: Self-efficacy for skills, managing own emotions, and knowledge to discuss issues with patients increased across 17 of the 20 items assessed ($p < 0.003$). Expectations of conversation outcomes also improved ($p < 0.036$). A greater understanding of the challenges and benefits of talking with patients about communicating openly with their dependent children was demonstrated. Subsequent reflective practice indicated more focus on documenting the presence of children and using applied strategies for having conversations. Areas for training improvement included more content for talking directly with children and working with ethically and culturally diverse families.

Conclusions: The pilot evaluation provided recommendations for providing and testing the training more broadly. The training offers the opportunity to increase pre-bereavement care provision by providing nurses with the skills and confidence to help patients support their dependent children when a parent is dying.

P 14.025 Communication of Poor Prognosis between Secondary and Primary Care: A Systematic Review with Narrative Synthesis

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Background/aims: In the UK, up to a third of people admitted to hospital as an emergency die within the next 12 months and people spend, on average, 3 weeks of their last year of life in hospital. Hospital discharge presents an opportunity for secondary care clinicians to communicate to General Practitioners (GPs) which patients may have a limited life expectancy. This would allow GPs to prioritise these patients for Advance Care Planning. This study aims to produce a critical overview of evidence regarding the communication of poor prognosis between secondary and primary care through a systematic review with narrative synthesis.

Methods: We searched Medline, EMBASE, CINAHL and the Social Sciences Citation Index for all study types, published since 1 January 2000. In addition, key journals were hand-searched from January 2000 to January 2022. Reference and citation searches of all included papers were undertaken. Study quality was assessed using the Mixed-Methods Appraisal Tool. We used narrative synthesis, following the iterative framework from Popay et al (2006), adapted for a review which does not focus on an intervention.

Results: The search yielded 23,853 papers, of which 30 were included in the synthesis. Information about poor prognosis is rarely communicated between secondary and primary care, particularly for non-cancer diagnoses. Where this communication does take place, it occurs late in the disease trajectory e.g. weeks not months before death. The difficulty of identifying patients with a limited life expectancy is a barrier to this information sharing. GPs use this information to determine the palliative phase for patients, allowing them to present appropriate treatment options and coordinate care. Shared registers and electronic records facilitate this communication.

Conclusions: Further research is required to understand the barriers to this communication in secondary care, and to explore the views and information needs of patients and GPs.

P 14.028 The Impact of Decision Aids, Communication Tools and Shared Decision-making Approaches Regarding Palliative Treatments on the Experiences of Patients with Advanced Cancer? A Realist Review

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Background/aims: Patients with advanced non-curative cancer are typically offered active palliative treatments (chemotherapy and radiotherapy). Research evidence suggests that when these treatments are used near the end of life they can result in worse quality of life and 10% of patients die within 30 days of starting treatment. Offering supportive care as an alternative option and ensuring patients' personal preferences are incorporated in decision-making are important at this time. We aimed to identify contextual factors and mechanisms associated with communication and decision-making in clinical consultations when patient aids and shared decision-making approaches are used to support palliative treatment decisions, and explain how they impact on patients' experiences.

Methods: A realist review method was used to identify, appraise, synthesise and analyse research evidence by creating a list of theories explaining connections between contextual factors, intervention mechanisms and patient experience outcomes and synthesising them with a middle-range theory of end-of-life decision-making to create a programme theory.

Results: The evidence presented in 41 papers in this review were integrated into a programme theory. This explains how patients' (and family) experiences, clinician support and communication can influence patient's engagement with decision-making and satisfaction with decisions via mechanisms such as enabling preparation for decision-making, accessible information, palliative care clinician involvement and patients' reflections on their preferences and prior experiences of treatment decision-making.

Conclusions: To improve patient's experiences of making decisions about palliative treatments and supportive care they need time to engage with key information and reflect on previous communication and decision-making. The programme theory developed from this review can help inform improvements in communication and treatment decision-making for patients with advanced and non-curative cancer.

P 14.029 Non-verbal Communication between Patient and Loved Ones – A Qualitative Study

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Background/aims: Communication, often through verbal conversations, is a fundamental part of the care of seriously ill patients. But communication also consists of non-verbal communication which can include gestures, facial expressions and visual impressions. The purpose of the study was to increase understanding of communicating difficult messages between patient and loved ones. Aim: By examining how the non-verbal communication is experienced, knowledge about processes that take place between patient and loved ones can increase.

Methods: The study has a qualitative design with in-depth interviews with patients and their loved ones. The interviews were recorded and written verbatim. Qualitative content analysis was applied.

Results: 15 patients and 7 loved ones were interviewed. The results showed that both patients and loved ones express a clear awareness that it is not only what is said about the disease that constitutes communication about sickness. The patient is aware that bodily changes provide information about what is happening in the disease process, which

is also perceived by the loved ones. But also the patient's need for aids, such as a wheelchair, help from home health care and consequences of the disease such as difficulty eating, fatigue also provide information. This information occur without words. Patients may choose whether or not to verbally comment the non-verbal communication.

Conclusions: Both patients and loved ones are aware of the silent information given by changes in the patient's body as well as in his/her daily life. They interpret and consider what they see and through the non-verbal impressions this form of communication takes place. Healthcare professionals should be aware of the non-verbal communication between patients and loved ones to get an understanding of how they communicate.

P 14.030 Core Elements of Serious Illness Conversations: A Systematic Review

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Background/aims: The Serious Illness Care Program (SICP) and Serious Illness Conversation Guide (SICG) have been adapted for use in a variety of contexts and diverse patient groups. Explicating the core elements of serious illness conversations could ensure that these components are present (or justifiably absent) in existent and future versions of the SICP and SICG. This systematic review aimed to identify and describe core elements of serious illness conversations in relation to the SICP and SICG.

Methods: Literature published between 01 January 2014 and 20 January 2022 was searched in four databases (MEDLINE, PsycINFO, CINAHL, PubMed). The Joanna Briggs Institute Critical Appraisal Guidelines were used to assess the trustworthiness and relevance of the articles. Data were analyzed with thematic synthesis analysis.

Results: The review included 56 articles. Three themes were revealed: (1) Serious illness conversations are multifaceted and can serve different functions that are influenced by how the conversation is framed for the patient; (2) Serious illness conversations endeavor to discover what matters to the patient in the context of their illness/health; and (3) Serious illness conversations align what a patient wants with future care.

Conclusions: Core elements of serious illness conversations have been compared, contrasted, and elucidated. Serious illness conversations were revealed to be multifaceted with nuanced content and understandings. These findings add to the theory supporting serious illness conversations and may be used to inform future versions of the program and the guide.

P 14.031 Communication in Palliative Care: A Cross-sectional Survey of Swiss Palliative Care Clinicians' Comfort, Confidence and Learning Experiences of Key Communication Tasks

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Background/aims: It is often emphasised that palliative care clinicians (PCCs) are among the best communicators in health care, mainly because communication is seen as a key mechanism through which palliative care (PC) improves the patients' quality of life. Although these assertions are widespread, little is known about how communication skills are learnt or how competence and comfort levels with different communication tasks may vary within PC. We aimed to understand how

Swiss PCCs learn key communication skills, their level of competence, and their comfort when engaging in different communication tasks, as well as the frequency in which the tasks are practiced.

Methods: Between October and November 2021, we surveyed Swiss PCCs via an online survey containing 22 communication tasks.

Results: A total of 242 PCCs participated. Participants were on average 50 years old. The majority were female (79%) and had a nursing background (64%). Fifty per cent had practiced for 11 years or more, and did so in a variety of contexts, including specialist PC units (19%) and mobile teams (18%). The great majority had learnt their skills by doing (89%) or from role models (70%). The level of competence and comfort with specific tasks was variable: e.g. over 85% were comfortable and confident about discussing what PC is, introducing their role, or discussing physical symptoms. Participants felt much less confident and competent when discussing spiritual aspects (<36%) or guiding patients' discussions with their children (<20%). We identified significant differences in comfort and of competence levels according to key variables (e.g. profession).

Conclusions: Although PCCs' comfort and competence with some communication tasks was high, gaps remained in specific areas. Our study shows how the expertise of PCCs can be widened to increase their comfort and confidence. This should help ensure that the work of PCCs continues to impact patient care as well as to be a source of professional and personal satisfaction.

P 14.032 The Role of Face-to-Face Interaction in Establishing Certainty of Interpretation and Action in Patients Treatment in Multi-professional Teams – A Case Study

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Background/aims: In order to reduce the suffering of patients and maintaining quality of life as long as possible in the last phase of life, palliative care relies on the collaboration of different professions. Different perspectives and professional expertise of the actors involved characterize the joint work. This results in divergent interpretations and relevancies concerning the treatment of patients within the team. Face-to-face interaction plays a crucial role in bringing together those various assessments and in generating an intersubjectively shared understanding of cases. Concrete further action - the treatment of patients - is based on these shared interpretations. A case study demonstrates how certainty of interpretation and action is created interactively. The aim is to examine how shared priorities regarding patient management are developed and how different perspectives are negotiated within the multi-professional team on a palliative care unit.

Methods: The data used for the case study originates from a participant observation of several weeks, which was carried out on a German palliative care unit. The field protocols were qualitatively analysed following the grounded theory approach and coded in MaxQDA.

Results: The selected case study shows how different, profession-specific relevancies and case interpretations lead to conflicting views on the assessment and further procedure with the patient in question. It is not until the multi-professional team meeting that the different perspectives are collectively processed and lead to a new focus in the treatment of the patient.

Conclusions: The direct continuous interchange, interaction and negotiation between the different professions and individuals involved in a

palliative care unit has clearly more functions than the mere exchange of information. Interactively establishing certainty of interpretation and action is essential to care holistically for patients.

P 14.033 Information-provision across the Spectrum of Wishes of Patients and Families in Advanced Illnesses: An International Interdisciplinary Approach

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Background/aims: How clinicians approach information sharing with those with life-limiting conditions who prefer non-disclosure or for whom information preferences are unclear remains understudied. We aimed to develop a conceptual framework and practical guidance for clinicians around information provision across a spectrum of information preferences.

Methods: A scoping review of the literature, followed by an international (covering five continents) and multi-disciplinary expert group written reflection and online consultative meeting (Feb 2022). Extracted data from the scoping review, individual reflections and consultative meeting were analyzed using qualitative thematic analysis.

Results: The conceptual framework consists of 3 core components: Information provision holds value within a relational framework that includes health care providers, patients, and families.

Ethical and socio-cultural tensions may arise in the process of information provision and may cause harm. These include (i) Respecting patient autonomy vs. avoiding medical futility; (ii) Safe-guarding individual autonomy vs. maintaining family harmony; (iii) The difficulty of knowing what the other implicitly knows & wants.

Potential benefits and harms associated with information provision can occur along multiple axes, including empowerment-disempowerment and trust-mistrust.

To mitigate tensions and harm in information provision, we propose the following recommendations:

1. Making a connection and building trust, e.g. through empathy.
2. Taking time to build relationships and enable staged information provision.
3. An attitude of openness to social and cultural diversity.
4. Inquiring about patients' illness experience and information preferences.

Conclusions: Potential harms of open information provision for patients who prefer limited or non-disclosure may be mitigated by: building trust, taking time, openness to diversity, and inquiring about illness experience.

P 14.034 The Nursing Perspective of the First Encounter with the Palliative Care Patient

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Background/aims: A meaningful first encounter with the palliative care (PC) team is shown to promote positive outcomes, especially for the quality of life of the patient and their family. Palliative care (PC) nurses have a crucial role in this first encounter with patients and family as they provide first contact care and support the quality and length of consultation visits. Therefore, understanding the meaning of this first encounter as described by PC nurses is essential to ensure the goals of PC and provide the foundation for patient-centred care from initial contact.

Aim: To explore the meanings that palliative care nurses assign to the first encounter with the patient in palliative care.

Methods: We conducted an interpretive phenomenological study using content analysis of semi-structured interviews with 20 PC nurses from PC wards and community teams in Dublin.

Results: The analysis revealed that PC nurses see the first encounter as an opportunity to (1) Build a bond of trust with the patient through an active listening of what the patient needs and by giving them a sense of security; and to (2) give a meaning to the patient by providing them comfort and care and making a difference to their lives.

Conclusions: This qualitative insight into the first encounter from the perspective of PC nurses reveals the significance of the first encounter for PC nurses in order to set the tone of the therapeutic alliance and likely patients' satisfaction with the quality of care.

P 14.036 Barriers and Facilitators When Talking about Personal Values, Wishes and Needs Nearing the End-of-Life. A Qualitative Exploration of a Patient and Partner Perspective

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Background/aims: Pulmonary fibrosis is a chronic, progressive disease with a median survival of 4.5 years. *Talking about the end of life and exploring and monitoring personal values, wishes and needs is essential for the implementation of palliative care in pulmonary fibrosis care.*

Aim: To gain insight into the barriers and facilitators to talk about end of life experienced by patients with pulmonary fibrosis, and their partners (p&p).

Methods: This was a qualitative study was performed from march 2021 and November 2022 using semi structured interviews and focus groups with p&p. Interviews were performed by two interviewers with a care-relationship with half of the patients. Coding and data-collection were performed iteratively. A thematic analysis was performed using atlas.ti.

Results: The perceived barriers and facilitators revealed five themes:

Timing: P&p declare they want to talk about the end of life earlier in the process and more often. Partners wish to be involved earlier in the illness trajectory for additional information, care support and for remembering the information provided.

Knowledge: P&p lacked knowledge about the disease resulting in poor prognostic awareness. They also declared not knowing what topics could be discussed with the pulmonologist of the nurse.

Initiative: P&p declare that the invitation should be from a healthcare professional (HCP) since it is difficult for most of them to start the conversation.

Trust: P&p prefer continuity of caregivers. Some patients feel more comfortable talking with their general practitioner about the last phase of life.

Empathy: Patients prefer a HCP with whom they feel trusted and safe. P&p do feel when an HCP does not feel comfortable in the conversation.

Conclusions: P&p want to talk with the HCP about the end of life. P&p need empathic HCPs who are comfortable to talk about their end of life preferences and to regularly educate them about prognosis, care and treatment options during the illness trajectory.

Funding: Penders foundation

P 14.037 Using Simulation to Help Healthcare Students Learn to Talk to Patients about End-of-Life Questions, Including Euthanasia

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Background/aims: Partly due to the increasing ageing of the population, healthcare professionals will be more confronted with patients who request euthanasia, or ask end-of-life questions. Healthcare professionals must have sufficient competencies to deal with these questions. A lack of these competencies is shown by a study in which Belgian final-year nursing students indicated that they did not have sufficient knowledge, and skills to deal with end-of-life questions, and euthanasia. Adequate attention must be paid to this during their training since euthanasia is legal in Belgium. The aim of this study is to develop an educational module with interactive simulation.

Methods: Before the simulation training, each student follows a blended learning lesson on the topic of euthanasia, and end-of-life. This lesson focuses on legislation in Belgium, as well as on the basic concepts of dealing with end-of-life questions, including euthanasia. Afterwards, students jointly watch an audiovisual story with a good practice example, followed by an in-vivo simulation, and debriefing. Students participated (n=17) in post-test session discussion groups to discuss the module, their experiences, and improvements.

Results: This simulation module helped students to overcome an initial 'fear' threshold, and to start exploring the euthanasia, or end-of-life question. There seems to be a very strong focus from students to do the simulation conversation in a protocolized way. Students find this simulation adds value.

Conclusions: The importance of conversation simulation exercises in healthcare education cannot be underestimated. By giving healthcare students an initial experience in a safe simulated environment, they are more confident to have an exploratory conversation, not only about euthanasia, and end-of-life in the future, but also to explore the end-of-life question, and the issues underlying it.

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P 14.038 Death Is an Unacceptable Outcome - How Nurses and Physicians in Specialist Wound Clinics Talk about the End-of-Life with Patients at Risk of Amputation due to Chronic Leg Wounds

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Background/aims: Chronic leg wounds are often symptoms of advanced ischemic disease, increasing the risk of amputation and early death. Palliative care is an entirely new approach in specialist wound clinics. This study explores clinical practice among nurses and physicians when talking about end-of-life with patients at risk of amputation due to chronic leg wounds.

Methods: An explorative qualitative design was adopted. Data was collected in specialist wound clinics at four Danish hospitals, may 2019 - august 2020, through a combination of non-participant observations of existing practice (n=85 consultations between clinicians and patients), and interviews with physicians (n=4 individual) and nurses (n=16, four focus groups). A semi-structured interview guide was developed based on the observed practice and literature about barriers to palliative counseling practice in other settings. A conventional qualitative content analysis procedure was applied.

Results: In the wound clinics, death is considered the worst thinkable outcome and is primarily referred to as an argument to get the patient to follow advice about restrictions or to have the leg amputated. However, some patients prefer to die, rather than have their leg amputated.

Conversations with patients about their thoughts regarding end of life are considered relevant but not systematically offered. Patients are experienced to be too ill for these conversations, increasing the risk of taking hope away from them. In addition, death is considered complex and difficult to talk about, making it easier and more comfortable to concentrate on the practical tasks in wound care.

Conclusions: Implementing conversations about end-of-life in wound care is relevant, and the attitudes and concerns of the clinicians should be considered during implementation. The Novo Nordisk foundation funded the study.

P 14.039 Factors that Influence Completion of Medical Orders for Life-sustaining Treatment (MOLST) Form and Do-not-Resuscitate Orders among Oncology In-patients in a Philippine Tertiary Hospital

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Background/aims: Advance care planning is important in providing high-quality care to oncology patients. The medical order for life-sustaining treatment (MOLST) form documents the orders regarding an individual's right to accept or refuse treatment, including decisions on resuscitation and overall aggressiveness of care. This enables patients' autonomy and allows them to participate in decision making regarding their care. In our country, due to a lack of awareness there is suboptimal utilization of this tool. The primary objective of this retrospective study was to determine the factors associated with the completion of MOLST form and do-not-resuscitate (DNR) orders among oncology inpatients in a tertiary hospital in the Philippines.

Methods: Records of patients who met the inclusion criteria between August 2021 and January 2022 were reviewed. Descriptive statistics and bivariate analysis were done.

Results: A total of 150 records of oncology inpatients were analyzed: 52 (35%) patients had completed the MOLST form and DNR orders, while 98 (65%) patients did not. The factors associated with completing the MOLST form and DNR orders were: age, referral to palliative service, discussion of prognosis and advance care planning by attending physician, functional status, and presence of metastasis.

Conclusions: Given the important role of attending physicians in advance care planning, programs and policies must be in place in our healthcare system to facilitate early referral to palliative care and to support access and acceptability of completing MOLST forms and DNR orders.

P 14.040 Barriers and Facilitators in Exploring Patients' Values, Wishes and Needs in End of Life, Perspective from Healthcare Professionals

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Background/aims: Pulmonary fibrosis is a progressive disease with a median survival of 4.5 years. Talking about the end of life, exploring and monitoring personal values, wishes and needs is essential for the implementation of palliative care in pulmonary fibrosis care.

Aim: Gain insight in the barriers and facilitators to talk about end of life with healthcare professionals(HCP).

Methods: A generic qualitative study was performed from March 2021 and Nov 2022. Semi structured interviews and focus groups with HCP were performed by two interviewers, both interviewers

had a working relationship with the HCP. Data collection and analysis were performed iteratively. A thematic analysis was performed using atlas.ti.

Results: The perceived barriers and facilitators revealed five themes

Timing: HCP search for the right moment to start the conversation and realize a proactive way of working and a better structure takes less time in the end. However, there is always a reason to postpone a conversation.

Knowledge: HCP talking with a patient with a better prognostic awareness is easier. HCP showed a lack of knowledge about coping, grieve, competences of other professionals and laws and regulations.

Professional competences in communication are necessary for HCP to feel confident to communicate with patients and partners.

Preconditions; shared values in palliative care integration, agreements in multiprofessional collaboration, time, and structured documentation.

Within the person; Experiences (professional or private) support or counter the conversation. Most HCPs are aware of their own pose and way of talking during conversations about end of life.

Conclusions: HCP want to talk about end-of-life values wishes and needs. Lack of knowledge, competences, experience and agreements are the main barriers. Education and training on the job are essential for implementing palliative care.

This study was funded by the Penders foundation

P 14.041 Preliminary Exploration of the Social and Cultural Factors to Engage Advance Care Planning among Cancer Patients: Perspectives from the Healthcare Professionals

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Background/aims: Advance care planning (ACP) is evident to improve end-of-life care outcomes for cancer patients and their family members via goal-concordant care provision. However, different social norm and cultural belief on healthcare might affect the uptake and delivery of ACP. This study aims to explore the social and cultural factors when cancer patients and their family members engage advance care planning from the healthcare professionals' viewpoints in Northern Taiwan.

Methods: In-depth semi-structured qualitative interviews with the healthcare professionals from inpatient hospital who provided ACP for cancer patients and their family members. Purposive sampling identified participants based on key characteristics including age, gender, and professions. Thematic analysis was conducted. Analytical rigour was enhanced by dual coding. Investigator triangulation was performed for consensus and agreement.

Results: Nine multidisciplinary healthcare professionals were interviewed including four physicians, three nurses and one social worker and one clinical psychologist. Five themes were identified: 1) *Gender and socioeconomic status:* highly educated males with better socioeconomic status were often the substitute decision makers for cancer patients; 2) *Religiosity:* patient with religiosity were more likely to engage ACP and complete advance directives; 3) *Medical education:* palliative care has not yet been the fundamental training for healthcare professionals; 4) *Healthcare insurance:* out-of-pocket fee for ACP services decreased cancer patient's willing to participate, and 5) *Public awareness:* misunderstanding of palliative care with limited public involvement.

Conclusions: Cultural and social attributes shape the content and delivery of ACP differently in Taiwan. We should take these findings into account to improve the access of ACP services for cancer patients and their family members to facilitate better end-of-life care.

P 14.042 Influences on Decision Making for Cytogenetic Testing in Patients with Uveal Melanoma

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Background/aims: Non-metastatic uveal melanoma can be successfully treated locally in most cases. Yet the risk for distant metastasis and thus the long-term survival of affected patients is significantly determined by genetic characteristics of the tumor. By means of a cytogenetic testing (CGT), a fairly accurate prognosis on the probable course of the disease can be determined pretherapeutically at the patient's request. However, due to the lack of effective targeted treatment options this has a purely informative character. We investigated possible factors influencing the decision making regarding CGT.

Methods: The interest in a CGT and factors influencing the patient's decision were determined using questionnaires (e. g. GAD-7, PHQ-9). Key question was: Who/what influences my decision for a CGT? On a Likert scale, patients rated the perceived influence of treating physicians, internet resources, family members, and friends. Multiple ordinal logistic regression was used to analyze the characteristics of decision-making.

Results: Of the 121 participating patients, 52 (43%) patients expressed no interest in CGT, 34 (28.1%) were undecided, and 35 (28.9%) expressed interest. In contrast to patients who were not interested in CGT, interested patients were more anxious and reported being significantly influenced in their decision making by their treating physicians and internet resources (≤ 0.014). Friends or family environment did not appear to play a role in decision making.

Conclusions: Almost half of our patients made use of their right not to know their prognosis (RNTK). This confirms the relevance of patient autonomy regarding the discussion of genetic paternalism. The study also shows that patients with interest in CGT are more likely to seek advice and support for this difficult decision in an objective, professional and externalized manner rather than communication within their personal environment. This should be taken into account by treating physicians accompanying decision making.

P 15 - Bereavement

P 15.001 When a Work Colleague Dies – Experiences of Work Colleagues and Lessons for Employers to Improve Care

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Background/aims: Fortunately, it is now uncommon for people to die in working age. When they do, work colleagues as well as family experience grief reactions due to: many hours spent together, team working, shared successes or external threats and camaraderie. Aim: To examine the experiences of work colleagues when a team member dies to improve workplace support.

Methods: A rapid qualitative thematic evaluation of experiences. Participants were employees from 6 teams in national public health organisations who had experienced the death of a team colleague. Experiences were analysed from team-based grief café discussions (3) and individuals' experiences (3 teams).

Results: 5/6 deaths were unexpected. Staff described significant distress at things they hadn't done (guilt) or futures (individual and team) lost. 5/6 deaths communicated sensitively, staff reported lack of empathy in one case and delays in one, evoking anger in team-mates. Contact with the deceased families was felt important or even a duty: cards, flowers, books of condolences (with photos and anecdotes celebrating the life of their colleague), attendance at funerals was thought important. One

team excluded from funeral by family, found this very difficult. This team planned their own memorial. People assigned to clear desks, liaise with family to give them possessions and take back work equipment found this distressing. Team specific grief cafes helped staff recognise/legitimise their grief and find ways to cope.

Conclusions: Sudden death increases the shock experienced by colleagues. The death of a colleague may be felt as strongly as a personal friend or family member as lives have often been interwoven over a long time. Senior managers need training for these unexpected events especially in communication and providing support to teams and individuals especially those dealing with personal effects and family interaction. Facilitation of dedicated team grief cafes especially explaining legitimacy of grief are considered helpful as are memorial events.

P 15.002 What Can We Learn from Outcome Data Collected in a National Online Bereavement Counselling Service (OBSC)?

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Background/aims: Following the pandemic's restrictions on face to face interaction, many services moved to virtual support. This national bereavement counselling service has always been online but had been in its infancy. Now matured, the service has been producing data to show case effectiveness and usefulness.

Methods: 824 people were assessed using the Adult Attitude to Grief (AAG) scale (Machin, 2014) which determines the presence of overwhelmed feelings and controlled functioning, and the resilient capacity to balance these. They were also asked items from the Detection of Emotional Distress scale, consisting of two questions that examine emotionally distress and coping efforts. Scores were completed at assessment and at the discharge counselling session (session 6/6). Clients were also asked about suicidality and other demographics.

Results: We found that of the 832, 85% were female. Median age 47.97 (11.6%) were identified with suicidal ideation prior to counselling. This reduced to 39 after counselling. Suicidality includes reunification fantasy. For each of these people there were additional factors affecting their grief e.g. loneliness, more than one bereavement, poor physical/mental health, family conflict etc. The DED scores showed the majority had a reduction in emotional distress. Compared to the score before, the score after counselling: decreased for 634 (85.6%), remained the same for 63 (8.5%) and increased for 44 (5.9%). The before and after counselling AAG scores showed a decrease in scores representing a reduction in vulnerability. Compared to the score before, the score after counselling: decreased for 691 (85.3%), remained the same for 52 (6.4%) and increased for 67 (8.3%).

Conclusions: Findings suggest that the OBSC is an effective service for most clients. To understand how grief impacts people in today's society, help normalise grief and shape the existing focus on formal support, we are currently analysing the data further to offer some more insights into contemporary grief for the conference attendees.

P 15.003 Expressions of Grief and Needs for Support in Contemporary Sweden

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Background/aims: Grief is a common human reaction to the loss of a loved one and can have a significant impact on health and have consequences not only for the individual but also for the context at the group and community level. Previous research on support for bereaved people has shown that social networks provide support at a basic level, which is

sufficient for most people. Offering adequate support to the bereaved should be considered a concern and a responsibility for the local community.

Aim: Based on current grief theories that emphasize grief as a natural process (non-pathological) for the vast majority, this paper reports results from a project investigating expressions of grief after the loss of a loved one/significant other over time and what needs for support bereaved people have.

Methods: A web-based questionnaire including the Prolonged Grief Disorder scale (PGD-13) was distributed between February and May 2022 to grief support associations' and a pensioners' association in Sweden, who had experienced the loss of a loved one. Ethical approval was obtained from the Swedish Ethical Review Authority.

Results: 281 bereaved individuals participated (female 200 and male 81). The most common relation to the deceased was spouse (42.3%), parent (19.2%), child (18.7%), sibling (8.2%). The cause of death was illness (59.8%), followed by suicide (15.3%), old age (8.5%) and accidents (8.2%). The most common needs for support were practical and emotional support followed by advice and information. Other factors that have an impact on grief were economy, social life, health, and spiritual beliefs.

Conclusions: The study contributes with new knowledge about expressions of grief and needs for support in the Sweden among bereaved people. Results will inform the development of grief support measures from individual, group, and societal perspectives, and will have significance for normalizing grief in the Swedish context.

P 15.004 Interviews with Children - The Seldom Heard Voices of Parentally Bereaved Children

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Background/aims: In the UK, a parent dies every 22 minutes. Parental death can profoundly affect children's future well-being, including mental health issues and negatively impact academic and social functioning. The voices of parentally bereaved children are under-represented in research. This study explores children's support experiences following parental death.

Methods: The study was developed with bereaved children and families. Using constructivist grounded theory, virtual, in-depth interviews were conducted. Data analysis followed initial, focused, and theoretical coding processes using the constant comparative method and theoretical sampling.

Results: Eleven children participated (aged 10-18, n=5 male, n=6 female). Findings were synthesised into six broad categories: 'what's helping', 'talking about it on your terms', 'dealing with a tornado of emotions', 'difficulties getting support', 'stepping up to help at home and 'learning to live without them. Children appreciated being involved in what was happening within the family to help them adjust and come to terms with the death. Children found that everyone grieves differently. At times children hid their emotions to protect those around them and often felt helpless supporting their parents and siblings. All children struggled with bringing their parent's death into a conversation. Children perceived that it made friends awkward and uncomfortable, and those who had not experienced parental death struggled to understand. Children found others forgot and felt an expectation to 'move on'.

Conclusions: Talking helps, but children do not know how to talk about parental death. They fear the reaction from others and do not want to cause discomfort. So, often they mask their grief or hide the death to protect their surviving parent and those around them. A greater societal understanding of parental death and the impact and longevity of grief is required to ensure children have ongoing and sustained support as they learn to live without their parents.

P 15.005 The Caregiver Care PROM. Development of an Assessment Scale for Family Caregivers and Early Bereavement Care in Palliative Care

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Background/aims: Supporting family caregivers and providing bereavement care is defined to be an integrated part of palliative care. However, systematic assessment of caregivers' need for support is not yet fully developed and implemented. In this study, the aim was to develop and pilot-test a Patient Reported Outcome Measure (PROM) scale for caregivers' need for support and at the same time assess their risk of adverse grief reactions to help initiate grief support early.

Methods: A five-phased iterative approach was used. 1) Literature reviews of caregiver needs and predictors of adverse caregiving and grief outcomes created the basis of drafting of questionnaire themes. 2) Focus group interviews with palliative care professionals were used to draft and initially test candidate items. 3) Repeated caregiver interviews helped refine item phrasing. 4) A questionnaire was developed and pilot tested resulting in the Caregiver Care Prom. 5) The Caregiver Care PROM was set up for validity testing in specialised palliative care.

Results: The Caregiver Care PROM was applied in a four specialised palliative care services in Denmark during 2020 and 2021 (N=358 participants). Participants answered questionnaires at entry into palliative care, two months post-death, and six months post-death. Beck's Depression Inventory (BDI), Burden Scale for family caregivers (BSFC), and Prolonged Grief-13 (PG-13) were also included in test battery. Scoring on the Caregiver Care PROM and association with validated scales are being analysed to calculate construct validity and predictive properties.

Conclusions: This study will present the first data on the Caregiver Care PROM and the validation analysis. With a validated and effective caregiver PROM, assessment of caregivers' risk of adverse grief outcomes and need for support during caregiving can be published for systematic use. The Caregiver Care PROM can aid the implementation of early bereavement care in palliative care.

P 15.007 Health Service Use, Costs and Associated Factors before and after Partner Bereavement among Same-gender vs. Different-gender Partners

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Background/aims: A national population-based study of same-gender (SGP) vs different-gender (DGP) bereaved partners found higher psychological distress among SGP. This analysis aimed to determine whether there are differences in health service use and bereavement support services between these groups.

Methods: A population-based, cross-sectional mortality follow-back survey of people bereaved of a civil partner or spouse 6–10 months previously. Responses to the modified client service receipt inventory (CSRI) questionnaire were used to compare service use between (SGP) and (DGP) using ANOVA and calculate costs with unit costs. Regression models estimated factors associated with costs.

Results: Mean age in years was 68.0 (SD 12.8) for SGP (n=232) and 72.6 (SD12.2) for DGPs (n=329); 106 (47.3%) SGP and 67 (21.4%) DGPs had university or higher level of education. Costs for district nursing (mean difference (md) £16, 95% CI £1 to £31), psychiatrists (md £15, 95% CI £2 to £28), psychologists (md £22, 95% CI £11 to £34) and spiritual care person (md £25, 95% CI £1 to £48) were larger among SGP than DGP in the 3 months prior to death. In the 3 months after partner death, more SGP met face-to-face with their GP (md 14%, 95% CI 1% to 22%), psychologist (md 10%, 95% CI 4% to 15%) or spiritual care person (md 8%, 95% CI 2% to 14%) than DGP. Partners with university education used less health care costs before bereavement ($\beta=-0.82$, 95% CI -1.51 to -0.14) than those with no university education. Retired partners incurred less costs before ($\beta=-3.42$, 95% CI -4.29 to -2.55) and after ($\beta=-4.01$, 95% CI -5.12 to -2.90) bereavement than non retired partners.

Conclusions: The differences in health services costs between SGP and DGP need consideration of the differences in labour force participation and informal care provision, leading to no net differences in overall costs from a societal perspective.

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P 15.008 Living with Grief: Extending and Unifying Services to Meet Increased Demand in a Collaborative Way

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Background/aims: Each hospice in our local HealthCare Partnership (HCP) offered various levels of support to those bereaved in the area, there was inequity of provision and lack of investment. The recent Covid-19 pandemic has greatly increased the numbers of people with more complex grief, in need of help. The local council were approached for assistance, and sourced funding to create a collaborative new service.

Aim: To develop and set up a timely, short-term solution to the gap in bereavement services, with a comprehensive programme of support across the HCP.

Methods: Funding was offered with a short timeframe to deliver. We devised a new package of bereavement support to commence in April 2022 working alongside the other 3 successful organisations. A three-tier approach was devised, involving information and advice, support/counselling, and group work. The service is available for both adults and children from 10 years upwards, regardless of how they have been bereaved. Adults and parents are given an information pack with advice, contacts and guidance. This is followed by up to eight sessions of 1-1 support/counselling and 6 group sessions providing psycho-educational support. The children's programme, whilst similar in structure, has more focus on individual memory-making activities. Referrals are triaged for suitability and services offered in parallel to the existing bereavement support. The new service is evaluated by feedback at the end of each set of group session, and questionnaires on completion.

Results: The project aims to reach 300 bereaved individuals in our area (1200 in total across the patch) over 1 year. At the six-month point, we have offered support to 176 clients, and are on track to exceed our target. Evaluations demonstrate the value of the service, and the difference it is making. The collaboration has helped to build relationships and ensure that bereaved people across the HCP access equitable care.

Conclusions: This successful model can offer a guide to others setting up a new service.

P 15.009 Posttraumatic Growth after Struggling with the Loss of a Parent in Young Adulthood

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Background/aims: Facing the death of a parent is a particularly challenging experience in adolescence and young adulthood (AYA) due to the comprehensive life changes that already exist in this period of life. Despite these difficulties the struggle with the trauma can lead to positive life changes such as posttraumatic growth. This study aims to examine posttraumatic growth and its associations with bereavement stressors and outcomes in a sample of AYA who lost a parent to cancer.

Methods: The study is based on data from a larger longitudinal study. In total 55 AYA, 16-28 years, who were about to attend a support group after the loss of a parent to cancer completed a questionnaire 5-8 months after the loss, and a follow-up questionnaire 14-18 months after the loss. The questionnaires included single items about bereavement stressors and outcomes and validated instruments. Posttraumatic grief was measured by The Posttraumatic Growth Inventory. Spearman's correlation coefficients were used for examining associations. The Cohen's *r* effect size was reported and interpreted as: 0.1-0.3 small, 0.3-0.5 medium, and >0.5 large.

Results: The AYA experienced posttraumatic growth, especially in Appreciation of life (Mdn=3.3) and Personal strength (Mdn=3). A higher life satisfaction was associated with more growth in Personal strength ($r_s=.55$) and Appreciation of life ($r_s=.48$). Psychological distress was associated with less growth in Personal strength (anxiety $r_s=-.41$, depression $r_s=-.44$). Receiving support from professionals was associated with more growth in New possibilities ($r_s=.27$), Personal strength ($r_s=.25$) and Spiritual change ($r_s=.16$).

Conclusions: Despite the problems following a parent's death this study shows that the process of dealing with the loss may still lead to growth for AYA. It is important that professionals who meets this vulnerable group also pay attention to and promote constructive rumination, thereby enhancing the development of positive psychological changes.

P 15.010 Death Rituals and Quality of Life of Bereaved Relatives: Results of the Swedish CO-LIVE Study

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Background/aims: Grief is a normal reaction after the death of a loved one. Death rituals, including funerals, are an integral part of cultural- and religious mourning systems, but may be affected by the COVID-19 pandemic and associated restrictions. Not being able to perform death rituals may intervene with the grieving process and affect the quality of life of bereaved relatives. Therefore, the aim of this study was to assess death rituals during the COVID-19 pandemic and their association with the quality of life of bereaved relatives.

Methods: This study was part of a nation-wide observational study in Sweden with questionnaires sent to relatives of persons who died during the first wave of the COVID-19 pandemic (CO-LIVE study). One and 4-6 months after the death, bereaved relatives received a questionnaire assessing, among other topics, quality of life, whether the deceased person had a COVID-19 infection and if and how relatives were able to carry out death rituals. The association between quality of life of bereaved relatives and death rituals was analyzed with linear regression.

Results: Of the 324 bereaved relatives included in this analysis, a minority indicated that their loved one's memorial (15%) or funeral (17%) fully met their wishes. Not having a death ritual as preferred, including the funeral ($p = 0.006$), death bell ceremony ($p < 0.001$), interment ($p = 0.037$), and other rituals ($p = 0.033$), was significantly associated with a lower quality of life of bereaved relatives 4-6 months after the death of their loved one. Whether the deceased person had COVID-19 was not related to the quality of life of bereaved relatives.

Conclusions: The COVID-19 pandemic demonstrated that it is important that people are able to perform death rituals as they preferred. Sharing experiences and solutions for adaptation of death ritual in difficult circumstances is important to optimize people's grieving process.

P 15.011 The Compassionate University, Death, Dying, Loss and Care as an Integral Element of University Life

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Background/aims: There is a global sense of urgency to recalibrate societal and institutional dealing with death, dying and loss. In the Netherlands, the national council of health and society recently published a whitepaper stressing the importance of raising awareness of dealing with death, loss and mourning.

The University of Applied Sciences (UAS) Rotterdam is a community with over 40,000 students and 4,500 staff. It inherently carries responsibility for the public health approach to end of life care. Being aware of this responsibility, it recently proclaimed to be targeting becoming a compassionate UAS.

This study focuses on getting insight in experiences and best practices, and in hindering and facilitating factors in the work and study environment with regard to recognizing and facilitating the diversity of needs around death, dying, loss and care.

Methods: A two-step qualitative approach was used. Firstly, dialogue sessions were held with UAS staff. Secondly, interviews were conducted with staff members having experienced a (recent) loss themselves, managers, counselors and experts. A preliminary topic list was developed. The interviews were recorded and transcribed. Data analysis was conducted by a team of researchers.

Results: Aligning the input diversity, four themes were identified:

- facilitating dealing with death, loss and care;
- both talking and not talking about it;
- peers' responses;
- managers' roles.

Conclusions: The variety of needs regarding death, dying, loss and care needs to be met by arrangements in time, expressions, regulations and the physical UAS environment. Both subjects and bystanders are often unsure what to say and ask. A compassionate UAS can contribute to an environment that regards these aspects of life as both normal and of critical importance, and therefore shape a setting that assists people in dealing with death, dying, loss and care. Further research should focus on how and in what way this might prevent (student and employee) drop-out.

P 15.012 Grief and Coping during COVID-19: Exploring the Lived Experiences of People Bereaved during the Pandemic

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Background/aims: The COVID-19 pandemic has been characterised by high levels of disruption to end-of-life and mourning processes, support networks and services, dramatically impacting the grief and coping experiences of people bereaved at this time. This study aimed to explore people's lived experiences of bereavement during the pandemic, including how they have coped and found meaning during these unprecedented times.

Methods: Semi-structured longitudinal telephone interviews were conducted with people bereaved during the first 10 months of the pandemic (March to December 2020), purposively sampled from a cohort of survey participants. Interview transcripts were analysed thematically, paying attention to individual and group-level themes.

Results: 24 participants (19 female; 5 male) took part in a first interview and 15 in a follow up interview, approximately four months later. Coping and meaning-making was analysed across two domains; 'processing the loss' and 'finding new meaning and purpose'. Participant accounts highlighted critical events/experiences that were difficult to accept and overcome, as well as examples of resilience, agency and positive meaning-making. When 'processing the loss', these experiences related to four main themes: end of life and the death; memorialisation; social relationships; and processing strategies. Key themes connected with 'finding new meaning' included: being alone; navigating 'normal'; social support and societal responses to Covid-19.

Conclusions: People bereaved during the COVID-19 pandemic have navigated their loss and grief through exceptionally challenging circumstances. Despite these difficulties some have demonstrated remarkable resilience and ability to cope and find meaning. These findings can help to improve the care and support provided to people throughout their bereavement journeys.

P 15.013 A Compassionate University? A Qualitative Study of Students' and Staff Members' Experiences and Support Needs around Serious Illness, Death and Bereavement

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Background/aims: The literature on Compassionate Communities suggests an important role for higher educational institutions in actively promoting wellbeing around serious illness, death, and bereavement. However, knowledge about the experiences of university staff and students remains largely unknown. This study aims to understand the experiences and support needs of university staff and students faced with challenges of serious illness, death, and bereavement.

Methods: We performed a qualitative study, among students and staff registered at the Vrije Universiteit Brussel in Belgium. Semi-structured

interviews were conducted with students (n=21) and staff (n=13), and three focus groups with staff members (n=12) took place. The data were analysed using thematic analysis.

Results: Similar experiences were found among students and staff: worries about taking time off from studies or work following bereavement, not knowing what support services exist, not knowing how to access support services, and a shared belief that they do not have the time to use them. Experience of support was heavily dependent on the empathy and understanding of direct colleagues, as well as specific regulations per faculty. In terms of support needs, there is a difference between the university as a day-to-day work context and as a study context, with staff indicating a need for formal support whereas students indicated relying more on their informal peer networks outside of the university context.

Conclusions: Our study indicates that only having support services and bereavement policies is insufficient. There is work to be done to ensure that support services and bereavement policies match the needs of university students and staff members. By increasing interpersonal skills, critically reviewing policies, and re-orienting wellbeing services, educational institutions can become supportive environments for serious illness, death and bereavement.

Funding: Compassionate Communities Center of Expertise (COCO) of the Vrije Universiteit Brussel.

P 15.014 The Widowhood Effect in Serious Illness: The Impact of Spousal Death on Mortality in Dementia, Organ Failure, and Cancer

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Background/aims: The "widowhood effect," in which mortality rises in the period following death of a spouse, may be heightened in people with serious illnesses, like dementia, cancer, and chronic organ failure, in which support needs are high and for whom spouses typically provide extensive caregiving support. Yet there are limited data on widowhood and mortality that account for these serious illnesses. The purpose of this study is to determine the relative mortality risk of widowhood among those with dementia, cancer, and chronic organ failure.

Methods: Retrospective cohort study among community-dwelling, married/partnered persons, ≥65 years, enrolled in the Health and Retirement Study, a longitudinal nationally representative survey of older adults in the United States linked to Medicare claims, from 2000-2018. We used cox proportional hazards model to determine short- and long-term mortality in people with dementia (PWD), heart failure (PWHF), and cancer (PWC).

Results: We identified 2,091 PWD (846 experienced widowhood), 463 PWHF (170 experienced widowhood), and 744 PWC (215 experienced widowhood). Compared to those with serious illness alone, those with serious illness and widowhood had increased 1-year mortality in PWD (7% vs. 5%; RR 1.4) and PWHF (11% vs. 7%; RR1.5) and decreased 1-year mortality in PWC (10% vs. 11%; RR 0.9). These effects were diminished beyond 1 year following the widowhood event (1-year mortality rate 6% for PWD [RR 1.2], 10% for PWHF [RR 1.4], and 8% for PWC [RR 0.73]).

Conclusions: Widowhood increases the risk of dying for those with serious illness within the first year following the event and is most pronounced in those with illnesses that have prolonged periods of poor function, such as in dementia and heart failure. Widowhood may be an important disruptive event that may deserve further clinical- or community-based interventions.

P 15.015 Promoting the Development of Bereavement Care in Palliative Care – Taking Delphi Findings forward into Practice

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Background/aims: The WHO definition of palliative care includes bereavement care. The aims of the EAPC Bereavement Taskforce were to describe current practice in bereavement care in palliative care in Europe; to make recommendations for best practice in bereavement care & to achieve through a Delphi Survey consensus on recommendations. Since completion of the White Paper (EAPC, 2021) Covid-19 and restrictions have significantly impacted bereavement experience and bereavement care. Palliative Care services need to consider the recommendations & respond to emerging pandemic-related need.

Aims: To review the EAPC guidance and explore the implications for palliative care relative to: 1. Covid-19 bereavement research and literature 2. The range of bereavement service provision which has emerged.

Methods: A systematic literature search & narrative review sought to identify:

1. bereavement experiences related to Covid-19 & restrictions;
2. trends in bereavement care provision.

Findings are reviewed in light of the EAPC bereavement care recommendations & implications for bereavement care in palliative care explored.

Results: There are indications of increased intensity in bereavement experience; of services adapting to use of technology; ongoing challenges in risk assessment and in accessing supports. However, the transition from Covid-19 restrictions to a stable & integrated provision of bereavement care is not yet presented in scientific literature.

Conclusions: Provision of equitable & responsive bereavement care requires the integration of Covid-19 related experiences with evidence-based decision-making & evaluation. More than ever, it requires national & international guidance. This study addresses the challenges & possibilities for the development of bereavement care in palliative care in light of the pandemic experience. Palliative care services must be flexible & responsive to changing need in the medium and longer term to ensure the provision of meaningful bereavement support.

P 15.016 The Experience of Growth for Survivors Bereaved of a Spouse by Cancer: Relying on Merleau-Ponty's Recombination of the Body Schemes

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Background/aims: While grief can be a stressful experience for families who have lost a loved one, it has also been suggested that it can lead to positive change, and its relevance to the emerging concept of posttraumatic growth has been explored. However, few studies have been on survivors bereaved of a spouse by cancer, and the nature of growth remains poorly understood.

Find out the nature of growth experiences for survivors bereaved of a spouse by cancer.

Methods: Design/ analysis: This study was a qualitative inductive study. Interviews were conducted and narratives were analyzed phenomenologically. The phenomenological analysis relied on the idea of reorganization

of habit, using Merleau-Ponty's theory of the body as a philosophical foundation.

Data collection: Forty-one semi-structured interviews were conducted between July 2019 and March 2021. Although developed based on the PTG conceptual framework, the interview guide was adapted as M.K. conducted pilot interviews with representative members of the bereaved association.

Results: 21 survivors bereaved of a spouse by cancer were included. The mean age of participants was 70.5 years, 11 months to 8 years after bereavement. The growth of survivors bereaved of a spouse by cancer began before the bereavement, with the questioning of habits with the living spouse due to illness and prognosis announcement and/or bereavement, reaffirming the connection with the spouse, realizing that it provides emotional support, and becoming accustomed to who they are now in the new environment.

Conclusions: New perspectives suggested for growth in bereaved families were "growth that begins before the bereavement," "the impact of the timing of reorganization of habit," and "the affirmation of connection with the spouse and the recognition that this provides emotional support. Future work is needed to explore specific caregiving methods that support the growth of bereaved families.

P 15.017 Severe Grief among Family Members of Patients Who Died in Acute Care Hospitals before and during the First Wave of the COVID Pandemic: A Prospective Cohort Study

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Background/aims: The COVID pandemic has caused millions of deaths worldwide and mass bereavement. Rates of prolonged severe grief and its predictors in the context of COVID have not been characterized.

Aim: To determine the prevalence and predictors of sustained severe grief and worsening grief symptoms among family members experiencing grief early in the COVID pandemic.

Methods: Prospective cohort study. Family members of patients who died of COVID in any acute care hospital in Ottawa, Canada between Nov 1 2019 and Aug 31 2020 (COVID+ve) were matched with family members of patients who died of non-COVID illness in the same period (COVID-ve) or just before the pandemic (pre-COVID). We abstracted decedent medical charts and called bereaved family members at baseline (>6 months post-loss) and 6-month follow-up (>12 months post-loss) to assess severe grief symptoms using the Inventory of Complicated Grief (ICG). A sustained ICG score of >25 or increase of >3 points from baseline to follow-up was considered severe/worsening grief. Analysis used Poisson regression with robust error variance.

Results: We abstracted data for 425 decedents; 121/176 contacted family members completed baseline ICG and 111 (92%) completed 6-month follow-up. Prevalence of severe grief (ICG >25) was 28.8% at both baseline and follow-up, and similar across cohorts. 37 (33.3%) participants had either sustained severe grief or worsened grief from baseline to follow-up; this was not associated with death during the pandemic [adjusted relative risk (RR) (95% CI) 1.51(0.81-2.81) and 1.29(0.56-2.94) for COVID-ve and COVID+ve cohorts, respectively], physical presence of

family in the last 48hrs of life [RR 1.46(0.65-3.28)], or intubation [RR 1.71(1.01-2.88)].

Conclusions: Severe grief is common more than 1 year post-loss among family members bereaved during the COVID pandemic. Aspects of experiencing grief during a pandemic may influence grief severity more than the timing or circumstances of the death.

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P 15.018 Supportive Care for Relatives of Patients Dying in the Intensive Care Setting; Development of a Toolbox (Project STRIC)

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Background/aims: In the Intensive Care Unit (ICU), treatment and care are primarily focussed on saving lives. However, each year 15.000 persons in the Netherlands die in the ICU. The high tech environment and the absence of intimacy might lead to prolonged grief in bereaved relatives in the ICU. In the Netherlands little effort has been made to develop a structured palliative care approach for bereavement support for relatives in the ICU. Our goal was to provide practical tools for nurses, to enable them to support relatives of dying patients in the ICU.

Methods: A multidisciplinary group of professionals, researchers, and patient and family representatives (IC-Connect and the foundation Family and patient Centered Intensive Care (FCIC)) was established in the project STRIC (Dutch acronym of 'Dying and Mourning in the ICU'). Assisted by nursing students, we used various methods and resources to develop tools, i.e: (inter)national ICU end-of-life care guidelines; best practices in adult and pediatric ICU's and hospice care settings; educational needs and preferences of ICU nurses; multicultural aspects of (education in) bereavement care; implementation science.

Results: We developed a practical toolbox, adaptable to the personal and cultural needs of relatives, the local ICU context and future trends. The toolbox includes (1) suggestions for creating a farewell basket with materials for relatives; (2) information and guidelines for nurses on how to use this toolbox and how to support families; (3) suggestions for implementation on the ward; and (4) training materials on multicultural bereavement care. Written and digital materials (videos and e-learnings) are freely available at the FCIC website (<https://fcic.nl/onze-projecten/rouwzorg/>).

Conclusions: A toolbox has been developed with evidence based interventions and best practices in ICU care.

By providing practical tools and knowledge, ICU-nurses have concrete tools for (implementation of) bereavement support for relatives of dying patients.

Funding: ZonMW

P 15.019 Who Helped and How? Findings from a UK-wide Online Survey on the Use and Perceived Helpfulness of Informal and Formal Bereavement Support during the COVID-19 Pandemic

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Background/aims: During the Covid-19 pandemic, accessing support after a bereavement was challenging for many. This study aimed to describe the use and helpfulness of different types of support in a cohort of people bereaved in the UK during this unprecedented time.

Methods: A longitudinal survey of people bereaved during the pandemic over four time points. At 7- and 13-months post-bereavement (T2 and T3), participants rated the helpfulness of support used and described how they had felt helped by this support.

Results: 420 participants completed at least one follow-up survey (T2, T3 or both). Most respondents were female (88.5%), self-identified as white (96.4 %) and had lost a parent (57.8%) or partner (24.3%). The majority (89.3%) were supported by family and friends, rating this informal support as 'quite helpful' (mean rating 4.3 out of 5) and describing help with practical tasks, expressing feelings/sharing grief, remembering, feeling cared for and less isolated. The most commonly used forms of other support were 1:1 support (e.g. counselling; used by 40.6% of participants) and online community support (used by 31.0%), with average helpfulness ratings of 4.1 and 3.9, respectively. 1:1 support helped participants feel listened to and process their grief. Engaging via written comments in online groups/forums enabled sharing with similar others, feeling understood and less alone. Informal and formal bereavement groups were rated as similarly helpful (4.2) while helplines and specialist mental health support were slightly less helpful (3.6) (used by 9.3%, 4.8%, 7.2% and 4.5% of participants, respectively).

Conclusions: Transitioning beyond Covid-19, these findings highlight the value of different forms of informal as well as formal support, particularly bereavement counselling. Policy makers must attend to the foundational and second tiers of the public health model of bereavement support, supporting communities as well as services.

This study was funded by UKRI/ESRC and Marie Curie.

P 15.020 'Part of Me Died with them, and There Is this Burning Hole': A Qualitative Analysis of Free-text Survey Data from People Bereaved of a Partner or Spouse

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Background/aims: A recent national survey of bereaved partners found a high prevalence of complicated grief and psychological distress. This study aimed to use free-text data from within the survey responses to elicit potential explanations for these findings and explore whether psychological distress is related to access to support.

Methods: Survey of people who had registered the death of a civil partner or spouse in England or Wales 6-10 months previously. Responses to free-text questions were analysed using thematic analysis and the discourse dynamics approach to identify figurative language.

Results: 143/182 respondents contributed free-text data within their survey responses. Participants described devastation after the death of their partner: losing part of themselves after the death; loss of joy, meaning and motivation from their lives; and feeling empty and alone. Feelings of isolation prevailed despite access to social support, and were

often exacerbated by spending time with other couples, where feelings of anger and jealousy arose. Regret and sadness were described in relation to the loss of a shared future, companionship, and new experiences together. Figurative language related to containers (e.g. 'I've put my memories in a box in my head, and cannot look at them. It is too heart breaking') and the vacuum left by the partner (e.g. 'burning hole', 'void', 'empty') were common as well as metaphors related to movement and a loss of control (e.g. 'everyone is getting on with their lives and mine is standing still', 'going through the motions', 'my emotions since have been a rollercoaster').

Conclusions: This study highlights the complex relationship between social support and partner bereavement. Social support is of great importance, but may not mitigate feelings of isolation and loss of meaning. Further research examining the relationship between grief, isolation, social support and social networks over time is needed.

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P 15.021 The Bereavement Experience of Family Members in Taiwan: A Narrative Synthesis Review

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Background/aims: The bereavement experience is shaped by cultural and social contexts. Emphasising the importance of family, filial piety, and harmony in a family and viewing death as a taboo issue are key cultural features in Taiwan.

Aims: To comprehensively understand the bereavement experience of family members following an expected death in Taiwan.

Methods: A narrative synthesis approach was employed (Popay, 2006). Five electronic databases were searched: MEDLINE, PsychINFO, CINAHL, China Academic Journal Database, and Chinese Electronic Periodical Services. Hawker's appraisal tool was chosen for assessing the quality of studies.

Results: 17 papers met the inclusion criteria: English (9) and Chinese (8), published from 2006 to 2021. The studies varied in quality with scores ranging from 22 to 33. The included studies differed in the relationship to the deceased, the bereaved time frames, and the definitions of bereavement. Most studies looked at cancer patients receiving specialist palliative care. Four bereavement theories and four bereavement tools were employed. Protective and risk factors of bereavement outcomes were presented. Four themes regarding the bereavement experience of family members following an expected death were generated: multiple impacts of death; problem-based coping strategies: taking actions and thinking positively; connections: continuing the relationship with the deceased and maintaining the relationship with others; influential religious beliefs and rituals.

Conclusions: Continuing the relationship with the deceased is a key element of the bereavement experience for the bereaved in Taiwan and it is highly influenced by religious beliefs and cultural values. Suppressing or hiding emotions during bereavement needs to be acknowledged as a culturally acceptable and religious behaviour in Taiwan and potentially others in East Asia. Preparing for death and bereavement of family members at the end of life would be beneficial for bereavement outcomes but it is not well understood.

P 15.023 Singing through Grief: An International Online Songwriting Project

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Background/aims: The arts play a vital role in enabling hospices to promote healthier attitudes towards death and dying. Songwriting in particular can be a powerful way to express, articulate and share experiences of loss and change. Working with schools is also crucial for shaping these healthier attitudes and for raising childhood grief awareness. Two hospice-school pairs from Scotland and Greece participated in this online project, during the Covid-19 pandemic. The aim of this project was to raise awareness on death, loss and grief to school children and Hospice patients through songwriting.

Methods: An 1.5 hours online training course was offered to school staff regarding childhood loss and bereavement. Four online songwriting sessions (one-hour weekly sessions) followed with each group of children and patients in Greece and Scotland respectively exploring and expressing their experiences on death, loss and grief, in their native language. The project was concluded with a celebration event that conveyed the songs and their key messages to the public.

Results: The results included a different song from each group (available on <https://vimeo.com/657354776>). Online evaluation forms, including open-ended and closed-ended questions, were completed from both the participants of the project and the invitees to the celebration event.

Conclusions: The participants named their group 'GRESKO Agape' highlighting 'agape' (the Greek word for love) as a core idea and feeling that connected their diverse experiences and explorations of loss, change and grief in life. Through the lyrics of both songs and the data from the evaluation forms emerged the strength that people receive from memories of their deceased loved ones and from the support of their family and friends. The project was kindly funded by The D'Oyly Carte Charitable Trust.

P 15.024 Evidence-based Guideline 'Grief': Development, Outcomes and Implementation

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Background/aims: Grief is a central theme in palliative care but guidelines that support the care for grieving patients and family members are scarce. The existing guidelines either only focused on persistent complex grief disorder or were not based on available evidence.

Aims: The objective of this presentation is to describe the development and outcomes of a Dutch palliative care guideline Grief.

Methods: Several stakeholders, including many associations for patients and professionals, developed an agenda with central topics that should be covered by the guideline. Next, a multidisciplinary group wrote the evidence-based chapters of the guideline, based on systematic searches in several electronic databases. The consensus-based chapters were based on review studies – if available – and expert opinions.

Results: The guideline covered the following evidence-based chapters: (1) grief support and treatment for: a) patients in the palliative phase, b) adult family members, and c) family members under 18 years; (2) distinction between grief and mental disorders, (3) identification of risk factors for developing complicated grief and (4) prevention of complicated grief. Consensus-based chapters were: (1) signs of grief, (2) informing patients, (3) cultural diversity, (4) well-being of the caregiver, (5) organization of health care.

Conclusions: The guideline Grief (published October 2022) is the first evidence-based guideline in the Netherlands, and to the best of our knowledge worldwide, that supports care for grieving patients and family members. In addition to the guideline, information about grief for patients and family members and educational materials have been developed. We also identified several gaps in knowledge. For example, there is no literature available on the effects of counseling and treatment of grief in patients in the palliative phase.

P 15.025 Music and Grief: Finding Innovative/Creative Ways to Support Informal Carers of Terminally Ill Patients Pre- and Post-bereavement

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Background/aims: Although known globally as the “backbone of health and social care delivery”, informal caregivers assume burden that can reduce quality of life and present up to 50% greater risk for mental-health problems, especially during bereavement. While developing and implementing effective bereavement support remains challenging, a recent WHO evidence synthesis highlights the role of music therapy for addressing complex problems for which there are currently inadequate solutions.

Aims: Develop a best practice research agenda for music therapy to support informal caregivers moving through pre- and post-bereavement.

Methods: Online half day workshop using a World Café approach; an innovative method for harnessing group intelligence within a diverse group of clinical and academic stakeholders.

Data collection: A pre-workshop survey gathered demographics, key priorities and methodological challenges to inform workshop discussions. The online workshop involved four rounds of rotating, 25-minute, small group parallel discussions using Padlet. One final large group discussion involved a consensus building activity.

Analysis: All data were analysed thematically to identify patterns to inform priorities and recommendations.

Results: Twenty-two provided consent and completed the pre-event survey (response rate 44%), representing countries spanning 10 different time zones. Sixteen participated in the workshop. Data analysis is underway and the results will be presented at this conference in relation to research priorities and methodological challenges.

Conclusions: Findings will inform future pre- and post-bereavement research for informal caregivers of terminally ill patients. This is an important step in supporting the statutory health services and third sector Specialist Palliative Care commissioners and service providers to make an evidence-based decision on how to incorporate music therapy as a core service in palliative care bereavement services.

P 15.026 The Effect of Loss and Secondary Trauma Experiences of Healthcare Professionals in Negative Outcome Perinatal Events and Perinatal Bereavement Care

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Background/aims: Losing a child in the pre- and perinatal period is a highly demanding event for both families and healthcare professionals as well. In Hungary in 2020 the perinatal death rate was relatively low (below 0.4%), the total number of babies lost in the perinatal period was around 500, yet, the burden it conveys is all the bigger.

Methods: (1) Examination of the presently available guidelines and institutional practices in obstetrics, gynaecology and neonatology departments; (2) Study of the available healthcare system practices in negative outcome perinatal events with focus on the provided bereavement care services; (3) Focus on professional and personal difficulties, challenges for the HCPs in adverse outcome events.

Qualitative approach, semi-structured interviews with 18 healthcare specialists, different fields of perinatal care, analysed in NVivo, applying Interpretative Phenomenological Analysis, concerning perinatal child loss and support for the bereaved families.

Results: No adequate knowledge and/or application of available measures in approx. 80% of the institutions and some local bereavement care in the remaining 20%.

Professional and personal requirements perinatal care specialists must meet show that while there is a growing need for individualised care, the levels of personal involvement and emotional burden are such that specific trainings are also necessary in the formation processes to balance the impact of loss and secondary trauma. Significant differences can be observed between institutions, regarding the application of legal and guideline measures and having own institutional procedures, protocols for bereavement care options.

Conclusions: For perinatal bereavement care a shift of attitude is needed in the competency fields as much as the established cooperation of a multidisciplinary group. New protocols, trainings, supportive and self-care measures are all required for a standardised national approach in care.

P 15.027 The European Grief Conference, Copenhagen 2022 – An Effort to Unite the Field of Bereavement Care in Europe

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Background/aims: Bereavement care in Europe is varied, provided in a variety of settings. Bereavement care must incorporate practice, research and educational perspectives. Through greater collaboration across Europe, there is an opportunity to improve bereavement care.

We discuss the vision and execution of the inaugural European Grief Conference (EGC), held in Denmark in 2022. We aim to inspire greater collaboration across the spectrum of bereavement care in Europe.

Methods: The EGC focused on bereavement care practice, research, and education/policy. It was structured around a public health 4-tiered model of bereavement care: Level 0_Society (grief literacy), Level 1_Normal Grief, Level 2_Bereavement support, and Level 3_Complicated grief reactions. This model is in line with the EAPC bereavement whitepaper.

Diverse European representation was prioritized on conference planning and scientific review committees, and among oral presenters. Efforts were made to invite participants from across Europe.

Evaluation was conducted through analysis of registration/submission data, one-word feedback on the final day, and a feedback survey.

Results: 250 participated from 27 countries. The last day ‘one feeling word’ activity resulted in 126 words, most were positive (*inspired, connected, hopeful, informed*). 170 participants completed the feedback evaluation. 80% found the conference to be of high/very high professional relevance. 70% found it to have met expectations to a high/very

high degree. 79% found it provided opportunities for networking to some/a high/very high degree. Many shared ideas/wishes for future conferences.

Conclusions: There is an interest in greater information sharing/collaboration across Europe around bereavement care, research and education. This conference was an effective vehicle. To improve the entire spectrum of bereavement care, we hope the palliative care perspective will be represented to a higher degree in EGC2024.

P 15.029 What Predicts the Adoption of End-of-Life and Bereavement Support to Families in Cancer Care? (BEST Care Study)

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Background/aims: The loss of a close other to cancer is an incisive experience. Comprehensive family support that starts during end-of-life (EoL) and continues into bereavement (BER) is recommended to promote family well-being and mitigate their suffering. However, best practice recommendations are often poorly adopted. This implementation study investigates enablers and barriers to EoL and BER support for families.

Methods: 81 nurses from seven acute and home care organisations providing cancer care in German-speaking Switzerland completed a survey about organisational (resources, guideline, culture, barriers, financial incentive) and individual determinants (characteristics, skills, training). Adoption of family support practices in EoL and BER care served as the outcomes, each measured by a self-developed eleven-item questionnaire. Cross-sectional multiple fractional logistic regression and ordinary least squares (OLS) identified the incremental effects of organisational and individual predictors.

Results: Reported adoption was significantly higher in EoL than in BER care ($p < 0.001$) while correlating strongly ($p < 0.001$). Working in a palliative care unit (49 of 81 nurses) was the strongest predictor in both EoL ($p < 0.01$) and BER care ($p < 0.01$). Further positive predictors were, among others, a supportive organisational culture (EoL, $p < 0.05$; BER, $p < 0.01$), having a family support guideline (EoL, $p < 0.05$), privacy with families (EoL, $p < 0.01$), reimbursement of conversations (BER, $p < 0.05$), young age of nurses (EoL, $p < 0.001$; BER, $p < 0.05$), and nurse training (BER, $p < 0.05$).

Conclusions: Family support that meets best practice recommendations is provided more consistently during EoL than BER, and more so in palliative care than in other services. A combination of organisational and individual context factors predicts this adoption. The study implicates barriers and facilitators that need to be targeted with future implementation strategies, particularly so in BER care.

P 16 - Volunteering

P 16.001 A Hospital End-of-Life Care Volunteer Service in Five European Countries: What Supports or Hinders Implementation? The iLIVE Project

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Background/aims: End-of-life (EoL) care volunteers in hospitals are a novel form to support dying patients and their families. The iLIVE Volunteer Study, funded by the European Union Horizon 2020 Programme, supported volunteer coordinators from five hospitals in five European countries to design and implement a culturally adapted hospital EoL care volunteer service. Exploring the implementation process within each country will increase understanding of such services across different cultures and contexts. This study aims to identify and explore barriers and facilitators to the implementation of hospital EoL care volunteer services in five countries.

Methods: A focus group interview and five individual interviews were conducted with volunteer coordinators from Norway, Netherlands, Slovenia, Spain and United Kingdom (UK). A theory inspired framework based on the five domains of the Consolidated Framework for Implementation Research (CFIR) was used for data collection and analysis. Results from the focus group were depicted in radar charts per country.

Results: A wide range of barriers and facilitators were identified – both those expected (such as the challenges of a service during the COVID-19 pandemic), but also many other ‘hidden’ factors. In Norway, the Netherlands and UK, implementation was facilitated by collaboration with an existing volunteer service within the hospital, which aided recruitment of volunteers. One of the benefits of the volunteer trainings in these countries appeared to be an increased motivation among volunteers; this facilitated continuity of the service. In almost all countries, raising awareness about the new volunteer service was necessary; a barrier was that hospital staff did not recognize the added value of EoL care volunteers.

Conclusions: While the purpose of the volunteer service was appreciated, a key barrier was unfamiliarity of the service by staff on the wards. Ways to effectively promote a hospital EoL care volunteer service is a crucial step in the implementation process.

P 16.002 Attentive Visitors: Developing a Training Program to Support Community-based Volunteers in their Palliative Care Signposting Role

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Background/aims: Community volunteers often notice palliative care (PC) needs that healthcare professionals (HCP) and family caregivers miss, potentially playing an important signposting role. In order to fulfill this role, volunteers need knowledge about PC needs and community resources; and they should have good relational, communication and observation skills. These skills and knowledge can be enhanced through training.

Aims: To develop a training program to support community homecare volunteers in their signposting function.

Methods: Learning objectives were formulated based on the results of a qualitative study in which 7 focus groups (15 community volunteers, 20

HCP's) and 10 in-depth interviews (6 community residents with PC needs, 4 informal caregivers) were conducted. The content and structure of the training were developed in collaboration with a psychologist trainer, stakeholder organizations and community volunteers.

Results: The training program consists of a didactic workshop (5-6 hours) and a follow-up session (2-3 hours) in which reflection, exchange of knowledge/experiences are central. The workshop aims to achieve learning objectives related to increasing awareness and knowledge of the volunteer role and signposting function, PC needs and signals, community resources, communication with the community resident and communication with HCPs. Case discussions, reflection exercises and role plays are used to enhance volunteers' insights and skills related to recognizing, describing, responding to and communicating patient needs to HCPs. During the follow-up session, participants will be invited to share experiences and reflect on what the didactic workshop has meant for their volunteer work since.

Conclusions: The training responds to existing needs in community homecare and tries to strengthen community volunteers in taking up their signposting function. The training program will be piloted and evaluated Fall 2022-Spring 2023.

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P 16.003 Paid Staff and Volunteers' Experiences of Working Together to Provide Palliative Care: A Systematically Constructed Meta-ethnographic Review

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Background/aims: Volunteers in palliative care settings are an essential part of care provision for patients and those important to them. Effective collaboration between volunteers and paid staff has been regarded as an important element of successful working, however, at times failures in coordination, information sharing and tensions within teams have been highlighted.

Aim: To explore the views expressed by volunteers and paid staff about their experiences of working together in palliative care settings.

Methods: A systematic exploration of qualitative research using a meta-ethnographic approach. PsycINFO, CINAHL, Medline Complete and AMED databases were searched from inception to December 2021 for the concepts 'volunteers' and 'palliative care'. Papers were assessed for quality using CASP tool. Repeated in-depth reading and appraisal of papers identified interpretive metaphors and concepts. Studies were considered for ways they added to, opposed, or compared to each other, providing new interpretations.

Results: Included papers (n=14) enabled the construction of five storylines: 1) "we are the cake and they are the cream": understanding the volunteer role – separate, but part of a whole; 2) ". . .we don't know what's wrong with people but sometimes we need to know": access to information and importance of trust; 3) "everybody looks out for each other": access to paid staff and their support; 4) ". . .we don't meddle in the medical": boundaries; 5) "it's the small things that the staff does for me that makes me feel good about my work": sense of value and significance.

Conclusions: Successful working between paid staff and volunteers providing palliative care should not be taken for granted to prevent potential problems in their relationships. For effective working relationships between paid staff and volunteers, proactive engagement, recognition of each other's role and contribution, mutual sharing of information, and intentional interaction between both groups is needed.

P 16.004 Building a Compassionate Community Initiative in the Netherlands: Grassroots Reflections about Structure, Process and Outcomes & Consequences for Designing Research

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Background/aims: When we prepared for a (stand alone) compassionate community in 2019 on a graveyard in a medium-sized city in the Netherlands, many aspects had to be figured out. In 2020 opened the Compassionate Community in a monumental building with 20 volunteers focussing on:

- death literacy
- encouraging dialogues about death, dying and bereavement
- remembrance rituals and activities
- community support to people after a loss.

We experienced a need to philosophical underpinning of the initiative. In doing so, we adopted Thomas Fuchs' phenomenological view on grief and on what is helpful for people coping with loss.

The aim of this contribution is to share reflections about structure, process and observed outcomes of this Dutch compassionate community and present insights for research designs in this field.

Methods: A case study approach is used.

Results: The initiative is described in terms of: figures and numbers, experiences with visitors and volunteers during the first two years, individual and collective rituals developed, collaboration with other organisations, art workshops, reflections about task-oriented versus relation-oriented contributions, types of observed outcomes.

The lessons learned address the value of listening-intelligence in our community. This became more and more central to our training, dialogues and reflection within this community. Comparable initiatives might benefit from our experiences with training in the art of listening and the use of listening assessments.

Conclusions: Discussion of the observed value of this compassionate community in terms of:

- (im)possibilities for bringing death, dying and bereavement back to the community
- taboos around death, dying & bereavement
- success of mobilizing support & compassion
- value of addressing listening-intelligence

We present consequences from these grassroots insights for designing research into compassionate communities and reflect about value of different evaluation instruments.

P 16.005 Making Wishes Come True for Neuromuscular Patients: A Volunteer Project

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Background/aims: The fulfilment of desires is an intervention carried out in palliative care, promoting the meaning of life and maintaining positive memories.

The "Magic Ambulance" Project aims to provide adults with neuromuscular pathologies, accompanied by palliative care, the fulfilment of an essential wish for their current life situation through a multidisciplinary team that will allow them to have specialized transport adapted to their needs.

Aims: Identify and characterize the volunteering “Magic Ambulance” Project.

Methods: A retrospective observational study included 24 volunteers, two patients and six family members.

Intentional samples were collected from January to September 2022. Clinical and demographic data were from anonymized integrated clinical records.

Data collection was an online questionnaire, with demographic characterization, with open and end questions.

Data analysis is done with descriptive statistics software.

This study complies with ethical procedures and authorization granted by the sample.

Results: The project granted two wishes to patients with Amyotrophic Lateral Sclerosis, proposed by the community palliative team. Family members were involved, making it a very emotional moment with positive memories.

Of the 24 volunteers, 15 are female, aged between 30 and 50. Thirteen do not have professional experience in PC. Seven already had training in PC before the project, and eight received training to integrate the project.

Volunteers participated in the different project phases: Four in project design (project team); thirteen elements in preparing the wishes (community team, ambulance crew and project team). Seven, in the execution phase.

Conclusions: Myths about PC by the general population and health professionals are a barrier to patient referral, making it difficult to experience the disease in a dignified, involved way and with the necessary family support. This project promotes literacy in PC and enables volunteers for interventions aimed at well-being and quality of life.

Conflict of interest: This project is funded by “La Caixa Foundation”.

P 16.006 What Knowledge and Skills Do Community Volunteers Need to Signpost Palliative Care Needs to Professionals? A Qualitative Study

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Background/aims: Volunteers often notice palliative care (PC) needs that healthcare professionals (HCP) and family caregivers miss, potentially playing an important signposting role. It is unknown what particular knowledge and skills are lacking and required to optimally fulfil this role in community homecare.

Aims: To explore the desired and required knowledge and skills for volunteers to recognize, describe and communicate PC needs to HCPs.

Methods: A qualitative study design with 7 focus groups (15 community volunteers, 20 HCP’s) and 10 in-depth interviews (6 community residents with PC needs, 4 informal caregivers).

Results: We identified 5 themes in our data:

- (1) the organization of community-based volunteer work,
- (2) the volunteer,
- (3) the resident with PC needs,
- (4) the volunteer – community resident relationship, and
- (5) communication/sharing of information with HCPs. Knowledge about types of PC needs and about community resources were considered important. Examples of required skills are: willingness to listen, being present, responding empathically, being able to relate to the person they visit, balancing personal distance and proximity, starting and maintaining non-threatening conversations, and building a relationship of trust

with the resident. Insight into missing skills and knowledge was obtained by discussed experienced difficulties with regard to learning from other volunteers, finding the right information to help residents, exploring care signals with the resident and making their presence known and contributing to professionals.

Conclusions: In order to fulfill their signposting role, it is important that volunteers have knowledge about PC needs and community resources. Ideally, they have good relational skills, communication skills, observation skills and skills that enable them to provide practical help. Volunteers should make their presence and role known to professionals and find out what they can mean for each other.

Funding: Flemish Cancer Fund

P 16.007 Social Capital of Palliative Care Service Partnerships: The Case Study of Volunteering Local Community in Kalasin Province

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Background/aims: 1.To synthesize the types of social capital(SC) of palliative care service partnerships(PCSPs) during 2016-2020. 2.To recommend the formal community palliative care policy of Thailand’s government municipality-level administrations(GMAs) in the Northeast.

Methods: Literature review on social capital theory relating to public health care,Public Health Long Term Care policy in Thailand and volunteering concept. Survey and study palliative care service(PCS) activities of Kalasin municipality(KM)’s volunteer network(2016-2020). In-depth interview 50 key informants,3 focus group meetings;1)Kalasin municipality’s Managements and MNDVG members 2)Public health group and 3)Community and civic groups. Synthesis and conclude the study for policy recommendation and the best practice of official PCS at GMAs.

Results: The result showed that informal community organization PCSPs aligned with palliative care concept focusing on patients and families’ psychosocial and socioeconomic need. The social partnerships based on a mutual relationship and gradually developed collective social capital(CSC);shared value or norms,trust,reciprocity and network resulting community engagement,evident from the in-depth interviews and site visits. The obstacles occurred due to social services focusing only the poor and the middle-income groups,lack of official leadership role and risk management plan.(the COVID-19 pandemic etc.) SC of PCSPs was verified into 3 types;Bonding,Bridging and Linking SC,from focus group meetings. The policy recommendation and the best practice were synthesized. KM administration published a booklet for knowledge sharing.

Conclusions: The study concluded that Kalasin’s PCSPs was initiated by SC and gradually enlarged SC(CSC). Consequently,the PCSPs between the local public and private were enhanced to fabricate the social structure of formal community PCS in the future,leading to the inclusive community welfare and compassionate community, which to supplement social resilience for ageing society.

P 16.008 We Are All in Need of Kindness, We Are All in Need of Human Touch (Opening Line of a Beloved Israeli Poem)

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Background/aims: The study was conducted for the purpose of evaluating a project initiated by two staff members at Home Hospice. From their experience in treating hundreds of patients and the constant search for a comprehensive and wide-ranging answer to their plights, it was decided to add volunteers whose expertise is in complementary

medicine treatments (e.g. massage, touch therapies and acupuncture). In view of the suffering of the patient because of isolation, lack of intimacy and other distressing symptoms, an approach was proposed that would provide an embracing and stabilizing touch. The purpose of the study was to evaluate the response, the benefits of the project and the quality of its realisation. Depending on the results we hope to improve and expand the project.

Methods: The volunteers were required to report in writing on each visit. Also the project was documented in writing at all stages of its execution. Interviews and a review of the documentation in the patients' files were conducted, referring to 4 palliative care quality indicators:

1. Stimulating dignity of the patient and his family.
2. To improve communication and exchange of information within the multidisciplinary team.
3. Alleviating symptoms and improving quality of life.
4. Reducing hospital admissions and allowing for patients to pass away at home.

Results: The research findings showed an improvement of outcomes of all indicators mentioned above. The interviews showed the importance of the support by the project coordinator. The results supported the assumption that the introduction of volunteer caregivers significantly contributed to the well-being of the patients and their families. The limitations of the study mainly concern the limited numbers of the participants in the project at this stage.

Conclusions: Introduction of volunteer caregivers significantly contributed to the well-being of the patients and their families. All carers who took part in the project reported professional, spiritual and mental growth.

P 16.009 The Role of Volunteers in Quality Palliative Care Delivery.

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Background/aims: Here in India almost 75% of cancer patient die a sad death of neglect due to lack of awareness about palliative care and low economic level. Surveys in India show that two third of cancer patient do not get proper care during the terminal phase of their life. Palliative care through volunteers can make a significant difference in this respect. To identify and try to solve, to the extent possible, the main difficulties in giving palliative care to the terminal cancer patients of the area. And evaluate the impact of volunteer's direct care of palliative patients and their families.

Methods: Feedback from patients and their relatives regarding the palliative care they receive from nursing home and from volunteers and compare the two. Also feedback from volunteers regarding their positive and negative experience while delivering palliative care service. Then evaluate the data to compare and improve the quality of service.

Results: We carried out two studies. One study was undertaken in nursing home palliative care and another was in home setting by volunteers. Both studies were in adult palliative care services. Since January 2022, 550 cases were studied to enquire about their experience in both home based care and nursing home care. Both the studies fulfilled our quality appraisal criteria. One found that those families and patients who received home visits from volunteers were significantly more satisfied. The study highlighted the value of the role of volunteers in better satisfaction of patients and their families.

Conclusions: Further research is needed to evaluate the role of volunteers in palliative care and how it can be delivered appropriately and effectively. We also wish to compare our findings with similar studies elsewhere.

P 17 - Research Methodology and Methods

P 17.001 How Is Impact of Prognostication Measured in Palliative Cancer Studies? Findings from a Systematic Review of Quantitative Measures and Qualitative Experiences

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Background/aims: We are developing a Core Outcome Set (COS) for prognostication (prediction of survival) in palliative cancer care, as there is a lack of consensus about which outcomes are the most important to measure. This systematic review aims to identify and synthesise outcomes used in palliative cancer prognostic research, and patients' and caregivers' experiences of prognostication.

Methods: We searched five databases (MEDLINE, Embase, PsycINFO, CINAHL, and the Cochrane Library) from inception to March 2022. We included studies that reported on the outcomes of prognostication or explored the experiences and perceptions of prognostication in an adult palliative cancer population, or their caregivers. We reported quantitative outcome data by prevalence, and thematically synthesised qualitative findings. We mapped all results on the five core domains of the Core Outcome Measures in Effectiveness Trials (COMET) initiative taxonomy: death, physiological/clinical outcomes, life impact, resource use, adverse events. PROSPERO ID: CRD42022320117 (registered 29/03/2022)

Results: Out of 8,075 studies, 42 were eligible: 32 quantitative, 6 qualitative, 4 mixed methods. 70 outcomes were identified and organised into twelve domains: survival, psychiatric outcomes, general outcomes, spiritual/religious/existential functioning/wellbeing, emotional functioning/wellbeing, cognitive functioning, social functioning, global quality of life, delivery of care, perceived health status, personal circumstances, and hospital/hospice use. Quantitative studies varied in the outcomes they assessed, and the measures they used, most frequently assessing treatment preferences (26%), prognostic awareness (26%), and quality of life (26%). The main qualitative themes were: treatment preferences, avoidance/denial, maintaining hope, and preparedness for end-of-life.

Conclusions: We identified 70 outcomes for potential inclusion in a COS for prognostic trials. The next stage of the study will prioritise these outcomes through a Delphi process.

P 17.002 The Development of Questionnaires for Patients with Advanced Cancer and their Family Caregivers Participating in a Six-country Trial

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Background/aims: The randomized controlled DIAdIC trial evaluates the effectiveness of two psychoeducational interventions in six European countries for patients with advanced cancer and their family caregivers (i.e. dyads). One of the challenges in conducting an international study with several outcomes is the use of equivalent instruments

across countries and ensuring their relevance to dyads. We describe the development of questionnaires used in the DIAdIC trial and ways to address these challenges.

Methods: The expected outcomes of the trial were mapped and matched to relevant instruments, which were then reviewed by the trial consortium in an iterative process. The selected instruments were translated and culturally adapted to each participating country. The translated versions were then pilot tested using cognitive interviewing techniques with 8-12 dyads in five countries.

Results: Identifying instruments that measured key study variables was challenging. One difficulty arose from our inclusive definition of a family caregiver, who could be a partner, other family member or friend.

Several potential instruments were inappropriate for dyads who were not in an intimate relationship (e.g. when asking about sex life). In addition, terms used to refer to the patient/caregiver differed extensively across instruments. These problems reasoned adaptations and testing of various terms for 'patient' and 'family caregiver', which had to match the context of the different instruments. After testing, the terms for patients as 'partner/family member/friend' and caregivers as 'carer' were agreed upon. The developers of the instruments approved these adaptations. The final patient questionnaire consists of 141 items, the caregiver questionnaire of 145.

Conclusions: We identified and adapted measures that cover all outcome variables and employ a standardized way to refer to patients and caregivers. This makes the response process appropriate to all trial participants in all six countries.

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P 17.003 Determining Which Outcomes Are Most Important to Stakeholders for Trials of Complementary Therapies in Palliative Care: A Modified Delphi Process

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Background/aims: Touch-based complementary therapies (such as massage and reflexology) are widely used in palliative care settings. Clinical trials evidence of therapy effectiveness however is inconclusive. Developing a core outcome set (a list of outcomes deemed most important by key stakeholders) can ensure meaningful outcomes are consistently measured as a minimum in clinical trials. We aimed to achieve consensus on a shortlist of outcomes for touch-based complementary therapies in palliative care.

Methods: An online modified Delphi process was conducted with people with life-limiting illness, complementary therapists and researchers. Participants rated the importance of outcomes on a 1-9 scale, provided their reasoning in free-text comments and voted on the timing of outcome measurement. Outcomes which $\geq 70\%$ of participants rated as critically important (7-9) were shortlisted and outcomes which $\geq 70\%$ of participants rated as limited importance (1-3) were removed. Participants received a summary of results and comments before rating the outcomes which did not meet criteria in a second round of survey.

Results: Round 1 involved 43 participants and round 2 involved 29. Consensus was reached on a shortlist of 17 outcomes. These were anxiety; sleep quality; stress; mental relaxation; pain; satisfaction with therapy effects; receiving supportive and empathetic care; muscle relaxation; satisfaction with the therapy session; depression; being in control of care decisions; nausea and vomiting; breathlessness; overall mental wellbeing; adverse events; satisfaction with the context of therapy delivery; and energy level.

Conclusions: The shortlist encapsulates the priorities key stakeholders and informed core outcome set development. Consistently evaluating meaningful outcomes in clinical trials will improve the evidence base and allow us to better understand the value of complementary therapies in palliative care. Research funded by the Economic and Social Research Council and Marie Curie Cancer Care [grant: ES/P000592/1].

P 17.004 Implementing Recommendations on Sedation in Palliative Care: Theory of Change Can Help to Identify the Most Effective Mechanisms of a Complex Intervention

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Background/aims: The Theory of change (TOC) approach was used to meet the difficulty of defining outcome parameters for the implementation of a complex intervention that aims to support best practice use of sedative drugs in palliative care. The ToC facilitates to open the black box between the input delivered by the intervention and the desired outcomes by setting out the supposed mechanisms to achieve the intended effects.

Methods: The ToC approach follows a participatory procedure, involving the study group iSedPall, representatives of patient and public involvement and medical experts. First, the overall impact was defined, leading to longterm outcomes and pre-conditions. In the course of an iterative process, the participants (n = 13) designed a ToC map that identifies the underlying mechanisms of change and describes why, how and under what conditions the intervention works.

Results: The ToC revealed several target groups affected by the intervention. Besides patients as main target group, also next of kin and the healthcare team were considered. Three longterm outcomes were identified: Patients receive sedative treatment according to their needs and values Patients and their next of kin trust in the team and feel empowered in dealing with the situation

Healthcare teams feel confident in their professional skills while conducting sedation

Assumptions about external factors, rationals, indicators and interventions for achieving the longterm outcomes have been developed.

Conclusions: The Toc of iSedPall describes the mechanisms of change of the intervention to support the use of sedative drugs in palliative care and to ensure high quality patient care. By defining indicators for the hypothetical pathways, the ToC can support process evaluation. In contrast to outcome evaluations aiming for evidence of effectiveness, the ToC helps to identify the most effective mechanisms of change.

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P 17.005 Psychometric Evaluation and Analysis of the Swedish Self-efficacy in Palliative Care Scale (SEPC-SE) with Physicians and Nurses in Hospitals

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Background/aims: Background: Providing palliative care in hospitals can be challenging due to healthcare professionals' self-efficacy in delivering palliative care. The Swedish Self-efficacy in Palliative care Scale (SEPC-SE) measures self-efficacy and consists of three domains, patient management, communication, and multidisciplinary teamwork. However, SEPC-SE scale has not yet been assessed for its psychometric properties.

Aim: To evaluate the psychometric properties of the SEPC-SE scale for physicians and nurses by exploring construct validity and reliability. A further aim was to describe and compare the level of self-efficacy of physicians and nurses working in hospital settings and explore contributing factors that can affect the levels of self-efficacy when delivering palliative care.

Methods: The SEPC-SE scale was distributed to 1200 registered nurses and 386 physicians via emails with a response rate of 25%. Factor analysis and Cronbach's alpha explored construct validity and index reliability. Multiple linear regression analysis explored nurses' and physicians' levels of self-efficacy and associated factors.

Results: The analysis displayed three factors and strong reliability. Both nurses' and physicians' level of self-efficacy was highest in patient management and communication and lowest in multidisciplinary teamwork. Physicians had higher confidence in all domains. To have undergone education in palliative care through the workplace and having experiences in advanced homecare were associated with higher self-efficacy.

Conclusions: The SEPC-SE is considered a valid instrument in the Swedish context. This study reflects that self-efficacy is not enhanced solely by education but through a person's experiences, which are vital for developing practical knowledge and judgement. Before planning for education, the organization should acknowledge that healthcare professionals' social surroundings are vital for education to lead to preparedness for palliative care.

P 17.006 Keteparaha: A Kaupapa Māori Community Co-design Research Method

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Background/aims: In this project we aimed to co-design, build and pilot a toolkit (Keteparaha) for Māori, First Nations people of Aotearoa, New Zealand. McLeod (2016) identified there will be a significant increase in the number of older Māori (over 65) many of whom will experience chronic and complex health issues at end-of-life. This places a significant responsibility on the local community, *whānau (family)* and communities have a cultural obligation to provide good care across the ageing trajectory and at end-of-life. Many Māori people continue to experience racism, exclusion, and have an inherited intergenerational and lived experience of cultural trauma.

Methods: This Kaupapa Community Co-design project was Māori led for Māori people; this is a Māori agenda (kaupapa) project. Kaupapa Māori is also a theoretical framework, or lens, through which to view the world and the community. This lens informs ways of knowing, being and doing for Māori people and includes the legitimization of Māori knowledge. There are key principles or understandings that are inherent to Kaupapa Māori research, these include: the use of *te reo Māori* (language), *Whakapapa* (connection to people, place, spirit), *Tino-Rangatiratanga* (self-determination), *Tikanga and Kawa* (customs, protocols and knowledge).

Results: The Keteparaha Framework Community Co-Design Methodology demonstrates the interconnection with Māori knowledge and the process of research development through community co-design. Although

the pandemic impacted on methods of research, the underpinning philosophical methodology remains to guide a respectful knowledge exchange.

Conclusions: The Kaupapa Māori process enabled the development of the Keteparaha Framework and community desired tools. The collection of final research products are as a direct result of the community input and community aspirations for end-of-life care, transformed into functional tools.

P 17.007 Basic Research Competencies for Palliative Care – European Experts Consultation

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Background/aims: To define identify individual and team core research competencies for palliative care (PC) professionals through international experts' consultation.

Methods: Following a literature review and Nominal group technique study a draft Framework with 19 core competencies for PC professionals was developed as part of a European International Project. In order to refine the framework a European expert consultation was undertaken. The competencies were transferred into an English online survey. The survey was piloted and underwent minor changes in format. Experts assessed whether the 19 identified competencies were core competencies and if they were required by all individual team members or by the team. Responses were on a 5 points Likert scale from strongly agree to strongly disagree. A weighted average was calculated for each competency using the following marks: 10 = strongly agree, 5 = somewhat agree, 0 = neither agree or disagree -5 = somewhat disagree and -10 = strongly disagree. A threshold of 7 for the weighted average was used to accept the competencies. For the second question if the competency was a team versus an individual one Z test was used. Z value over 1.96 and P<0.05 were considered significant.

Results: Out of 120 experts contacted 53 fully completed the survey (response rate 44%). Respondents were from 17 countries. All participants were part of the multidisciplinary team, with experience in organizational development(64.41%),in palliative care education (89.83%) and in palliative care research (62.71%). Two competencies did not reach the threshold and were excluded from the framework. For nine competencies there was a statistically significant allocation: 6 as individual competencies and for 3 were allocated to the whole team.

Conclusions: 17 out of 19 competencies were considered core research competencies for PC clinicians 6 individual, 3 for the team as a whole and the rest with no clear allocation.

P 17.008 Oral Symptom Assessment Scale (OSAS): Validity and Reliability

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Background/aims: The OSAS is a novel patient-rated oral symptom-specific assessment tool. Patients are asked about the presence of twenty

oral symptoms in the previous week and, if present, their frequency, severity, and distress. Initial testing of the OSAS provided provisional validation. Further psychometric testing was needed to investigate the tool's reliability and validity. This study's aims were to further investigate its reliability and validity in patients with advanced cancer receiving specialist palliative care.

Methods: 54 participants (median age 70 years; range 35-93 years) were recruited to this prospective observational study. Participants completed the OSAS and EORTC QLQ-C30 and EORTC QLQ-OH15 (a validated quality of life assessment with an oral health module) to investigate criterion (concurrent) validity. Participants repeated the OSAS 24 hours later to measure reliability. Demographics including age, sex, primary cancer diagnosis and ECOG performance status were also collected.

Results: 51 participants completed the study. Test-retest reliability for the absence/ or presence of each OSAS symptom was assessed using Cohen's kappa. This analysis showed values of moderate and higher for agreement for all symptoms. All kappa values were statistically significant. The test-retest reliability for symptom severity, frequency and distress was assessed using Intraclass Correlation Coefficient. Concurrent validity between the OSAS and EORTC QLQ-OH15 was assessed using Spearman's rank correlation coefficient. There was a moderate to strong correlation for the 'distress' of the symptoms of "dry mouth", "mouth discomfort/pain", "cracking of corner of mouth" and "taste disturbance" on the OSAS with the 'extent' of these symptoms on the EORTC QLQ-OH15.

Conclusions: Reliability of OSAS was demonstrated. Concurrent validity was demonstrated for certain symptoms however this was limited as the EORTC QLQ-OH15 is a quality of life of measure that includes symptom measurement rather than a dedicated symptom assessment tool.

P 17.009 Using Validated Patient Outcome Measures in Nephrology Palliative Care: Integrated Palliative Outcome Scale-renal (IPOS-r)

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Background/aims: Patients with advanced kidney disease suffer from burdensome symptoms, which are often overlooked. Using validated tools can improve symptom assessment and management. IPOS-r has been validated in the English version only. Our study aimed to provide a translation, cultural adaptation, and validation of the Czech version of the IPOS-r.

Methods: We translated and culturally adapted IPOS-r to Czech using cognitive interviews. Patients and staff in renal clinics completed the IPOS-r. Internal consistency was tested with Cronbach's alpha, its reliability via intraclass correlation coefficient for total IPOS-r score, and weighted Kappa for test-retest and interrater reliability of individual items. Convergent validity was tested with Spearman correlation to Kidney Disease Quality of Life Survey-Short Form 1.2 (KDQOL-SF 1.2). We assessed sensitivity to change using a distribution-based approach.

Results: Forward and backward translations of the IPOS-r were provided. Ten patients and healthcare professionals participated in cognitive pre-testing. The sample size for validation included 88 patients who were treated with hemodialysis (70.5%), home hemodialysis (5.5%), peritoneal dialysis (3%), and conservative management (21%). Cronbach's alpha was 0.72, and the intraclass correlation was 0.84 for test-retest reliability and 0.73 for interrater reliability. The IPOS-r correlated with KDQOL-SF 1.2 had a rho between 0.4-0.8 for most of the IPOS-r items, showing good convergent validity. The IPOS-r measure is feasible and takes 9 minutes to complete. Patients who reported a change in health status after 1 month demonstrated a total IPOS-r score change of eight points in both positive and negative directions.

Conclusions: We recommend using the Czech IPOS-r to assess symptoms in patients with advanced kidney disease as it is a valid and reliable tool. Validation of the disease-specific outcome measures can improve the symptom burden of the patients and so make their quality of life better.

P 17.010 Lessons Learned from the Development of a Process Evaluation of Two Psychoeducational Interventions for People with Advanced Cancer and their Family Caregivers in the Context of a Multi-country Trial

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Background/aims: The international DIAdIC trial is evaluating the effectiveness of two psychoeducational interventions for people with advanced cancer and their family caregivers; a web-based intervention (iFOCUS) and a face-to-face nurse-led intervention (FOCUS+). In addition to the randomised controlled trial (RCT), DIAdIC includes a process evaluation that is designed in line with the Medical Research Council (UK) framework for the evaluation of complex health interventions. The process evaluation aims to examine the implementation of the two interventions, and the aim here is to share the lessons learned from the development of the core process evaluation components.

Methods: The process components combine analysis of routine data with post intervention surveys and qualitative interviews, with the lessons identified through team reflection and discussion.

Results: During development of the process evaluation, several challenges were identified. These included developing process components for implementation across six countries with language variation and planning the use of routine data where variation in practice may be expected. In addition, the project required a strategy for assessing the fidelity of the two interventions. Key solutions included developing a protocol for the collection of routine data to assess reach across all six countries, designing interview schedules for use across all sites, and agreeing a qualitative analysis plan accommodating initial analysis in the local language and a higher-level analysis across partner countries. Finally, reflective and objective fidelity checks ensured buy in from intervention nurses delivering FOCUS+ while maintaining rigour.

Conclusions: With the growth of process evaluations in the context of RCTs, and recognising the challenges of multi-country trials, the paper captures important points for consideration in the design of process components.

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P 17.011 Methodologies and Characteristics of Studies on the Cost of Cancer's Palliative Phase: An International Systematic Review

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Background/aims: The impact of physical and psychological symptoms on the quality of life of cancer patients is undeniable and frequently studied in the field of palliative care. One of the least studied effects of cancer in palliative care is its economic impact on patient's quality of life. In order to better understand the expenses of patients and their relatives in connection with cancer and before considering a national study on the subject, the first step is to carry out a systematic review. The aim of this review is to describe the characteristics and methodologies of studies already carried out on the costs of cancer in the palliative phase at the international level.

Methods: We performed a systematic review of studies published from 2011 to 2021, on Pubmed, Web of science, NHS, EconLit and Google Scholar databases, between 11/01/2020 and 12/01/2021. The selected articles had to be focused on solid cancers and on an adult population.

Results: From 494 initial references, 63 articles were included in the final analysis. Most of articles (58%) used a retrospective methodology while a smaller part (25%) used a prospective methodology. Almost all (98%) articles studied direct costs, while a smaller proportion (19%) studied indirect costs. No article in this review investigated intangible costs. The total cost of cancer in the palliative phase was therefore not studied. The most used perspective was payer's one (59%). Time horizon was less than 6 months in most cases (54%). The main way of collecting costs was medical-administrative registers (79%).

Conclusions: This literature review – the first of its kind on an international level – provides a synthesis of the methodologies and characteristics of studies concerning the costs of cancer in the palliative phase, on an international level.

The number of French studies is still too low in the field of medico-economic analysis.

We are planning a nationwide prospective study that will try to describe and quantify these costs in the most complete way.

P 17.012 Evaluation Setting of the Czech Program for the Development of Palliative Care in Nursing Homes

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Background/aims: In the year 2020 died 129 000 people in the Czech Republic and more than 16,5 % passed away in nursing homes (ÚZIS 2021; ČSÚ 2020). That gave us the impulse for designing a two-year program to enhance the accessibility of palliative care in this type of care. The program provided extensive education, mentoring and individual financial support to the 15 nursing homes. The main aim of the presentation is to describe the setting of program evaluation and to share the experience with the process of evaluation.

Methods: The program evaluation has been developed according to social impact measurement and the theory of change approach. Through the impact value chain, we defined impact, outcomes, outputs, activities and inputs. The internal and external impact was monitored at all levels of the chain. To identify the internal impact we conducted a questionnaire-based pre and post-scan of the level of palliative care, 8 quarterly checklists, 50 semi-structured interviews with palliative care coordinators and mentors throughout the program. Through the media, public and political activities we observed the external impact.

Results: This type of evaluation has proven to be very functional at all stages of the process. The phase of designing helped us to determine the impact and the two main outcomes and plan the different outputs and activities of the program. During the program we had the opportunity to present and explain the program in a structured way, to evaluate if the program delivers the expected results in a timely manner. In the last phase, it allowed us to verify the pre-planned indicators and verify the effectiveness of the program.

Conclusions: An evaluation design based on the theory of change and social impact measurement increases the probability of the effectiveness of the intervention under consideration. Evaluation becomes an integral part of the intervention in the preparation and planning phase (ex-ante), during the intervention (ongoing) and the overall results (ex-post).

P 17.013 Early Consultation to Palliative Care in the Intensive Care Unit Decreases Length of Stay

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Background/aims: Use of ICU resources at the end of life with low likelihood of survival is common. Studies have shown that use of specific criteria ("triggers") which prompt proactive referral for palliative care (PC) consultation reduces intensive care unit (ICU) length of stay (LOS) without a change in mortality. We aimed to analyze primary outcome measures of total and ICU lengths of stay (LOS), time from ICU admission to hospital discharge, with secondary measures of mortality rates and discharge disposition, in relation to time to PC consultation.

Methods: We performed a descriptive retrospective cohort study identifying characteristics and analyzing outcomes of patients with PC consult during ICU stay at our institution from January to December 2021.

Results: A total of 84 patients with mean age 70 years, majority (n= 44, 52%) of female patients, from home (n=60, 71%) were included. Most had at least two out of six co-morbidities (n=65, 77.4%). Mean hospital and ICU LOS were 26.5 and 16.5 days, respectively. Mean number of days (MNOD) from ICU admission to initial PC consult was 8.6 days and the MNOD from palliative care consult to discharge was 13.4 days. 62 patients expired during the same admission (75.6%), 59.5% in an ICU. 47.6% (n=40) had a code status change with PC consult, with it resulting in hospital and ICU LOS reduction by 11.4 days and 7.64 days respectively (p<0.05). Hospital and ICU LOS were significantly associated with an increased duration from ICU admission to PC consult: β -coefficient 0.66, 0.79 for each day, p=0.015, p<001, respectively. No variables were identified to be predictors of earlier PC consult during ICU admission.

Conclusions: Earlier PC consult can lead to code status change and shorten LOS. High risk patients (older age, >2 co-morbidities, nursing home residents) did not lead clinicians to consult PC earlier but should be evaluated as triggers in future studies to facilitate earlier consults in order to optimize patient care and resource allocation.

P 17.014 How Does Complexity in the Diagnosis Related Groups Relate to the Palliative Care Phase?

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Background/aims: The Palliative Care Phase (stable, unstable, deteriorating and terminal) is routinely used for communicating clinical status, care planning and funding. We aimed to conduct an exploratory analysis to determine any association between clinical complexity defined by the Diagnosis Related Group (DRG) to the Palliative Care Phases of their hospital admissions in the last year of life.

Methods: Data of all palliative care patients who died between 1 January 2018 and 31 December 2019 at a tertiary hospital in Sydney, Australia, was extracted from the hospital costing, medical and palliative care electronic records. Clinical complexity was derived from the DRG using DRG Grouper software and categorised into *higher* (major) or *lower* (intermediate or minor). Chi-square tests were performed to compare the Palliative Care Phase and the complexity of each phase.

Results: 577 patients had 2,509 Palliative Care Phases for analysis: stable (n=732, 28.9%), unstable (n=684, 27.0%), deteriorating (n=624, 24.6%), and terminal (n=469, 18.4%). 82.7% of all Palliative Care Phases were classified as *higher complexity*.

The stable phase had higher odds of being of *higher complexity* than those not in the stable phase (OR 1.49; 95% CI 1.17, 1.90). The non-ter-

minal phase had higher odds of being of *higher complexity* than the terminal phase (OR 1.64; 95% CI 1.29, 2.10).

There were no statistically significant differences between *higher complexity* and the unstable phase (unstable: 82.5% versus not unstable: 82.7%, $p=0.867$); and between *higher complexity* and the deteriorating phase (deteriorating: 83.2% versus not deteriorating: 82.5%; $p=0.867$).

Conclusions: Higher complexity within the DRG is associated with some but not all of the Palliative Care Phases suggesting that clinical complexity within the DRG alone is insufficient to guide funding of inpatient palliative care in hospitals. Other components to consider include the intensity of care which may not be related to clinical complexity.

P 17.015 Cross-cultural Qualitative Palliative Care Research: Developing a Methodological Framework

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Background/aims: The aim was to describe a methodological approach for cross-cultural qualitative studies in palliative care.

Methods: Cross-cultural qualitative research into palliative care remains uncommon. There are no specific methodological guidelines available in this area and existing studies do not address a number of relevant linguistic and cultural issues. We have developed and applied a comparative qualitative approach to a cross-cultural study on the perceptions of what would be a good death among people living with dementia in Brazil and the UK. A methodological framework was developed through interdisciplinary discussions among international researchers within and external to the research team.

Results: The proposed methods involve nine sequential steps:

- 1) Definition of a research problem relevant to the involved countries, along with the rationale for a cross-cultural comparison;
- 2) Design of joint research questions and cross-culturally equivalent interview schedules;
- 3) Jointly determine pragmatic sampling approach(es) for each country;
- 4) Conduct interviews and code transcripts independently, matching researcher and interviewee cultural background;
- 5) Perform independent qualitative analysis for each country using the same analytical approach (e.g. inductive thematic analysis);
- 6) Jointly develop a combined framework representative of all datasets;
- 7) Explore commonalities and differences among countries within each theme of the combined framework through group discussions;
- 8) Map and compare the relationships among concepts and/or themes of the combined framework for each country (iterating steps 7 and 8); and
- 9) Discuss key cross-cultural insights.

Conclusions: This methodological approach proved feasible, allowed us to meet study aims and provided valuable insights beyond those of

conducting separate studies. This framework may foster new qualitative palliative care research, contributing novel cross-cultural insights for the field.

P 17.016 Understanding Barriers and Facilitators to Palliative Care Research: Survey and Working Groups with Generalist and Specialist Health, Social Care and Research Professionals

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Background/aims: Palliative care provision should be driven by high quality research, but staff and organisational issues that affect research involvement are less known, with most research attention on patient barriers. The aim is to understand professional and organisational facilitators and barriers to conducting palliative care research.

Methods: We performed a descriptive, observational study, using an open cross-sectional online survey, and working groups using nominal group techniques. Participants were professionals interested in palliative care research, working as generalist/specialist care providers, or research staff across areas of North West England, recruited via local health organisations, personal networks and social media in 2022. Data were examined using descriptive statistics and content analysis.

Results: Participants (survey $n=293$, working groups $n=20$) were mainly from clinical settings (71%) with 45% nurses and 43% working more than 10 years in palliative care. 74% were not active in research but 72% indicated a desire to increase research involvement. Key barriers included lack of organisational research culture and capacity (including prioritisation and available time); research knowledge (including skills/expertise and funding opportunities); research infrastructure (including collaborative opportunities across multiple organisations and governance challenges); and patient and public perceptions of research (including vulnerabilities and burdens). Key facilitators included dedicated research staff, and active research groups, collaborations and networking opportunities.

Conclusions: Professionals are keen to be research active, but lack time, skills and support to build research capabilities and collaborations. A shift in organisational culture is needed to enhance palliative care research capacity and collaborative opportunities across clinical and research settings.

P 17.017 Undertaking Observation of End-of-Life Family Meetings within the Medical Ward in a Regional Victorian Hospital: A Case Study Methodology

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Background/aims: Patients with palliative and end-of-life care needs and their family members are regarded as an emotionally and physically vulnerable population. Therefore, research needs to be sensitively and flexibly designed so as not to cause additional distress. A flexible,

multi-method qualitative research design can be found within a case study methodology and is suitable for researching a vulnerable population. The study aimed to develop a case study methodology within palliative care that is considered and appropriate for the vulnerable population.

Methods: A qualitative case study was designed and informed by the Therapeutic Landscapes framework to understand the interplay between the built, natural, social and symbolic environments in an acute medical ward. Data collection tools were developed to collect data using ethnographic and phenomenological approaches.

Results: A case study methodology was chosen due to its flexible data collection methods and suitability to observe and understand real-life situations and contexts holistically and intensively which are often complex within a health environment. A case study does not require the sample to be statistically generalisable, instead allowing a small sample which is important when researching a vulnerable population such as patients receiving palliative or end-of-life care. An ethnographic approach allows the researcher to immerse themselves in the ward environment, observing the behaviour and interaction of staff with each other and with patients and family members in order to obtain thick description. Semi-structured interviews seeking to understand the perceptions and lived experiences of nurses in the ward enable the data to be triangulated.

Conclusions: It is important to carefully design palliative care research projects to observe the ward environment and family meetings to obtain the latest evidence and a case study provides a suitable methodology within which to do this.

P 17.018 Facing the Challenges of Cancer, "Reintegration within the Family". A Cross-sectional Longitudinal Study

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Background/aims: When a family member is diagnosed with cancer, the entire family system is afflicted. The cancer trajectory causes changes in various aspects of everyday family life, requiring the patient and family members to adapt to the new situation. It is of importance to focus on the experience of how the patient and their partner manage challenges in daily family life when living with a serious illness, to gain a better understanding of these processes which may be seen as integrative while other processes are considered to be adaptive.

The objective of this study which is part of a larger dyadic research program conducted at a university hospital is to identify adaptation processes of patients diagnosed with cancer when integrating the illness experience into family life. These processes were measured by the new Likert type scale of Family Integration of Chronic Illness into Family Life (FAM-INT-CIFL) which was developed based on Family Systems Nursing and the Reintegration Within Families in the Context of Chronic Illness Model.

Methods: A cross-sectional longitudinal study was conducted. Data were collected from 100 patients (67% females, 33% males) receiving cancer treatment and some participants were also receiving specialized palliative care. Data were analyzed using descriptive statistics and *t*-tests.

Results: The main findings indicated that majority of the cancer patients used both integrative and adaptive processes to adjust to their cancer situation. Findings also revealed that patients reported significantly lower levels of adaptation 8-12 months after diagnosis than those who had been diagnosed within 7 months. Further research results will be discussed.

Conclusions: The findings offer better understanding of how patients adapt at a family-level to challenging situations when dealing with

cancer. This knowledge can be useful when developing a dyadic-based intervention focusing on improving the adaptation processes of both the patient and their partner.

P 17.019 Patient and Public Involvement and Engagement: Improving Practices in Palliative Care Research

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Background/aims: Patient Public Involvement and Engagement (PPIE) was an integral part of a wider study focused on implementing monthly 'Palliative Care Needs Rounds' in care homes. PPIE members were involved in the design of the study, ethics processes, selecting measures, co-production workshops, data interpretation and dissemination.

Aim: To critically report an evaluation of the PPIE input embedded within a larger project.

Methods: This inductive qualitative study collected 1:1 interviews with research team members, including the academics/clinicians and people who contributed by drawing on their lived experience (total n=11). Analysis followed a thematic approach to generate new understandings and insights into PPIE.

A researcher independent of the main study conducted the interviews and analysis to aid rigour.

Results: Interviewees welcomed the opportunity for PPIE to engage in a range of tasks and roles (such as developing analytic coding frame, appointing the academic researcher and dissemination through verse). PPIE engagement positively impacted the team dynamic. Positionality of people spanning both lived experience of palliative care and being academic researchers requires greater examination, to understand how these insider perspectives contributed to strengthening the research and its impact. Participants also identified areas that would benefit from greater criticality with the PPIE literature and reflexivity.

Conclusions: Research being informed by people who have expertise through personal experience rightly continues to gain recognition, space and funding. Reflexivity and documenting 'lessons learned' underpin two core areas for progressing and improving the value and role of PPIE. This research moves the evidence base and discussion forward, by highlighting the nuanced perspectives of academics/clinicians and PPIE research team members.

P 17.021 Designing a Post-bereavement Survey to Understand the Impact of End-of-Life Doula Provision

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Background/aims: Current health and care systems do not always fully meet the needs of dying people and those who support them. End-of-life doulas (EOLDs or death doulas) can provide community-based care for people. In the first project of its kind, doulas have been commissioned by the healthcare system in Leeds, England to complement and extend existing palliative and end of life care supports. Since EOLD roles are emerging and involve in-home support, evaluation is underway of this new arrangement.

Methods: To evaluate how EOLDs support the dying person and those who care for them, we have designed a post-bereavement survey as part of a wider evaluation strategy. The survey includes questions about quality of care, key performance indicators aligned with the commissioning

arrangement, and questions aligned with other quality of end-of-life questionnaires, such as CODE. There is a mixture of closed and open questions, with 18 questions in total. The survey can be completed online or on paper.

Results: The survey received favourable ethics opinion and is currently available for use (request to complete is approximately three months after the death). Detailed results will be produced at the end of the study period. The survey was piloted by users who had previously engaged with doula services to check wording, understandability, and appropriateness of questions.

Conclusions: Identifying the person to complete the survey can be difficult, especially in contexts where doulas are involved due to a lack of identified next-of-kin or informal carers. Further work is underway to evaluate services via user records. The funding for this collaborative project was provided by End of Life Doula UK and through a Knowledge Transfer Voucher via The Open University.

Conflict of interest: End of Life Doula have paid for the design of the survey and their director is a co-author/presenter.

P 17.023 The Collaboration of a Multidisciplinary Team to Set up Research on Sedative Practices in Palliative Care: Wealth and Resistance(?)

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Background/aims: Continuous Deep Sedation Until Death (CDSUD) is a worldwide palliative care practice. It aims to relieve pain and ensure a higher quality of life for patients and their families.

However, there is an essential gap in the scientific literature between the effects of CDSUD on formal (professionals) and informal (relatives and friends) caregivers.

For this reason, starting in February 2022, 20 French hospital institutions started to study the psychological consequences of people who lost their partners following a CDSUD.

Our purpose is to present the construction of this collaboration made up of clinical psychologists, anthropologists, philosophers, and medical doctors.

Methods: Meetings with the team are quarterly and online. They are recorded and studied through a thematic analysis by the principal promoters following the question: "How the recruitment of participants is going?"

Results: Up to now, 3 meetings of 1 hour have been held. The following topics of discussion have emerged:

- Enthusiasm, and agreement on the necessity of this research;
- Difficulties in following the instructions to propose the study and talking about loss with the participants (fear of adding pain);
- Heterogeneity of sedative practices and the different places of care[MFB1] (hospital/home) in France.

Conclusions: This analysis highlighted the usefulness of working with a multidisciplinary team to reduce one's resistance. While members initially found it difficult to recruit participants, the number of participants increased after each discussion.

During the meetings, the feedback allowed motivated but reluctant members to figure out how to manage a study on grief.

Furthermore, these meetings gave rise to essential reflections: if we cannot talk about grief in palliative care or cancer units, where would it be possible to talk about it? Is it possible to think of loss in a palliative care unit dedicated to the last moments but not to people after death?

P 17.024 Research for All Palliative Care Clinicians: An International Study

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Background/aims: The project Research for all palliative care clinicians-RESPACC(Ref.#2020-1-RO01-KA202-080128) is a 2-year Erasmus + international project bringing together clinicians, educators and researchers. The aim of the project is to define core research competencies for palliative care (PC) clinicians and to foster inclusion of research as part of the clinical practice of PC professionals.

Methods: To increase research capacity for PC professionals, the project included more phases:(1)development of the core competency framework for the multidisciplinary PC team, followed by a self-assessment quiz,(2)design of materials to improve critical reading and academic writing, to introduce PC professionals into basic research methodology and designs,(3)test materials during short-term trainings, multiplier events.

Results: During the project life-time, a PC core competency framework was developed and more materials are provided: a self-assessment quiz, a "How to... bring research in the daily clinical PC practice", a Research Proposal Flowchart, a Guideline for developing your own research proposal, a Research Proposal Template and a Repository with references regarding ABC methodology of research. Four videos, 13 recordings, 4 webinars (271 attendees), 20 lesson plans and Power Point presentations are completing materials available for PC multidisciplinary team to improve research competencies. All materials were tested during 2 trainings (78 attendees), 4 multiplier events (289 attendees) and 14 dissemination events (1463 attendees), followed by evaluation forms: materials, interactivity and practical exercises/tips were very much appreciated. One article on nominal group techniques was published.

Conclusions: Using a multi-method research project, the first framework with core research competencies for PC clinicians has been developed. Based on the framework, different learning materials are available for PC multidisciplinary team in English, Greek, Spanish and Romanian, with free access. More details on Studii Palliative – Research RESPACC.

P 17.027 Strategies to Reduce Missing Data in Complex Interventions for Patients with Palliative Needs – An Experience Report

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Background/aims: Missing data in palliative care (PC) research is frequent and should be anticipated, as the participating patients approach the end of their life. Reasons for missing data which are not due to natural attrition (eg. preference, frailty, death) should also be considered (eg. missed item, questionnaire). We aim to share the strategy used to reduce missing data in a before-after study testing a new primary palliative care intervention.

Methods: All 53 planned patients were recruited (via 9 GPs); 47 had their first consultation and 12 already completed the intervention (1 consultation every 3 weeks for 12 weeks). Patients self-report symptoms and problems using the IPOS measure. We use a two-axis strategy to reduce missing data:

- 1) close contact with the GPs (eg. Whatsapp®, e-mail) and
- 2) online forms regularly updated.

Contact with GPs happens at least monthly, aiming to address emerging questions, provide support and share struggles that may arise. The contact is also a way to reinforce the need to verify the data collected. The online form (with anonymised data only) is shared with all GPs and allows them to see each other's progress. If any GP does not complete the form on time, the researcher contacts him/her to assess whether everything is going as planned or if there is any difficulty, with a view to help resolve.

Results: We have collected 53 IPOS referring to the first consultation and 12 referring to the last. We have yet no missing data not due to natural attrition. The study ends in January 2023; final results will be reported at the conference.

Conclusions: Close contact with GPs and shared monitoring of progress are useful approaches to replicate in palliative care research to reduce missing data.

P 17.028 Conducting Psychological Research in Palliative Care: Challenges and Recommendations to Single Site Recruitment of Advanced Cancer Patients

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Background/aims: Palliative care recruitment research calls for improvements in how informed consent is conducted given the cognitive barriers of severe symptomatology. This study aimed to identify relevant single site challenges for psychological research in advanced cancer patients at an inpatient palliative care hospital that centers care around non-abandonment (i.e., kindness toward low-income and terminally ill patients, clinical competence, and care team collaboration). Then, the study aimed to identify whether its recruitment approach addressed issues of consent.

Methods: In person recruitment occurred over 10 months. Past and current medical records were reviewed for initial patient eligibility: advanced cancer (stage III/IV), English-speaking, absence of severe psychopathology, full orientation. Exclusion criteria were assigned 11 primary (e.g., cognitive impairment) and 40 secondary (e.g., dementia) codes reflecting advanced cancer symptoms in palliative care. Researchers and providers discussed the burden of participation to each eligible patient. Approved patients provided verbal consent, completed a brief cognitive screener, and those scoring ≤ 11 (0-13; 13=impairment) were enrolled.

Results: Of 411 screened (50.4% female, $M_{age}=73.4$), 34% (n=141) were approved, 29% (n=121) were approached by researchers, 15% (n=60) consented, and 12% (n=48) passed cognitive screening. Of all screened, 36% (n=148) were ineligible due to cognitive impairment, 93% (n=137) of whom were excluded prior to researcher approach. Of all approached, 2.5% (n=3) could not consent. Chi-square analyses revealed no significant sociodemographic differences in enrollment.

Conclusions: Challenges to single site enrollment in advanced cancer palliative care with a non-abandonment model were consistent with palliative literature. However, a strong majority of approached participants were able to consent. Results may suggest the psychological researcher is able to enhance recruitment through intensive screening with the greater care team.

P 18 - COVID 19

P 18.001 Admission Comorbidities and Symptoms and End-of-Life Medication Use in Hospitalized Decedents with and without COVID-19 Infection: A Retrospective Regional Cohort Study

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Background/aims: Few data exist on palliative medication use in patients dying with COVID-19 infection. This study aimed to compare comorbidities and symptoms, and palliative medication (opioids, antipsychotics, sedatives) use at end-of-life (EoL) among those who died before or during the COVID-19 pandemic.

Methods: Design: A regional multicentre retrospective cohort study; hospitalized decedents' electronic records were abstracted, generating a pre-pandemic (Pre-COVID) group and 2 intra-pandemic groups, one without (COVID-ve) and one with COVID-19 infection (COVID+ve). Pre-COVID (n=170) and COVID-ve groups (n=170) were matched 2:1 on age, sex and care service at death [Medicine or Intensive Care Unit (ICU)] with the COVID+ve group (n=85).

Setting: 3 regional tertiary care hospitals.

Data collection and analysis: demographics, comorbidity, symptoms, medication use and doses over each 24-hour period in the last 72 hours of life; opioid doses were standardized to parenteral morphine equivalent daily dose (MEDD). Categorical data and skewed continuous variables were compared with Chi Square and Kruskal-Wallis tests, respectively.

Results: The prevalence of dementia (41% vs 28% and 26%, $p=0.03$), breathlessness (63.5% vs 42% and 47%, $p<0.01$), cough (40% vs 27% and 19%, $p<0.01$) and fever (54% vs 9% and 13.5%) was higher in the COVID+ve vs the Pre-COVID and COVID-ve groups, respectively. The median (interquartile range) of MEDDs averaged over the last 72 hours of life was higher at 16.7, (9-36.5) vs 13.5 (5.7-21.8) and 10.5 (5.3-23.8) for the COVID+ve vs PreCOVID and COVID-ve groups, respectively, ($p=0.007$), an effect potentially mediated by ICU admission and greater symptom burden, which might similarly explain higher 24-hour lorazepam and propofol doses in this group.

Conclusions: Palliative medication dose requirements at EoL were higher in COVID-19 decedents than matched controls, particularly for those admitted to ICU. These significant findings should inform and guide clinical practice and warrant further study.

P 18.002 Association between the COVID-19 Pandemic and Disposition from Hospital among a Cohort of Palliative Care Patients with Malignant and Non-malignant Diagnoses: A Retrospective Cohort Study

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Background/aims: The COVID-19 pandemic imposed restrictions to the healthcare system. The differences between how these restrictions impacted patients with malignant and non-malignant diagnoses is uncertain. We sought to determine the association between the pandemic and disposition from hospital among a cohort of patients with malignant and non-malignant diagnoses who received specialist palliative care consultation.

Methods: A retrospective cohort study of patients who received specialist palliative care consultation at a tertiary hospital in Toronto, Ontario

from Jan 1, 2017 to Sep 31, 2022. Interrupted time series analysis was used to determine whether patterns in disposition from hospital changed from before (2017-2019) to after the start of the pandemic (2020-2022).

Results: The cohort comprised 4349 patients, 3043 of whom had a primary malignant diagnosis and 1292 of whom had a primary non-malignant diagnosis. Trends in disposition differed between diagnostic groups. Among cancer patients, interrupted time series analysis demonstrated a significant decrease in those discharged home without support ($p=0.022$; 2017-2019: 26.28%, 2020-2022: 20.59%) and increase in those discharged home with support ($p=0.018$; 2017-2019: 1.85%, 2020-2022: 14.21%) after the pandemic started. Among non-cancer patients, there was a significant decrease in in-hospital mortality ($p=0.021$; 2017-2019: 50.36%, 2020-2022: 36.44%) and increase in discharge to a palliative care unit ($p=0.0039$; 2017-2019: 33.72%, 2020-2022: 48.25%) after the pandemic started.

Conclusions: Our findings suggest that patients with non-malignant diagnoses, who historically have had less access to specialist palliative care services, had improved and potentially sustained access to a palliative care unit after the pandemic started. Examination of the association between the pandemic and increased discharge to a palliative care unit could inform policy that seeks to optimize access to specialist palliative care services among patients with non-malignant diagnoses.

P 18.003 Exploring Bereaved Next-of-Kin's Experiences of End-of-Life Care under COVID-19 Restrictions: A Qualitative Interview Study

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Background/aims: Under COVID-19 pandemic regulations, visits to hospitals, aged care facilities, and hospices were restricted, and at their most extreme, completely prohibited. Such restrictions are still likely to have had a profound impact both on the dying and the bereaved. The aim of this qualitative interview study was to explore the impact of COVID-19 pandemic regulations on whānau/family caregiving and bereavement practices during the first year of the COVID-19 pandemic in Aotearoa, New Zealand.

Methods: We conducted a survey with 194 next-of-kin who experienced a bereavement during March-December 2020. From this sample we conducted 30 in-depth, culturally-matched interviews which were analysed using reflexive thematic analysis.

Results: We identified five themes: 1) *Disconnection from family* relating to difficulties around families not being able to visit family in hospital or residential care or return from overseas in last days. 2) *Compromised end-of-life care*, centring on lack of communication and patients, whānau and medical professionals during this uncertain period; 3) *Cultural safety* including concerns about not being able to ensure spiritual rites and practices observed in moments after death and around burial; 4) *Complex bereavement* with mixed views on funeral restrictions and grieving processes and support; 5) *Silver linings* including ability to spend more time with family during last days of life if at home.

Conclusions: COVID-19 pandemic regulations altered the nature of family caregiving at end-of-life and their bereavement practices. The ability for family members to support their relative at end-of-life hugely depended on their place of care because of visiting restrictions. We emphasise the importance of designing pandemic regulations that also centre culturally-safe end-of-life care and promote bereavement care. This study was funded by the Auckland Medical Research Foundation.

P 18.004 The Psychosocial Impact of the COVID-19 Pandemic on Chronic Care Patients

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Background/aims: The COVID-19 pandemic has had a profound and pervasive impact on psychosocial health and disrupted care systems worldwide. Our research aims to assess the psychosocial impact of the pandemic and related changes in chronic care provision on COPD and heart failure patients.

Methods: A qualitative survey using semi-structured interviews was held among patients with a chronic disease. Using randomized sampling, 23 patients with either COPD, heart failure or both were recruited to participate in semi-structured interviews. Interviews were held by phone or videocall. The survey was held during the summer of 2021, when strict national containment strategies were widely implemented but gradually loosened and vaccination was ongoing. Inductive coding using Gioia's approach was used to analyze the data in Atlas.Ti 9.1 software. Using an iterative approach, the data was synthesized in a data structure and data table, which was analyzed using an interpretative approach.

Results: We found three aggregate dimensions in which the COVID-19 pandemic has a negative impact on psychosocial health of patients with chronic disease: 1) perceived vulnerability to disease, 2) influence of health policy, and 3) a mismatch of supply and demand of healthcare. In these dimensions, the impact of the COVID-19 crisis was found to have a negative impact on psychosocial wellbeing, compounded by national strategies to contain the pandemic and a disruption of chronic care for patients.

Conclusions: Healthcare providers should be aware of a multidimensional nature of psychosocial distress for chronic disease patients due to the COVID-19 crisis. Future practice and health policy could be improved by increasing awareness amongst healthcare providers, promote regular attention for psychosocial wellbeing of patients, provision of clear information related to the pandemic and strategies to secure continuity of care. Results of this study might be further explored in larger studies.

P 18.005 Impact of COVID 19 on the Function of Patients with Life-limiting Diseases – A Prospective Study from the Canadian Palliative COVID-19 Registry

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Background/aims: Patients with palliative care needs usually have limited functionality and face further deterioration when experiencing acute medical issues such as a COVID 19 infection. Whether or not COVID-19 infection further impacts patient functional state remains unknown. The study aims to understand if patients with life limiting diseases have functional deterioration when facing COVID 19 and if their initial function correlates with mortality from COVID 19.

Methods: The COVID-19 Palliative Registry was a national registry of baseline characteristics and clinical outcomes of patients with life-limiting illnesses and COVID-19 with data collected between September 2020 and December 2021 in various settings of care in Canada. Data included patients' Palliative Performance Scale (PPS) prior, during and after COVID

19 infection. For this analysis, PPS was categorized into three groups: high (70-100%), intermediate (40-60%), and low (10-30%). Multivariate regression analysis identified associations with change into a lower PPS range and with COVID 19 mortality.

Results: Mean age of the 1041 patients was 83 years, 55.1% were female and 80.9% were white. Initial PPS was high for 283 of them (27.6%), intermediate for 666 (65%) and low for 75 (7.3%). Overall mortality was 30.6%: 41.3% for those with high PPS; 24.5% for intermediate PPS, and 49.3% for patients with low PPS ($p < 0.001$). Most patients surviving COVID-19 maintained a stable range of PPS after the infection (564, 79.7%) but markedly less often (73, 46.9%) among the ones with high initial PPS.

Conclusions: Overall mortality was extremely higher than in the general population in Canada in the same period (30.65% against 1.02%), particularly for those with low functional status but surprisingly also among the ones with high PPS. Against our initial hypothesis, survivors tended to maintain their level of function despite the acute illness. Baseline PPS may be a valuable prognostic factor regarding mortality for patients with life-limiting disease and COVID 19.

P 18.006 How COVID-19 Associated Measures Impacted Distress among Healthcare Professionals Providing End-of-Life Care: Longitudinal Survey Study

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Background/aims: The COVID-19 pandemic impacted end-of-life care and healthcare professionals (HCPs) providing this care. The aim of this study is to examine distress during the COVID-19 pandemic and how COVID-19 measures were associated with distress over time.

Methods: HCPs from different settings were asked to complete a questionnaire four times: in spring 2020 (T1), fall 2020 (T2), Dec 2020-Apr 2021 (T3) and May 2021-Sept 2021 (T4). They were asked to what extent they agreed with five statements about distress (being more stressed, regularly exhausted, work being emotionally demanding, work being physically demanding and need for support). We used Generalized Equation Estimations to analyze differences between periods and associations with COVID-19 measures (restrictions regarding visiting and post-death personal care and availability of personal protective equipment (PPE)).

Results: Questionnaires were completed by 321 (T1), 308 (T2), 179 (T3), and 142 (T4) respondents.

For all statements, except the one about exhaustion, agreement among HCPs decreased significantly over time (e.g. from 64% in T1 to 35% in T4 for the statement about being more stressed (OR T4-T1 = 3.25). Agreement about being exhausted stayed between 40-44% over the time period.

When there were visiting restrictions, HCPs were significantly more often more stressed than usual (OR=1.68). When PPE was lacking, HCPs were more often more stressed than usual (OR=1.67) and found their work more often emotionally demanding (OR=1.43). When HCPs were not allowed to provide post-death personal care, they were more often stressed (OR=2.01), found their work more emotionally and physically demanding (OR=1.91 & OR=1.44, resp.) and needed more emotional support (OR=1.80).

Conclusions: This study highlights the distress HCPs experienced during the pandemic, especially in the beginning. There is need for explicit attention to how HCPs who provide care while dealing with restrictive measures to limit spreading of the virus can be supported.

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P 18.007 Association between Primary Diagnosis and Receipt of Goal-concordant Care in a Cohort of Patients with Life-limiting Illness and COVID-19: A National Retrospective Cohort Study

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Background/aims: Compared to patients with malignant disease, the end of life of those with non-malignant disease is characterized by more aggressive medical care, which may represent goal-discordant care. Whether this pattern holds among patients with life-limiting illness diagnosed with COVID-19 is unknown. This study sought to determine the association between primary diagnosis and receipt of goal-concordant care in patients with life-limiting illness during COVID-19 infection.

Methods: Retrospective cohort study based on a registry of patients with life-limiting illness diagnosed with COVID-19 in multiple healthcare settings across Canada from Sep 1 2020 to Dec 31 2021. The association between diagnosis and physician-defined receipt of goal-concordant care, survival, and location of death were assessed using multivariate logistic regression models.

Results: The cohort comprised 176 patients with cancer, 473 with frailty, and 363 with chronic organ failure. A high proportion of patients were judged to have received goal-concordant care for COVID-19 (85.4%, 88.8%, 75.1%, respectively) and died from COVID-19 (34.1%, 23.3%, 29.4%, respectively). Of patients who died, 86.7% with cancer, 85.5% with frailty, and 93.4% with chronic organ failure died in hospital. Compared to patients with cancer, there was no significant difference in the odds of receiving goal-concordant care among those with frailty ($p=0.48$) or chronic organ failure ($p=0.056$), controlling for demographic, functional, and clinical information. No differences in the odds of death or dying in hospital were found between diagnostic groups.

Conclusions: Patients with non-malignant disease did not have a lower odds of receiving goal-concordant care than those with malignant disease during COVID-19 infection. Understanding how COVID-19 mitigated the disparity in healthcare outcomes between patients with non-malignant and malignant disease could inform policies and practices that seek to optimize goal-concordant care among patients with non-malignant disease.

P 18.008 Visiting Restrictions during the COVID-19 Pandemic and Bereaved Relatives' Quality of Life

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Background/aims: During the 2020 SARS-COV-2 pandemic, overall care changed to accommodate the added threat of a new infection. Visiting a loved one in care institutions by relatives was restricted which presented a challenge to the healthcare system. We aimed to better understand relatives' appreciation of end-of-life care during the pandemic.

Methods: An online survey for bereaved relatives was created and distributed in 10 countries in April 2020: the Netherlands, the UK, Norway,

Sweden, and Czech Republic, Brazil, Argentina, Colombia, El Salvador, and Chile. Questions addressed visiting restrictions, respondents' appreciation of end-of-life care as measured by the CODE questionnaire, and their quality of life on a scale from 1-7 (EORTC QLQ-C30 item). Analyses were conducted using descriptive statistics and an ordinal regression analysis. The results were then pooled in a multilevel analysis.

Results: From the 2,359 participants, 75.9% (1,789) were female and 57.5% (1,354) reported on the death of their parent. 67% (1,572) respondents indicated that there had been visiting restrictions during the last phase of life. The average quality of life rating was above 4 in every country. Multilevel analysis showed no association between quality of life and visiting restrictions. Sufficient medical care and its association to QoL had an OR = 1.61 (95%CI 1.20-1.99). Sufficient nursing care had an OR =1.49 (95% CI 2.25-1.93).

Conclusions: There were many ways in which COVID-19 impacted healthcare settings but there are not all clear. The absence of effect for relatives QoL and visiting restrictions may have been because the restrictions were seen as protective. The OR show that perceived quality of care (nursing and medical) during COVID-19 had a greater association with relative's quality of life. This highlights the important role healthcare teams have at end of life.

P 18.010 Primary Palliative Care among a Cohort of Patients with Life-limiting Illness and COVID-19: A National Retrospective Cohort Study

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Background/aims: The COVID-19 pandemic exposed limitations in the capacity to provide specialist palliative care and a need to enhance primary palliative care (PPC). We sought to describe the degree to which a national cohort of patients with life-limiting illness received PPC during COVID-19 infection.

Methods: Retrospective cohort study based on a registry of patients with life-limiting illness diagnosed with COVID-19 in multiple healthcare settings across Canada from Sep 1, 2020 to Dec 31, 2021. Descriptive statistics were used to summarize the PPC received by the cohort, defined as any component of palliative care provided by physicians who did not identify themselves as palliative care specialists.

Results: The cohort comprised 844 patients, of whom 668 (79.1%) received care as outpatients and 174 (20.6%) as inpatients. The most common primary diagnoses were dementia (53.4%), cardiovascular disease (24.3%), and pulmonary disease (16.4%). The majority of patients (501/844, 59.4%) did not receive any component of palliative care. Of those who did, 36.1% received symptom management, 27.3% psychosocial support, 20.6% decision-making support, and 17.4% family support. The majority of patients (490/844, 58.1%) were started on morphine, hydromorphone, oxycodone, a benzodiazepine, or haloperidol. The most commonly provided palliative care medications were morphine or hydromorphone (44.1%) and a benzodiazepine (33.4%). Of the 384/844 (45.5%) patients who did not have advance care planning before infection, 122/384 (31.8%) engaged in advance care planning upon infection. The majority of patients wished to pursue a natural death (55.8%) and were judged to have received goal-concordant care during infection (81.6%).

Conclusions: A substantial proportion of patients with life-limiting illness diagnosed with COVID-19 received a component of PPC. An understanding of the quality of and barriers to PPC during the COVID-19 pandemic could inform the development of strategies to enhance PPC beyond the COVID-19 pandemic context.

P 18.011 Pharmacological Management at the End of Life of an Ethnically Diverse Cohort with COVID-19 - A Dual Centre Service Evaluation

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Background/aims: Evidence suggests that patients from minoritised ethnic groups may be less likely to be prescribed opioids and benzodiazepines. Even when prescribed, they tend to receive lower doses compared to those from White groups. It is not known if these differences exist in patients dying with Covid-19.

Table 1. Pharmacological management of hospital inpatients dying with COVID-19 by ethnic group.

	White n	(%)	Non-White n (%)	All n	(%)	Significance testing
PRN SC opioid in last 24 hours	188	(64.8)	102	290	100	
Fentanyl	45.0	(24.1)	25.0	70.0	(24.1)	X ² =0.535, p=.0.765
Morphine	70.0	(37.4)	34.0	104.0	(35.9)	
PRN not required	72.0	(38.5)	43.0	115.0	(39.7)	
Total PRN SC opioid dose in last the 24 hours (n=174) Median (Range)						
Fentanyl (µg)	37.5	(12.5-50)	37.5	37.5	(12.5-75)	z=-0.814, p=.416
Morphine (mg)	2.25	(1-26)	3	3	(1-26)	z=-.0562, p=.574
Number of people who received PRN SC midazolam in last 24 hours	77.0	(41.2)	48.0	125.0	(43.3)	X ² =0.930, p=.335
Total PRN SC midazolam dose in last 24 hours (mg)Median (Range) (n=125)	3	(1-25)	2	2	(1-45)	z=0.929, p=.353
Type of CSCI opioid administered						
Fentanyl	55.0	(29.6)	29.0	84.0	(29.2)	X ² =1.024, p=.599
Morphine	88.0	(47.3)	44.0	132.0	(45.8)	
CSCI opioid not required	43.0	(23.1)	29.0	72.0	(25.0)	
Final CSCI opioid dose administered Median (Range)						
Morphine (mg) (n=132)	10	(5-30)	10	10	(5-40)	z=-1.236, p=.217
Fentanyl (micrograms) (n=84)	100	(75-600)	150	100	(75-1000)	z=-1.304, p=.192
Number of people who required CSCI midazolam	137	(72.9)	67	204	(70.3)	X ² =2.372, p=.3.5
Final CSCI midazolam dose administered (mg) Median (Range) (n=204)	10	(2.5-30)	10	10	(2.5-30)	z=-1.822, p=.068

PRN= "as required", CSCI= Continuous Subcutaneous Infusion, SC= Subcutaneous

We aimed to describe the pharmacological management at the end of life for patients with Covid-19 referred to palliative care, examining differences between White and non-White groups.

Methods: Service evaluation of patients who died with Covid-19 referred to palliative care across two London hospitals Feb-May 2020. Palliative care drugs administered in the last 24 hours were analysed for differences between patients from White and non-White groups.

Results: 290 patients were included. 102 (35%) were from a non-White ethnic group; most commonly Black British (n=66, 23%) and Asian British (n=23, 8%). 174 (60%) and 215 (74%) received 'as required' and continuous infusion opioids, with no statistically significant difference between ethnic groups for drugs or doses, received.

Conclusions: Equity in the delivery of care for people with Covid-19 is essential. In this large cohort of patients with Covid-19 referred to palliative care, we found no difference in the pharmacological management for those from White and non-White groups.

P 18.012 Life after COVID-19: Our Contribution through the «Back to Life» Project

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Background/aims: «Long COVID» is defined as a condition in which patients maintain symptoms (fatigue, brain fog, muscle pain, anxiety, depression, and cardiovascular and respiratory symptoms) beyond 4 weeks from the infection, with relevant consequences on their daily life. Our project started in April 2021, following reported increasing needs for care, with respect to long-term symptoms related to COVID-19, from almost all of our healthcare professionals operating in the home-based palliative care services.

Methods: Considering the complexity of symptoms and the worsening of patient's quality of life, we applied an interdisciplinary approach, inspired by home-based palliative care, to meet patient's needs properly. In order to fight patient's general and muscular deconditioning, we adopted respiratory and motor rehabilitation programs, under constant medical supervision, and psychological support.

The project involved 109 patients in Sicily: after the initial multidisciplinary evaluation of the patient, conducted by a physician, a physiotherapist and a psychologist, we defined a personalized and multifactorial intervention program. The program consisted of 16 home-based and 4 additional remote rehabilitation sessions. Each session was aimed at contrasting breathlessness and improving effort tolerance, strength, endurance, static and dynamic balance, in order to regain autonomy in daily activities.

Results: EuroQol – 5D – 5L showed meaningful improvements in every dimension of the quality of life. Moreover, the modified Medical Council Research Questionnaire (mMRC), used to evaluate dyspnea, and the Berg Scale, used to evaluate the balance and the risk of falling, confirmed these evidences.

Conclusions: The project was funded by Fondo di Beneficenza di Intesa San Paolo and represented one of the first initiatives in Italy to support, at home, patients experiencing «long COVID», months before the official acknowledgment of the disease by National/Regional Health System.

P 18.013 Predictors and Outcomes of Specialist Palliative Care (SPC) Consultation in Tertiary Hospital Decedents before and during Wave 1 of the COVID-19 Pandemic: A Regional Retrospective Cohort Study

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Background/aims: Real-world data are limited regarding predictors of SPC consultation and outcomes for hospitalized patients. We conducted a secondary analysis of hospital decedent cohort data to determine predictors and outcomes of SPC consultation before and during Wave 1 of the COVID-19 pandemic.

Methods: *Design:* Regional multicentre retrospective cohort study; electronic records were abstracted, creating a pre-pandemic (Pre-COVID) and 2 intra-pandemic groups, one without (COVID-ve) and one with COVID-19 infection (COVID+ve). Pre-COVID and COVID-ve groups were matched 2:1 on age, sex and care service at death (Medicine/ICU) with the COVID+ve group. *Setting:* 3 regional tertiary care hospitals. *Data collection and analysis:* demographics, comorbidity, symptoms, SPC consult requests and completions, palliative medication use and doses over the last 72 hours of life. Categorical data and skewed continuous variables were compared with Chi Square and Kruskal-Wallis tests, respectively. SPC consult request predictors were examined using unadjusted and adjusted logistic regression with odds ratios (ORs) and 95% confidence intervals (CIs).

Results: In the study sample (N=425), SPC consults were requested in 70 (41.2%), 71 (41.8%) and 26 (30.6%) of the Pre-COVID (n=170), COVID-ve (n=170) and COVID+ve (n=85) groups, respectively (p=0.18). Admission to ICU (aOR: 0.23, 95% CI: 0.14-0.39), active cancer (2.5, 1.5-4.3), referral from long term care (LTC) (0.49, 0.25-0.95), days in hospital (1.01, 1.0001-1.02) were associated with a SPC consultation request. In subgroup analysis, decedents exposed to SPC consultation were more frequently prescribed palliative medications but not in higher doses.

Conclusions: In hospitalized decedents, SPC consultation rates were marginally below pre-pandemic levels. Referral from LTC and ICU admission negatively predicted SPC consultation, whereas active cancer and days in hospital were positive predictors. Our study findings warrant further communication and exploration regionally and beyond.

P 18.014 Adaptation and Multicenter Validation of a Patient-centered Outcome Scale for People Severely Ill with COVID (IPOS-COV)

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Background/aims: Patient-centered measures to capture symptoms and concerns have rarely been reported in severe COVID. We adapted and tested the measurement properties of the proxy version of the Integrated Palliative care Outcome Scale – IPOS-COV for severe COVID.

Methods: Expert consultations and followed COSMIN and FDA guidance for adaptation and analysis. EFA and clinical perspective informed subscales. We tested the internal consistency reliability, calculated item total correlations, examined re-test reliability in stable patients, and inter-rater reproducibility. We examined convergent and divergent validity of IPOS-COV with AKPS and known-groups validity. Ability to detect clinician rated change were examined.

Results: In the adaptation phase, 6 new items were added, 7 were removed, IPOS structure, preserved recall period revised to capture

fast deterioration. 572 patients with COVID from across England and Wales seen by palliative care services were included. Four subscales were supported by a factor solution explaining 53.5% of total variance. Breathlessness-Agitation and Gastro-intestinal subscales demonstrated good reliability with high to moderate ($\alpha=0.70$ and $\alpha=0.67$) internal consistency, and item-total correlations (0.62 - 0.21). All except the Flu subscale discriminated well between patients with differing disease severity. Inter-rater reliability was fair with ICC 0.40 (0.3 - 0.5, 95%CI, $n=324$). Correlations between the subscales and AKPS as predicted were weak ($r=0.13-0.26$) but significant ($p<0.01$). Breathlessness-Agitation and Drowsiness-Delirium subscales demonstrated good divergent validity. Patients with low oxygen saturation had higher mean Breathlessness-Agitation scores ($M=5.3$) than those with normal levels ($M=3.4$), $t=6.4$ (186), $p<0.001$. Change in Drowsiness-Delirium subscale correctly classified patients who died. **Conclusions:** IPOS-COV is the first patient-centered measure adapted for severe COVID to support key to timely management. Future studies could further evaluate its responsiveness.

P 18.016 Comparing Hospital Costs of Palliative Care Patients before COVID-19 and during the Second Wave in Germany

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Background/aims: COVID-19 caused disturbances in hospitals, for example through visitor restrictions and staff shortages. This changed daily work routines. Thus, higher costs for palliative care (PC) patients can be expected. Recent literature mainly analyzed perceptions of workload for professionals, but little is known about cost implications of COVID-19. Hence, this study compares daily hospital costs at patient-level for two settings, the PC advisory team and the PC unit, using real-world data before and during the second wave of COVID-19.

Methods: Retrospective, cross-sectional data from a single university hospital in Germany between October and December 2019 and 2020 were collected. Statistical analyses were conducted with Mann-Whitney-U tests. Total costs consisted of costs directly related to the patient and overhead costs. Directly related costs were collected bottom-up with minutes for physicians, nurses, and other professionals. Overhead costs were calculated top-down mainly as the difference between collected minutes and overall labor time.

Results: 386 patients were included. For both settings, no statistically significant differences were found before and during COVID-19 for directly related costs for physicians and nurses, and minor differences ($p=0.005$) for other professionals. Overhead costs were different ($p<0.001$) for both settings. Thus, total costs for the PC advisory team rose (+24.4%), due to decreased cases and subsequently higher overhead costs, while total costs for the PC unit declined (-12.2%) due to increased cases and hence lower overhead costs. Despite length of stay decreased, total days increased (+20.6%) at the PC unit, due to increased cases (+38.2%).

Conclusions: Costs directly related to patients did not change due to COVID-19. Differences resulted in overhead costs, which directly depend on the number of cases. This indicates that daily resources were well-balanced by professionals, despite the increased workload due to the higher number of cases at the PC unit during COVID-19.

P 18.017 Death and Mourning Processes in the Times of the Coronavirus Pandemic (COVID-19)

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Background/aims: The Research Topic of Death and Mourning Processes emerged during the COVID-19 pandemic, and an international group of 12 researchers committed to handling and analyzing the topic from different multidisciplinary perspectives and cultures.

Methods: 174 authors from 22 countries and 5 continents wrote 46 scientific papers, reviewed by 89 peers. Content analysis of the 44 papers that were published in *Frontiers in Psychiatry* was performed by the editors.

Results: 9 main topics emerged: 1) Cross-cultural bio-psycho-social perspectives, 2) The role of spirituality, faith and meaning of life, 3) Risk groups, challenges, and controversies in regulations and priorities implemented by governments and policymakers in COVID-19, 4) The secondary impact of COVID-19, 5) Educational needs on death and mourning process 6) Challenges and management of loneliness, palliative care, and dying alone, 7) The impact of death from COVID 19 and the mourning process on front-line professionals and their families, 8) Companions animals, mobile and internet-based interventions, and psychosocial tools to mitigate fear and grief and 9) The psychophysiological stress due to the pandemic situation in the general population.

Conclusions: Complicated grief in adolescents was underrecognized and misdiagnosed. Mental health professionals and organizations should respond to the “bereavement pandemic”, and the importance of understanding the complex scenarios of children mourning a parental loss during the COVID-19 pandemic was emphasized. International collaborations showed different ways of seeing and dealing with the death and mourning processes during the pandemic. They highlighted cultural, clinical, and social differences but also a common condition, which is human nature, that has allowed raising our voices as one to express and analyze death and mourning processes from the five continents.

P 18.018 The Impact of the COVID-19 Pandemic on Care Processes and Resources in Palliative Inpatient Care

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Background/aims: The COVID-19 pandemic affected all health care levels. Little is known on the pandemic's effects on processes and resource use in palliative care (PC). We aim to describe differences in patient

characteristics, care processes and resource use in PC before and during the first pandemic year.

Methods: Retrospective, cross-sectional study using routine data of all patients cared for in a PC unit (PCU) and a PC advisory team of a German hospital during 10-12/2019 and 10-12/2020. Data included patient characteristics (age, sex, cancer/non-cancer, symptom/problem burden using Integrated Palliative Care Outcome Scale (IPOS)), information on care episode, and labour time by care minutes. Descriptive statistics and comparisons between years using parametric and non-parametric tests.

Results: Inclusion of 55/79 patient episodes in 2019/2020 from the PCU and 135/120 episodes from the PC advisory team. Patient's age, sex, and diagnosis did not significantly differ comparing the two years. IPOS scores were lower in 2020 (PCU: 3.3 points, $p=.097$; PC advisory team: 2.8 points, $p=.037$). The share of completed IPOS assessments differed considerably between years (PCU: 30.9%/54.0%; PC advisory team: 47.4%/40.0%). Care episodes were shorter in 2020 in both settings (PCU: by 1.3 days, $p=.538$; advisory team: by 0.9 days, $p=.422$). Deaths on PCU 72.7%/72.4% and in advisory team 25.2%/18.3%. No significant differences were observed regarding total minutes/day and patient (PCU: 148.7/147.4 min, $p=.539$; PC advisory team: 62.2/64.8 min, $p=.533$). Staff minutes showed a significant decrease in minutes spent in direct contact with relatives (PCU: 29.4/23.4 min/day, $p=.040$; PC advisory team: 10.2/6.2 min/day, $p=.019$).

Conclusions: The COVID-19 pandemic and accompanying regulations affected daily work routines, especially time spent with relatives and PC problem assessments. This might have consequences for care processes and quality of care with different outcomes during a crisis such as the COVID-19 pandemic.

P 18.020 End of Life Cancer Care in the COVID-19 Era: A Retrospective Population Based Study in the Netherlands

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Background/aims: The COVID-19 pandemic led to a decline in cancer diagnoses and alterations in diagnostic and treatment pathways. Little is known on how the pandemic impacted end of life (EOL) care. This study aimed to investigate the potentially inappropriate EOL care for cancer patients before and during the COVID-19 pandemic.

Methods: The EOL care of all deceased patients with cancer in five periods between January 2020 – July 2021 was compared with reference data from 2018 and 2019. Patients were included when they were diagnosed with or received care for cancer in the year preceding death. Data from the Netherlands Cancer Registry and Dutch National Hospital Care Registration was used. Six international indicators of potentially

inappropriate care in the last 30 days of life were compared by period: chemotherapy administration, >1 emergency room (ER) contact, >1 hospitalization, hospitalization >14 days, intensive care unit (ICU) admission and in hospital death.

Results: The proportion of patients receiving potentially inappropriate EOL care was lower during the COVID-19 pandemic compared to the preceding years, most pronounced during the first COVID-19 peak in 2020 (22,4% vs 26,0%, $p<0.01$). The proportion of patients admitted to an ICU, hospitalized >14 days or dying in hospital was lower during the entire COVID-19 period, mainly during the first COVID-19 peak (2,6% vs 4,4%; 4,0% vs 6,6%; 14,6 vs 16,9%, $p<0.01$). The proportion of patients with >1 hospital admission was also lower during the first COVID-19 peak (5,9% vs 7,8%, $p<0.01$). Chemotherapy administration slightly increased between the first and second COVID-19 peak in 2020 and in 2021 (5,9% vs 5,2%; 6,2% vs 5,4%, $p<0.01$). No changes were observed in ER contacts.

Conclusions: Cancer patients experienced less potentially inappropriate EOL care during the COVID-19 pandemic. This might be related to reluctance to go to the hospital and increased awareness for triaging and advance care planning, of which the latter will hopefully be retained.

P 18.022 Mortality due to SARS-CoV2 Infection in a Long Term Care Hospital: Creation of a Pronostic Scale

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Background/aims: Coronavirus disease 2019 (COVID-19) was first detected in China in December, 2019. It was declared as a pandemic by the World Health Organization (WHO) on March 11, 2020. The clinical management of COVID-19 is based on supportive therapy and treatment to prevent respiratory failure. The antiviral therapy and vaccination are the cornerstone of clinical and epidemiological strategies. Our main objective is to create a prognostication scale based on clinical and sociodemographic variables of patients attended in a long-term care hospital.

Methods: Prospective and single center study. Patients who died from SARS-CoV2 during 2021 were included. Sociodemographic and clinical data were collected. Bivariate and multivariate analysis (logistic regression) was performed. The ROC curve was calculated. A p value < 0.05 was considered statistically significant.

Results: 177 patients were included in the study. Mortality due to SARS-CoV2 infection was of 24.85%. Three independent variables (age, <60 Barthel index and >2 FRAIL test) had prognostic significance. The AUC was 0.8707.

Conclusions: Age, frailty and patients performance are three variables easy to collect. They can be used as a prognostication scale to predict SARS-CoV2 mortality in a long-term care hospital.

P 18.023 A Study on the Predictors of High Opioid and Benzodiazepine Use in COVID-19 Patients (PHOBIC) - Interim Analysis

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Background/aims: Dyspnea is the most common symptom experienced by patients dying from Covid-19. Systematic review showed that these

patients require higher subcutaneous opioid (mean Morphine Equivalent Daily Dose (MEDD) of 45mg) and/or adjunct benzodiazepine (BZD) infusions reflecting high dyspnea severity. Furthermore, they deteriorate rapidly, making it challenging to control escalating dyspnea towards the end of life. The PHOBIC study aims to identify predictors of high opioids (MEDD \geq 45mg) and/or BZD usage (high user) to manage dyspnea in Covid-19 patients.

Methods: This is a retrospective cohort study of non-intubated Covid-19 patients admitted to a tertiary hospital in Singapore from 1 Jan 2021 to 1 May 2022, reviewed by Palliative Medicine and needed opioids/BZD for dyspnea. We excluded patients dying from other causes.

We collected baseline demographics, co-morbidities and vaccination status. Clinical status, laboratory results, medication dose, Edmonton Symptom Assessment System (ESAS), and Palliative Performance Scale (PPS) were recorded based on key timepoints of a patient's admission. Fisher's exact, Wilcoxon rank sum and logistic regression were done for univariate and multivariate analysis respectively.

Results: 146 patients were analysed. Their median age was 85 years old, median Charlson Comorbidity index was 7 and PPS was 30%. 58.9% were cognitively impaired, 50% were not fully vaccinated and 75% died during admission. High user had higher respiratory rate, oxygen requirement and ESAS dyspnea score at first palliative consult (Tp) compared to low user with no other significant difference. Multivariate analysis showed that lower ISARIC (International Severe Acute Respiratory and emerging Infections Consortium) score and higher ESAS dyspnea score at Tp were predictors of high users.

Conclusions: High dyspnea scores can identify patients who are high opioid or BZD user at the end of life to target limited palliative care resources. We aim to complete full data collection and analysis.

P 18.024 The Use of Non-invasive Respiratory Support at the End of Life in Patients Dying of COVID-19: A Retrospective Observational Study

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Background/aims: Non-invasive respiratory support (NIRS) includes high-flow nasal cannula (HFNC) oxygen, continuous positive airway pressure (CPAP), and non-invasive ventilation (NIV). NIRS has been used to reduce symptom burden at the end of life. However, there is limited existing literature on the role of NIRS in Covid-19. We aimed to explore the use of NIRS in patients dying of Covid-19.

Methods: This single-centre, retrospective observational study collected data from electronic records for patients admitted to one London hospital between December and February 2021. Patients were included if they were diagnosed with Covid-19, required NIRS, and subsequently died. Data collected included demographic, clinical (type of NIRS and reason for commencing), and clinical outcomes (signs of improvement and/or discomfort). Descriptive statistics were used to analyse patient characteristics and outcomes.

Results: Thirty patients were included. 43% (n=13) were men and median age was 76.5 (range 57-88). The most common reason for NIRS initiation was hypoxia (n=21, 70%), followed by increased work of breathing (n=6, 20%).

Initial improvement was observed in 20 (67%) patients, the most common being increased oxygen levels (n=15, 50%). No signs of improvement were observed in 11 patients (36.7%). Signs of discomfort were reported in 20 patients (67%), with the most frequently being general discomfort (n=12, 40%).

More than half of the patients discontinued NIRS before dying (n=17, 56.7%). Of the 13 people that continued NIRS, the most reported reasons were symptom control (n=6, 46.2%) and comfort (n=4, 30.8%). Most patients who had NIRS removed, died <24 hours after removal (n=13, 76.5%).

Conclusions: Our data shows a potentially high burden of discomfort may be experienced by Covid-19 patients at the end of life while receiving NIRS. Further research is needed to clarify the role and effectiveness of NIRS in these patients.

P 18.025 COVID-19 Vaccination Choices in Palliative Care: Results from an Online Qualitative Survey with Palliative Care Physicians

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Background/aims: The anti-COVID vaccine is the solution to reduce morbidity and mortality, and hopefully to end pandemic: nevertheless, pre-existing lack of integration between Public Health System and Health Services, together with vaccine hesitancy are the main factors in reducing coverage and hinder the herd immunity needed.

This challenging scenario could be even more complex for vaccine allocation in Palliative Care setting because of high complexity raising from clinical conditions, prognostic evaluation, expected outcomes and personal values of patients, families, and healthcare workers.

Methods: The research question was: "What are the decision-making factors reported by palliative care specialists when proposing anti-covid vaccination to patients with palliative care needs?"

We applied an online qualitative study design involving the critical incident technique, a qualitative research methodology with a flexible set of principles that can be modified and adapted according to the phenomenon under study. The critical incident method focuses on the context of the event (namely, according to what the decisions about vaccine proposal were made).

Results: Main factors involved in the decision-making about vaccination were: role of health-care professionals, health conditions, patients' preferences, family members and surrogates' relationship, setting of care.

Excepting three cases, the data did not show any significant relationship between being vaccinated, recommending the vaccine to loved ones and proposing it to patients

Besides, we did not identify recurrent patterns between the proposal/recommendation of vaccines (to none, a few, or many) and the decision-making modality.

Conclusions: Our study highlighted how investigating decision-making process in such a complex scenario could be an opportunity to improve integration among professionals, Health Systems, patients and their caregivers or proxies.

P 18.026 The COVID-19 Pandemic Didn't Change the End-of-Life Care in Finnish Hospitals-at-Home

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Background/aims: Hospitals-at-home (HAH) are an essential part of end-of-life care providing healthcare services in Finland. We have previously examined the HAH network in Finland and in this study we wanted to find out whether the COVID 19 pandemic influenced the end-of-life care provided in these.

Methods: We contacted 13 Finnish hospitals-at-home (HAH) of different size and geographical location and conducted a retrospective questionnaire survey. In our survey we compared years 2019 and 2020 to find out what changes in operations happened after the onset of the pandemic.

Results: The questionnaire was sent to 13 hospitals-at-home, 10 of these answered. Half of the HAHs did not report significant change in operations between 2019 and 2020. In one HAH the number of both end-of-life care patients and patients treated for infection increased and in another number of end-of-life care patients increased between years 2019-2020. Although the mean number of patients in end-of-life care declined, the average number of deaths at home increased. Two HAHs reported increased demand for services in nursing homes in 2020.

Conclusions: Our study shows that despite of downshifting of many health care service, the HAH operations did not suffer from the pandemic. The care of COVID 19 -infected patients was not common in HAHs although half of the HAHs reported participating in end-of-life care of COVID 19 -infected patients at home. The HAH model of service provision could be more widely used during pandemics as has been the case in some other countries.

P 18.027 Resilience of Relatives of Palliative Care Patients in Mainz, Germany, during the COVID-19 Pandemic: Different from Resilience of the General European Population?

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Background/aims: Resilience is a mechanism to cope with distress. The Covid-19 pandemic has an impact on resilience. Relatives of palliative care patients as care givers show an intense stress risk. Additionally, relatives of inpatients experience several regulations during the pandemic. The aim was to investigate resilience of relatives of stationary palliative care patients compared to resilience of participants of the European study on resilience during the Covid-19 pandemic (DynaCORE-C; www.dynamore-project.eu).

Methods: During the Covid-19 pandemic, data on resilience was collected from relatives of palliative care patients at two palliative care units in Mainz. The DynaCORE-C questionnaire was supplemented with palliative care specific items. Quantitative data were analysed by means of comparisons, frequency tables, and Pearson correlations. Qualitative data were collected to deepen the understanding for the relatives' responses within the questionnaire.

Results: 69 questionnaires were analysed. An expected correlation between resilience and positive appraisal (PA) was found. In contrast to the general population there was no significant correlation between resilience and perceived social support or problem-oriented coping. Interestingly, no correlation between perceived burden of visit restrictions and resilience was found. No demographic factors were found to influence the resilience score. Noteworthy, higher levels of stress due to an increased risk of a serious illness in case of a Covid-19 infection were evident in the relatives of palliative care patients compared to the general population.

Conclusions: Our findings support the theory, PA being important for resilience. For relatives of palliative care patients, the distress level due to Covid-19 is higher than the general distress level. Further research is needed to understand and support this specific subgroup during a pandemic.

Acknowledgment: We thank Leibniz Institute for Resilience Research supporting this project with the DynaCORE-C questionnaire.

P 19 - PC in Times of Humanitarian Crisis

P 19.001 What Matters to Patients with Advanced Cancer and Family Caregivers Including Refugees: A Qualitative Study from Jordan

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Background/aims: The integration of palliative care into standard oncologic care has shown clinical effects on alleviating symptom burden and improving quality of life. However, palliative care is not routinely available across Jordan, and has been excluded in humanitarian emergency and crisis response until recently. This study aimed to identify what matters to patients with advanced cancer and families particularly refugees in Jordan, and explore their unique needs and experiences of receiving cancer and palliative care.

Methods: Face-to-face, semi-structured in-depth interviews were conducted. Adult patients with advanced cancer and caregivers including refugees were purposively sampled to achieve heterogeneity by age, gender, country of origin, and primary diagnosis. All interviews were digitally audio recorded, anonymised, and transcribed verbatim for thematic analysis.

Results: 50 patients (22 refugees) and 20 caregivers (7 refugees) participated, and four themes were identified: (1) Information, communication, and decision-making. Honesty was valued, and participants expressed concerns that information was not shared. (2) Priorities and concerns for care and support. Participants' top priority remained cure and recovery, followed by returning to their "normal" life and "own" country, and contributing to their family. (3) Role of spirituality and Islam. Most participants had strong faith in God. For refugees whose social network was fractured, prayer and Quran reading became particularly important. (4) Unmet support needs of family caregivers. Family caregivers were affected physically and emotionally by worrying about and caring for the patients.

Conclusions: Providing person-centred and culturally appropriate care is essential. Further research is required to explore the specific models and approaches to holistic cancer and palliative care in Jordan, the role and influence of spirituality among Muslim patients and their families, and the support of family caregivers, particularly following bereavement.

P 19.002 How Limited Access to Caregivers and Palliative Supports Influenced Care for Patients with COVID-19 and Life-threatening Disease

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Background/aims: The COVID-19 pandemic brought many changes including restrictive visitor policies and shifting resources. Little is known about how caregiver availability and access to services such as home care or hospice placement played a role in patient care during the pandemic. Our aim was to examine the relationship between resource availability (PPE, caregivers, home care, hospice) and location of death and clinician-reported goal-concordant care.

Methods: Retrospective cohort study based on a registry of patients with COVID-19 and life-limiting disease in Canada from Sept 2020 to Dec 2021. Association between resource availability and both place of death

and receipt of goal-concordant care was assessed using multivariate regression models.

Results: Of 1,041 case reports of patients with COVID-19 and life-limiting illness, 218 indicated that care was affected by availability of home care, caregivers, hospice or by restrictive visitation policies. Few (<1%) reported concerns with availability of PPE or medications. Patients with reported resource availability concerns were more likely to die (36.6 vs 16.1%) and over 90% died in hospital. Younger, male, non-White, patients with cancer, prior non-COVID-19 disease progression, a higher functional status (PPS 70-100%) prior to COVID-19 infection, and a larger decrease in PPS during and after COVID-19 were more likely to report accessibility in hospice placement and caregiver and home care support affected their care. A lack of access to supports was associated with lower odds of receiving goal-concordant care [OR 0.55 (0.31-0.99)] when controlling for sociodemographic, functional, and clinical information.

Conclusions: As a result of shifting resources due to the COVID-19 pandemic, variable access to caregivers, home care supports, and hospice placement was associated with lower odds of receiving goal-concordant care. The majority of patients dying from COVID-19 died in hospital, regardless of resource accessibility concerns.

OM - 2 G EAPC Reference Group Palliative Care and Intellectual Disability

P 7.001 Exploring the Views and Preferences of People with Intellectual Disabilities, Families and Professionals on End of Life Care Planning with People with Intellectual Disabilities: A Focus Group Study

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Background/aims: Reviews and inquiries into end of life care for people with intellectual disabilities (PwID) consistently recommend that services involve PwID in end of life care planning (EOLCP). However, there is limited evidence on how to do this.

Aims: To explore the experiences, views and preferences of PwID and other stakeholders on EOLCP with PwID within social care settings.

Methods: The research/author team includes 3 co-researchers with an intellectual disability (ID). Participants were purposively selected as follows: 3 focus groups with PwID (n=14; each group meeting twice; 1 online group and 2 face-to-face groups) using accessible data collection methods; plus 13 single stakeholder 2-hour online focus groups (n=4-6 participants per group) with family carers, frontline ID support staff, ID service managers, palliative care and ID professionals and policy makers. Data were analysed deductively using a framework matrix, organising and discussing the data in a visual way, thus enabling full-team involvement.

Results: The different stakeholders had a range of views on whether EOLCP should be in place for all PwID supported by social service providers; when in the life trajectory different aspects of EOLCP should be instigated; who should be involved; how EOLCP should be approached; what skills are needed by social care staff; and what the barriers and facilitators are to EOLCP planning and involvement of PwID. Involvement takes different forms, depending on the PwID's capacity as well as their wish to be involved in EOL decisions. The importance of relationships and understanding of life stories and individual needs is highlighted.

Conclusions: There is a need to focus on approaches to EOLCP and developing staff competence and confidence. Tools and resources can be useful but they rely on staff/carer skills and flexibility. These findings will be used to co-produce a toolkit of guidance and resources, to be tested within social care settings in 2023-24.

P 7.003 "We MUST Be Involved!" Developing and Testing Inclusive Data Collection Methods for End of Life Care Research with People with Intellectual Disabilities

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Background/aims: Studies of end of life care for people with intellectual disabilities (PwID) have mostly been conducted with staff and carers; very few studies have involved PwID. Lack of inclusive and accessible data collection methods is a major barrier for including PwID in such studies.

The lead authors are 3 co-researchers with ID. They would have liked to write this abstract in a more accessible easy-read format but in order to comply with academic convention, they wrote it with help from their non-disabled colleagues.

Aims: To develop and test data collection methods that enable participation of PwID in studies about death and dying.

Methods: Our research questions were "Why, When, How, and with Who do PwID prefer to be involved in end of life care planning?" We utilised our previous experiences of creative ways to talk about death and dying with PwID. This includes story-telling using pictures, and visual ways of expressing preferences with pictures and voting boxes. We developed a "washing line/time line" method for the "When" question. We piloted the methods with 3 groups of PwID before using them in research focus groups, which were video recorded and transcribed. We had team analysis days to discuss researchers' reflections on the data, where the co-researchers' perspectives were important.

Results: The inclusive data collection methods enabled us to explore all our research questions. Participants experienced the methods as enjoyable "games". They were empowered to take control of their contributions, including some participants choosing to leave or sit away from the group when they found the discussions too challenging. It was important to be flexible, adapt to individual and group need and have frequent breaks including moving around. The presence of co-facilitators with ID encouraged rich group contributions.

Conclusions: Conventional data collection methods are insufficiently accessible to PwID. New, creative and flexible methods should be explored, described, shared, replicated and validated.

P 7.004 Co-producing a Toolkit of Approaches and Resources for End-of-Life Care Planning with People with Intellectual Disabilities, Using Experience-based Co-design

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Background/aims: National mortality reviews have shown that the deaths of people with intellectual disabilities (PwID) are often unplanned for and poorly managed. PwID are rarely involved in their own end-of-life care planning (EOLCP), and there is insufficient evidence about how to improve this.

Aims: To co-produce a toolkit of EOLCP approaches and resources that is beneficial to PwID and workable within adult social care services.

Methods: Six Experience-Based Co-Design workshops informed by a review of existing resources, and focus groups with key stakeholder groups, including PwID, family carers, support staff, ID service managers, professionals working in ID and/or Palliative Care (PC) and policy makers. The co-design team includes representatives from these stakeholder groups and researchers with and without ID. A 'trigger film' of clips from focus groups was developed to share the views of the different stakeholder groups. Workshops include assessing existing resources, and

agreeing on key principles, preferred approaches, and core staff skills required for EOLCP with PwID.

Results: Each stakeholder group brings an important perspective to the co-design group. PC/ID professionals bring experiences of involving people in EOLCP. However these approaches are not always practicable within ID services. Staff bring ideas for approaches and potential barriers, both organisational and personal concerns about tackling difficult topics. PwID and families can ensure approaches are accessible and often have different views on whether and when EOLCP should be done and with whom. Including researchers with ID is vital to ensure inclusive approaches and a flat hierarchy within co-design sessions.

Conclusions: Including a range of stakeholders in the development of approaches and resources for EOLCP with PwID enables the creation of a toolkit which is accessible for PwID, useful for support staff, and practical for use in adult social care services.

P 7.018 Exploring the Factors Associated with Avoidable Deaths of People with an Intellectual Disability in England in 2021

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Background/aims: Concerns about the premature deaths of people with intellectual disability (PwID) in England led to the establishment of the *Learning from Lives and Deaths (LeDeR)* programme. 3,304 deaths of PwID were reported to LeDeR in 2021.

Aims: (1) Understand the concept of avoidable mortality; (2) Investigate the factors associated with avoidable deaths for PwID; (3) Explore the views of PwID on the findings.

Methods: (1) Describe the international avoidable mortality definition (Organisation for Economic Co-operation and Development (OECD)) of preventable and treatable causes of death, using the underlying cause of death recorded on death certificates; (2) apply this to data on 2,392 PwID who had a recorded underlying cause of death, and explore the effects of demographic, clinical, social and care variables on avoidable deaths; (3) co-produce this information in accessible format and explore recommendations with 7 co-researchers with an intellectual disability.

Results: (1) Causes of death that can be largely prevented or treated once they have occurred, are defined as “avoidable” if the age at death is below 75. This is specified by a list of causes of death, using the International Classification of Diseases (ICD-10). (2) 49% of deaths of PwID in 2021 were rated as “avoidable”, compared with 22% for the general population. Place of death, age, ethnicity and some long-term health conditions were predictors of avoidable deaths. (3) The concept

of avoidable mortality was difficult for PwID to understand, but they thought it was highly important. The group developed an accessible video of findings and recommendations.

Conclusions: Within-population variations and risk factors provide a focus for future investigation and development of prevention and care pathways; but most importantly, there should be investment and focus on closing the gap between avoidable deaths of PwID and the general population.

P 5.048 Our Name on the Door: The Importance of Employing People with an Intellectual Disability as Researchers in End of Life Care

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Background/aims: It is important that we get end of life care right for everyone, including for people with intellectual disabilities. Therefore, people with an intellectual disability must also be included in research about death and dying. We are three people who have an intellectual disability, employed as researchers at a university. We work on several studies about the end of life. Not many people with intellectual disabilities have a paid job like this. We want to explain why that matters.

Methods: We have talked together and with our non-disabled colleagues about the experiences we have had in our lives and how that has led us to this work. We thought about what we bring to end of life care research and about what other teams and universities can learn from us.

Results: Each of us has different life experiences. What we have in common is the experience of not being heard, being pushed aside and not being involved. For example, Richard’s parents were told to “put him away” when he was born as he would “never achieve anything”, and Amanda experienced not being told that her mum was dying. These life experiences mean that we can help the non-disabled researchers understand better what people with intellectual disabilities tell us in focus groups and interviews.

We also help make the research easy to understand for everyone. We work together on the research projects from beginning to end and contribute to everything – planning, helping with interviews and co-production groups, analysis and telling people about the results. This is important. Each of us needs different help with the work, so we have two colleagues employed specially to support us, which is very good.

Conclusions: NOTHING ABOUT US WITHOUT US but involving people with intellectual disabilities in research is not just ticking a box. It takes effort and time, which costs money. We show that it can be done well, even in research about dying. More universities should employ people like us.

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