



## Public Health and Palliative Care: What do the Public Know and What Lessons can be Learnt?

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# Public Health Research in Palliative Care: Towards Solutions for Global Challenges

An international audience of 122 delegates attended the 'Public Health Research in Palliative Care: Towards Solutions for Global Challenges' seminar hosted online by All-Ireland Institute of Hospice and Palliative Care (AIHPC) on November 17 and 18, 2020. This was the second International Research Seminar of the European Association for Palliative Care (EAPC) Research Network and EAPC Reference Group on Public Health and Palliative Care. This major international event included live presentations from leading researchers in the area of public health and palliative care including from the island of Ireland, Scotland, Belgium, Australia, the Netherlands, and Sweden. Event organisation was overseen by a scientific committee which included leading researchers from public health and palliative care. The seminar was supported by the Irish Hospice Foundation. The scientific committee is pleased that seminar abstracts accepted are being published in the journal *Palliative Care and Social Practice*. Abstracts were invited over a range of topics including: public health palliative care and the response to COVID-19, compassionate communities, caregiving and bereavement, health promotion and palliative care, population health models for palliative care, and issues of equity.

*Professor Joanne Reid, Queen's University, Belfast, and Chair of EAPC Public Health 2020 International Seminar Scientific Committee*

## Abstract 1

### Covid-19 and Compassionate Communities: Renewed Opportunities for Connection

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**Background and aims:** Compassionate Neighbours is a well-established compassionate communities movement initiated through a series of

hospices in the south-east of the United Kingdom. When the Covid-19 pandemic hit, it brought death and dying into the living rooms of the nation and new requirements to drastically alter patterns of social contact. For many organisations, volunteering was immediately halted and perceived as being too risky. But what was also being thrust onto the front pages was people's wish to connect, to take local action and support those vulnerable on their street.

The Compassionate Neighbours movement did not step back during Covid-19 and in fact grew in numbers of volunteers and connections. This presentation will describe the experiences of one Compassionate Neighbours hub in south-east London and how Covid-19 has altered the landscape for connections at the end of life.

#### Approach taken:

- Rapid reassessment of risk which led to routine volunteering being superseded by new flexible, responsive, and safe roles.
- Overcoming barriers such as the need for face to face training, identification badges.
- New models of connecting such as 'furlongteering' (short, time-limited volunteering options), virtual and telephone communication, deliveries, and practical support for vulnerable.
- Early integration with local groups such as the grassroots mutual aid organisations.
- Capitalising on the groundswell of interest in volunteering to grow numbers of Compassionate Neighbours.
- Bringing a compassionate and experienced response to the fearful narrative on death and dying.

**Results:** Referral numbers for volunteer support peaked during this time, with 2.6 times the number of referrals for the same quarter in 2019 (32 vs 84 referrals per quarter).

**Keywords:** Compassionate communities, Covid-19, new public health approaches to end-of-life care

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## Abstract 2

### The Contribution of and Support for Volunteer Palliative Care: A Survey of Volunteers Across the Health Care System

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**Background:** Volunteers across various health care organisations are an important resource for compassionate communities to bridge palliative care (PC) services and the community. However, to date, no studies have systematically mapped volunteers' actual contributions to PC provision and how well they are supported by and within different health care organisations. Such insights are important to shape and optimise supportive environments for volunteering in PC.

**Aims:** To describe current volunteers' social backgrounds, their activities in terms of tasks, the training and supervision they receive, as well as how they evaluate these in PC.

**Design:** We conducted a cross-sectional postal survey of PC volunteers in Flanders and Brussels in 2018 using a disproportionately stratified cluster random sample of 2273 volunteers across dedicated and generalist PC services.

**Results:** Response was obtained for 801 (35.2%) volunteers. Volunteers were predominantly women (75.5%), retired (40.8%), aged 61 to 70 (46.2%) and had a professional or academic degree (58.7%). Two dimensions in task performance emerged from the data during volunteers' last session with a patient with serious illness. The 'multidimensional support' dimension was mainly associated with dedicated PC volunteers, and represented broad task performance, emphasising psychosocial, existential, and signposting tasks. It was associated with receiving structured ( $P = .001$ ) and group ( $P < .05$ ) supervision, and extensive training ( $P < .001$ ). The 'nursing support' dimension was mainly associated with sitting services and represented narrow task performance, emphasising nursing tasks. It was mainly

associated with receiving training in nursing tasks ( $P < .001$ ). With the exception of those active in nursing homes, volunteers tended to evaluate their role, training, and support as satisfactory.

**Conclusions:** Results indicate that with training and consistent supervision, volunteers can offer versatile support for patients with serious illnesses. This currently happens in dedicated PC services; however, results indicate that volunteers in nursing homes and community home-care may have suboptimal support and training.

## Abstract 3

### Embeddedness of Volunteers in Belgian Palliative Care Services: A Survey of Volunteers Across the Health Care System

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**Background:** The empowerment and engagement of volunteers and volunteer-professional collaboration in palliative care (PC) services can facilitate a more comprehensive contribution of informal care networks, provides a link with the community, and aids to bridge the gap between professional and community care. Insights into volunteer embeddedness and how it can be improved can help shape and optimise supportive professional environments for volunteering in compassionate communities.

**Aims:** To describe volunteers' involvement in organisation of care and collaboration with professionals, and how they evaluate this.

**Design:** Postal survey of 2273 volunteers across dedicated and generalist PC services in Flanders and Brussels in 2018.

**Results:** Response was 35%. Two thirds of volunteers are often to always informed about organisation of patient care and around half feel the organisation often takes their opinion into account, while a minority report having decision rights

(18%) or autonomy (24%). For some, their organisation fails to inform (17%), consult (27%), take into account their opinion (21%), give them decision rights (20%) or autonomy (16%) often enough. Across healthcare organisations, volunteer-professional collaboration is (very) low, and mostly limited to information sharing – as opposed to task coordination or decision-making. However, in dedicated PC services nurse-volunteer contacts are fairly frequent and often involve task coordination (46%). Ambiguity regarding tasks, agreements and/or rules (15%) and lack of information exchange (14%) are the most cited barriers to volunteer-professional collaboration. Volunteers seem least embedded in nursing homes and community healthcare services.

**Conclusion:** Some volunteers are open to a higher degree of involvement in the organisation of care in PC services. Collaboration with professionals seems lacking both in width and in depth. In Compassionate Communities, PC services, particularly those with strong community links, can endeavour to enhance the embeddedness of their volunteers and support them into more comprehensive roles as exponents of community care.

#### Abstract 4

### Transition From Children's to Adult Services for Adolescents/Young Adults With Life-limiting Conditions: Developing Realist Programme Theory Through an International Comparison

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**Background and rationale:** Managing the transition of adolescents/young adults with life-limiting conditions from children's to adult services has become a global health and social care issue. Suboptimal transitions from children's to adult services can lead to measurable adverse outcomes. Interventions related to a successful transition to adult services are emerging, but there is little theory to guide service developments

aimed at improving transition. The **Transition to Adult Services for Young Adults with Life-limiting conditions (TAYSL study)** involved the development of the TAYSL Transition Theory based on a research study in the context of the island of Ireland, which describes 8 interventions, which can help prepare services and adolescents/young adults with life-limiting conditions for a successful transition to adult services.

**Aims:** The aims of this study were to assess the usefulness of the TAYSL Transition Theory in a Canadian context; to identify interventions, mechanisms and contextual factors associated with a successful transition from children's to adult services for adolescents/young adults with life-limiting conditions; and to discover new theoretical elements that might modify the TAYSL Theory.

**Methods:** A cross-sectional survey focused on identifying the organisational approaches to transition was distributed to 3 organisations providing services to adolescents with life-limiting conditions in Toronto, Canada. These data were mapped to the TAYSL Transition Theory to identify corresponding and emerging theoretical elements.

**Results:** Invitations were forwarded to 411 potentially eligible health care professionals with 56 responses from across the 3 participating sites. Results validated the 8 key interventions and identified one new intervention: effective communication between health care professionals and the adolescent/young adult and their parents/carers. There was very strong support for 3 of the 8 interventions: early start to the transition process; developing adolescent/young adult autonomy throughout the transition process; and the crucial role of parents/carers. There was also support for a number of contextual factors including those related to staff knowledge and attitudes, and lack of time.

**Conclusion:** The Transition Theory developed in the context of the island of Ireland was transferable to the context of Toronto, Canada, indicating its potential to guide both service development and research in different contexts.

#### Funding

The TAYSL study was funded by the All-Ireland Institute of Hospice and Palliative Care (AIHPC). The research collaboration with

Toronto, Canada, was supported with the finance from the Martha McMenemy scholarship, School of Nursing and Midwifery, QUB.

## Abstract 5

### Idiolectics in Palliative Care

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**Aims:** Palliative care requires special conversational skills. Various existing strategies show significant weaknesses in practice. Idiolectics can be described as an idiosyncratic language that uses the patients' resources and improves their individual values and views considerations. Therefore, idiolectics are a way to strengthen resources that create mental freedom and trust. Only recently, idiolectic conversation has been introduced to therapeutic contexts.

**Methods:** Linguistic reflection stimulates the interviewee to think in new ways. Open questions and personal keywords, that are considered a key to the patient's current experience of reality, activate the resources of the interviewee. These processes can be further supported by nonverbal signals and the activation of other brain areas. As a result, patients identify previously unrecognised potential for change in their own behaviour, and target-oriented developments can be initiated. This means of conversation is entirely free of pressure and coercion. It leaves the respondent largely in control of the conversation; the patient determines the topic, tempo, and tone. It is of crucial importance that the respondent feels comfortable. An understanding and considerate manner of conversational so serves to build a solid foundation of trust between the communicators so that autonomy, uniqueness, and value-free recognition of the respondent is ensured.

**Conclusions:** Palliative care patients are exposed to extreme physical and mental stress. A respectful and worthy doctor-patient relationship is essential for the success of the treatments. Recent clinical research suggests that by means of special conversational techniques, idiolectics open up new approaches to palliative care patients and their needs. Hence, activation of resources

through idiolectics and a significant contribution improves the quality of life of these patients.

**Keywords:** Idiolectic, autonomy, palliative, resources, quality of life

## Abstract 6

### Health Policy Guiding Palliative Care for Patients with Noncancer Diagnosis: A Systematic Scoping Review

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**Background:** Deaths from a noncancer diagnosis pose a challenge for clinical practice with evidenced barriers in the provision of palliative care (PC) being reported for patients with chronic obstructive pulmonary disease (COPD), dementia, heart failure, and Parkinson's disease.

Responding to the evidenced inequalities in access to services, the World Health Organisation (WHO) (1) stated that a major obstacle to the implementation of PC worldwide was the lack of health policy (HP). In response to the WHO commentary, influential organisations developed statements (2-4) urging governments to develop HP that ensures equality of access to PC.

This scoping review aims to map current HP in the EU that specifically respond to the PC needs of patients with COPD, dementia, heart failure, and Parkinson's disease.

#### Aims:

1. To map current HP across the EU that specifically refers to the provision of PC for patients with COPD, dementia, heart failure, and Parkinson's disease.
2. To identify recommendations in current HP that aim to influence the availability and quality of PC for the selected diagnosis.

**Methods:** We use a scoping review methodology.

The concepts: HP (C1), PC (C2), COPD (C3), dementia (C4), heart failure (C5), Parkinson's disease (C6) were expanded into search terms and combined using Boolean operators, truncation, and mesh terms.

The following combinations: C1& C2& C3; C1& C2& C4; C1& C2& C5; C1& C2& C6 were entered in databases (Medline (EBSCO), PsycINFO, Scopus, Cochrane, CINAHL, and Web of Science) in April 2017. Relevant journals (BMC Palliative Care, Progress in Palliative Care, European Journal of Heart Failure, Journal of COPD, Journal of Parkinson's Disease and Alzheimer's and Dementia Journal) were searched in the same period.

Published health policies developed after 2008 in countries of the EU (including the United Kingdom) written in English or Portuguese were included.

The search retrieved a total of 5269 results, of which 5179 were excluded by title and abstract. Out of the 92 articles included for full-text screening, 43 were duplicates and a further 28 were excluded.

Results were assessed as discussing/not discussing the following (2-4):

- (a) PC integration into health care systems.
- (b) Health professional's training in PC and pain management.
- (c) Drug availability.

**Results:** Twenty-one HPs were included for review: dementia (8), heart failure (7), COPD (4), Parkinson's disease (2). Only 6 health policies were specifically developed to address PC for the selected diagnosis, while the remainder addresses disease management with subsections on how PC should proceed.

#### 1. COPD:

- (a) Two HPs encouraged the integration of PC in the disease management but do not expand on how and when this integration ought to be achieved or by whom.
- (b) No recommendations regarding the need for specific training in PC or symptom control.
- (c) Two HPs advised on the use of opioids for the management of pain and breathlessness.

#### 2. Dementia:

- (a) All HPs discussed the integration of PC in dementia care, with a general agreement that it should be part of dementia care. There was no consensus as to

when PC should start in the course of disease.

- (b) Six HPs discussed training of health care professionals, with advice that staff should be trained in both PC and dementia, communication skills, and pain management.
  - (c) Two HPs recommend the use of opioids for pain and breathlessness.
- #### 3. Heart failure:
- (a) Six HP advocate the integration of PC in the heart failure journey through contact between the specialist PC team and the heart failure team and/or the primary care physician, the development of PC programmes in heart failure, and the commissioning of PC services in heart failure.
  - (b) Three HPs discussed staff's training, highlighting the need for communication skills training, postgraduate training in PC specifically directed at heart failure and joint educational opportunities.
  - (c) Two HPs recommend opioids for the symptomatic relief of anxiety, breathlessness, congestion and thirst, depressive symptoms, dyspnoea, and pain.
- #### 4. Parkinson's disease:
- (a) One HP discusses the integration and commissioning of PC services and how these could be achieved in line with the end-of-life care strategy.
  - (b) Both HPs discuss health staff training with different levels of detail which extends from both PC teams and neurology teams having a degree of knowledge of each other's competencies to specifying that training can take the form of e-learning modules, study days, formal teaching, interdisciplinary education between teams and 'informal' initiatives with information being cascaded through teams. Training needs should focus on the end-of-life pathway with special focus on communication, assessment/care planning, symptom management, and advanced care planning and the understanding of neurological conditions.
  - (c) Both recommend opioids for the relief of pain.

**Conclusions:** Despite the existence of HP for each of the selected diagnosis, this scoping review highlights the lack of policies specifically

focussing on PC and the lack of guidance for symptom control, workforce training, and PC integration into health systems.

**Keywords:** Health policy, palliative care, chronic obstructive pulmonary disease, dementia, heart failure, Parkinson's disease, European Union

### Abstract 7

#### Care in the Interstices: Exploring the Outcomes and Significance of Interactions Occurring Outside of the Formal Clinical Consultation

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**Background:** In hospital settings, patients, visitors, and staff engage in many interactions outside the formal clinical encounter. While many of these may be inconsequential, other encounters may be of significant importance to the manner in which patients and their caregivers experience cancer and its treatment.

**Aim:** This study aims to explore the outcomes and significance of interactions that occur outside of the formal clinical encounter in hospital cancer treatment settings.

**Methods:** Semistructured interviews were conducted with cancer patients, caregivers, and staff recruited from the chemotherapy day unit, oncology/haematology wards, cancer support groups, and palliative care units. Hermeneutic phenomenology informed lines of questioning and data analysis.

**Results:** Thirty-one people participated in the study: 18 cancer patients, 5 caregivers, and 9 staff members. These interactions realised outcomes occurring in 3 differing domains: in the provision of care, providing support, and as offering potential to entertain, distract, and share emotionality. The participants reflected upon these engagements as having a wide range of personal

meanings occurring in 3 major themes: enabling them to feel connected, making sense of their experiences, and helping others.

**Conclusions:** Interactions outside of the formal clinical encounter play an important role contributing to care, addressing needs for information, sharing of personal narratives, social interaction, and connectivity. Staff frequently interacted within the informal domain and realised similar meanings; using these conversations to connect with others on a personal level, engage in formal tasks such as eliciting important social information, and engage in helping others outside of their formal tasks. In addition, this domain of interaction presents challenges, particularly in negotiating personal and professional role boundaries.

### Abstract 8

#### Developing a Model of Bereavement Care in an Acute Tertiary Hospital

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**Objectives:** Hospitals are the most common place of death in Australia. Bereavement care is recognised by national standards as being central to providing high-quality care at the end of life and has significant health implication on morbidity, mortality, and health service usage. Despite this, bereavement care is not routinely or systematically provided in most Australian hospitals. This study aimed to develop a comprehensive, evidence-based model of bereavement care specific to the needs of an Australian tertiary acute care hospital.

**Methods:** We employed a multiple-methods design for our study, which included (1) scoping literature review, (2) a survey of current institutional bereavement practices, (3a) interviews with bereaved family members, (3b) staff focus groups, and (4) development of a model of bereavement

care for the acute hospital service through advisory group and expert consensus.

**Results:** Staff and bereaved family members strongly supported a systematic approach to bereavement, perceiving the need for greater support, training, coordination, and follow-up. A total of 10 core elements were developed to support a structured model of bereavement care provision and follow-up for the acute hospital organisation.

**Conclusions:** This evidence-generated model of care promotes the provision of quality, systematic and universal bereavement care in the acute hospital setting. All primary caregivers will be offered bereavement care and opportunities for follow-up; with specialist services available for those who are at high risk for prolonged grief disorder, or who self-identify as requiring additional supports.

## Abstract 9

### Collaboration Between Family and Professional Health Carer in Home Care at the End of Life: An Interview Study

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**Background:** Health care professionals' attention is mainly focused towards the patients who need care, but less towards the family carer. This health care professionals' attention is less focused on the family carer. However, collaboration between health care professionals and family carers is proven to be vital to provide a high quality in palliative and end-of-life care. However, such collaboration is understudied, and especially in a palliative care context.

**Aim:** This study aimed to investigate how family carers of persons who live at home with a life-limiting long-term illness experience and perceive the collaboration with different professional care providers in the last phase of life.

**Design:** Face-to-face semistructured interviews with a phenomenological approach conducted with the primary family carers of persons with a life-limiting long-term illness.

**Setting/participants:** A heterogeneous group of 30 family carers of persons with cancer, heart failure, or dementia was recruited through a variety of care providers and services, including treating physicians, general practitioners, a palliative home care team, and family support groups.

**Results:** Five main themes emerged from interpretative phenomenological analysis as essential aspects for high-quality collaboration between family carers and professionals: (1) dual approach by health care professionals concerning family carer roles; (2) continuous availability and accessibility of health care professionals; (3) information and communication; (4) coordination of care between all parties; and (5) contextual factors.

**Conclusions:** This study highlighted plenty of missed opportunities for an effective collaboration between family carers and professionals. The themes identified provide a number of opportunities to address the issues that hamper collaboration according to family carers.

**Keywords:** Family carers, collaboration between health care professionals and family carers, end-of-life care; palliative care, interview study

## Funding

Flanders Innovation & Entrepreneurship (Strategic Basic Research SBO-IWT grant no. 140009)

## Abstract 10

### Application of Health Behaviour Change Theory to Understand Barriers and Facilitators to Talking About Death and Dying

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**Background:** Improving communication around death and dying is an important component of the international movement towards a public health approach to palliative care. As with other regions, there is a lack of public openness around death and dying across the United Kingdom. Alongside developing an understanding of why individuals at a population level are not having these conversations, there is also a need to build a theoretical understanding of mechanisms towards informing public health initiatives.

**Aims:** The purpose of this study is to explore barriers and facilitators to talking about death and dying in a UK region (Northern Ireland), alongside a novel application of health behaviour change theory to enhance understanding of the determinants of behaviour.

**Methods:** This study involves the analysis of responses from 2 open-ended qualitative items in a large online public survey. The questions ask respondents to identify as a society what the barriers and facilitators are to talking about death and dying. The qualitative data were analysed with thematic analysis, with constructed themes mapped to the COM-B Behaviour Change Model and Theoretical Domains Framework (TDF).

**Results:** A total of 387 respondents provided qualitative data. Themes constructed for barriers reflected concern over the skill to sensitively navigate conversations, a perceived risk of upset in others and a belief that others are unwilling to have the conversation. Themes constructed for facilitators reflected the broad range of stakeholders with opportunity to encourage discussion, the need for increased engagement throughout the life course and the opportunity to optimise existing health care structures.

**Conclusion/Discussion:** Respondents identified a diverse range of barriers and facilitators to discussing death and dying as a society and were mapped to the COM-B and TDF. The findings may help to inform public health approaches to palliative care on a regional level.

**Keywords:** Public health, health behaviour change, death and dying, perceptions, barriers

## Abstract 11

### Physical Activity and Pain in Patients with Bone Metastases (Ex-Met study)

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**Background:** Despite evidence supporting the safety of exercise in patients with metastatic bone disease (MBD), clinicians remain reluctant to advise exercise due to concerns about skeletal-related events, particularly in patients with higher symptom burden.

**Aims:** To examine physical activity (PA), pain and quality of life (QOL) in patients with MBD using baseline data from the Ex-Met study.

**Methods:** Patients with MBD due to breast, prostate, or lung cancer were recruited. Physical activity levels were captured objectively by accelerometry. Pain (brief pain inventory (BPI)) and QOL (EORTC-QLQ-C30) were collected subjectively. Pain and QOL scores in those with high ( $\geq 150$  min moderate-vigorous intensity activity (MVPA)/week) and low PA levels ( $< 150$  min MVPA/week) were compared using independent samples *t*-tests ( $P < .05$ ).

**Results:** To date, 20 participants ( $n = 17$  female), mean (SD) age  $59.4 \pm (11.9)$  years, have been recruited. The majority ( $n = 17$ ) had  $\geq 3$  metastases and severity of MBD was classified as major ( $> 2$  regions). Only 7 participants (35%) were accumulating  $> 150$  min MVPA/week. Pain interference scores (BPI) were significantly higher for the low PA group ( $4.76 \pm 1.26$ ) compared to the high PA group ( $1.32 \pm 3.46$ ;  $P = .05$ ). Pain symptoms score in the EORTC-QLQ-C30 were significantly higher in the low PA group ( $51.28 \pm 32.24$ ) compared to the high PA group ( $14.28 \pm 14.99$ ;  $P = .01$ ). Subjective physical functioning (EORTC-QLQ-C30) was higher in the high PA group ( $80.95 \pm 20.87$ ) compared to the low PA group ( $59.48 \pm 21.33$ ;  $P = .01$ ).

**Discussion:** Results demonstrate that 65% of people with MBD are not accumulating the recommended 150 min of MVPA/week. Those with high PA levels had higher levels of physical functioning, lower pain interference, and pain symptomology. These early findings suggest that higher symptom burden may be a barrier for clinicians recommending exercise in patients living with MBD.

**Keywords:** Bone metastases, physical activity, quality of life, pain, skeletal-related events

### Funding

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### Abstract 12

#### Identifying the Most Important Behavioural Determinants of Starting a Conversation About Palliative Care with the Physician: A Cross-Sectional Structured Interview Study in People With Cancer

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##Equal contribution of the last authors.

**Background:** Patients' empowerment and their own communicative behaviours are deemed important for the timely initiation of palliative care. Rigorous empirical data are needed about what factors influence patients to start a conversation about palliative care with their physician.

**Aim:** To assess which factors are (most strongly) associated with having started or intending to start a conversation about palliative care with the physician (=behaviour) in people with cancer.

**Methods:** We performed a cross-sectional single-centre survey among people with incurable cancer, from August 2019 to March 2020. We developed a specific questionnaire based on an extended version of the theory of planned behaviour and included knowledge, attitude, perceived behavioural control, subjective norm, and social influence. Computer-assisted personal interviewing was used for data collection. Univariable and multivariable logistic regression analyses were performed.

**Results:** Eighty-eight participants (response rate: 65%), of whom 29 already started a conversation about palliative care themselves ( $n=10$ ) or had the intention to do so ( $n=19$ ). Holding a more positive attitude (e.g. important to start the conversation about palliative care myself) (OR 3.312 (1.541; 7.118) and having more positive outcome expectations (e.g. receiving information about palliative care) (OR 4.438 (1.633; 12.062) were positively associated; perceiving more barriers (e.g. feeling good) (OR 0.258 (0.104; 0.636) was negatively associated with having started a conversation about palliative care or having the intention to do so.

**Conclusion:** This study suggests that attitudinal factors are the strongest determinants of people with cancer initiating a conversation about palliative care. Interventions aiming to help them take the initiative in communication about palliative care with their physician should focus on the importance and relevance of behaviour change, elements of behaviour that might be beneficial or difficult and how to overcome barriers.

**Keywords:** Quantitative research, palliative care, neoplasms, health communication, health promotion, behaviour, behavioural theory

### Funding

Research Foundation Flanders.

### Abstract 13

#### Health Care Professionals' Views of Palliative Care for American War Veterans With Nonmalignant Respiratory Disease Living in a Rural Area: A Qualitative Study

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**Background:** Long-term lung diseases, such as long-term obstructive pulmonary disease, are a growing health concern within the veteran population. Palliative care programmes have mainly focused on the needs of people with malignant disease in the past; however, the majority of those worldwide needing palliative care have a nonmalignant diagnosis. In addition, palliative care provision can often be fragmented and varied dependent on a patient's geographical location.

**Aims:** Explore palliative care provision for veterans with nonmalignant respiratory disease (NMRD), and their family carers, living in a rural area of America.

**Methods:** Qualitative study involving a convenience sample of 16 health care professionals from a large veteran hospital in Boise, Idaho. Data collection consisted of 5 focus groups which were transcribed verbatim and analysed using thematic analysis.

**Results:** Findings highlighted that the uncertain NMRD trajectory impeded veteran referral to palliative and hospice services due to health care professionals' own ambiguity regarding prognosis. A barrier related particularly to veterans was a perceived lack of ability to afford relevant services, and a lack of local palliative service provision. Findings highlighted that a compounding factor to palliative care uptake was also the perceptions held by veterans. Alongside aligning palliative care with dying, veterans also viewed accepting palliative care as 'surrendering' to their disease. Findings indicated that telemedicine may be an effective platform to enhance equity of access to palliative care provision for veterans with NMRD living in rural areas.

**Conclusion:** A new model of palliative care for veterans with NMRD, using a dynamic digital platform, may provide an optimal way of providing efficient holistic care to rural areas with limited palliative services.

**Keywords:** Veteran, nonmalignant respiratory disease, palliative care, rural

### **Funding**

Florence Nightingale Travel Scholarship.

### **Abstract 14**

#### **Compassionate Communities as a Therapeutic Landscape**

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**Background:** The concept of compassionate communities is part of a public health palliative care approach to supporting people at end-of-life care.

**Aims:** How is compassionate communities approach experienced by people approaching the end of their life and their care providers?

**Design:** A qualitative multisite case study examined 3 contrasting examples of the development of compassionate communities approach to end-of-life care.

**Methods:** The main methods of data collection was, semistructured interviews with primary participants at the end of life, plus their carer, family and friends; contact diary logs; and focus groups with professionals and volunteers.

**Data Collection:** Participants included: 8 primary participants (people at end of life), 4 primary carers (spouses), 3 members of family/friends, and focus groups with 19 volunteers and 23 professionals with a total of 29 interviews, 10 focus groups, and 5 diary logs.

**Data Analysis:** The analysis of the lived experience was interpretative drawing on phenomenology, supported by NVivo 10 for data management. The analysis drew on the primary participants' interviews data plus diary logs and mapping of the care network of people being cared for.

**Findings:** Home was the preferred place of care for all the primary participants, their inner circle of care (care networks) included both formal and informal carers. A key element of the compassionate communities approach across all the sites was a volunteer befriender role.

**Discussion:** Within the stories there were highlights of how compassionate communities approaches in different ways had extended formal

care with volunteer support. The study identified the characteristics of compassionate communities as a therapeutic landscape.

**Keywords:** Compassionate communities, therapeutic landscape, interface of formal and informal care, volunteers

## Abstract 15

### International COVID-19 Palliative Care Guidance for Nursing Homes Leaves Key Themes Unaddressed

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**Background:** COVID-19 mortality disproportionately affects nursing homes, creating enormous pressures to deliver high-quality end-of-life care. Comprehensive palliative care should be an explicit part of both national and global COVID-19 response plans.

**Aims:** To identify, review and compare national and international COVID-19 guidance for nursing homes concerning palliative care, issued by government bodies and professional associations in low-, middle-, and high-income countries.

**Methods:** We performed a directed documentary and content analysis of newly developed or adapted COVID-19 guidance documents from across the world. Documents were collected via expert consultation and independently screened against prespecified eligibility criteria. We applied thematic analysis and narrative synthesis techniques.

**Results:** We identified 21 eligible documents covering both nursing homes and palliative care; from the World Health Organisation ( $n=3$ ), and 8 individual countries: United States ( $n=6$ ), Canada ( $n=1$ ), the Netherlands ( $n=2$ ), Ireland ( $n=1$ ), United Kingdom ( $n=3$ ), Switzerland ( $n=3$ ), New Zealand ( $n=1$ ), Belgium ( $n=1$ ).

International documents focused primarily on infection prevention and control, including only a few sentences on palliative-care-related topics. Palliative care themes most frequently mentioned across documents were end-of-life visits, advance care planning documentation, and clinical decision-making towards the end of life (focusing on hospital transfers).

**Conclusion:** There is a dearth of comprehensive international COVID-19 guidance on palliative care for nursing homes. Most have a limited focus both regarding breadth of topics and recommendations made. Key aspects of palliative care, that is, symptom management, staff education and support, referral to specialist services or hospice, and family support, need greater attention in future guidelines.

**Keywords:** COVID-19, nursing homes, long-term care, palliative care

## Funding

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## Abstract 16

### How to Educate Citizens About Death and Dying? Lessons Learned From the Implementation of Last Aid courses in 16 Countries

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**Aims:** The majority of Europeans want to die at home. To make this happen, both knowledge and attitude are important. Knowledge and reflection about death and dying are parts of *Last Aid Courses*.

The main goals of the international *Last Aid Course* project are to empower citizens to participate in end-of-life care.

**Methods and approach:** An International Last Aid working group was established between 2017 and 2019. Participating countries can send up to 2 delegates to the Last Aid working group. During

meetings of the International Last Aid working group, the country representatives agree on a consensus about the curriculum and contents of the Last Aid course slide presentation.

**Results:** At present 16 countries participate in the international Last Aid working group. Commitment to participate in an international working group and respect for the consensus reached in the group are paramount to ensure quality of the courses in all participating countries. The main barrier encountered within the last 4 years for international cooperation is the assumption that major changes to address cultural differences are needed in all countries.

**Conclusions/lessons learned:** Our experiences from different countries so far show that a consensus common curriculum with minor national adaptations is possible. Furthermore *Last Aid Courses* are well accepted by the citizens in all participating countries although cultural differences exist. Standardisation of the Last Aid is as important as for First Aid courses to ensure quality and to enable international research on the effects of the courses. Last aid courses can be seen as educational foundation for compassionate communities.

**Keywords:** Citizen death education, health-promoting palliative care, public health palliative care, public palliative care education, compassionate communities

## Abstract 17

### Development of the 'Care & Inform' Information and Support Hub

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**Introduction:** When COVID-19 reached Ireland, there was a need for clear, concise, and compassionate palliative and end-of-life information. The 'Care&Inform' information and advice hub" was developed and launched.

**Aim:** To inform and support the Irish public and health care professionals about matters relating to end-of-life and bereavement care during COVID-19.

**Design and Approach:** The need for up-to-date, grounded, comprehensible, and audience-specific information was identified early in the pandemic through work with different sectors: health care, bereavement services, and the general public.

Each resource was developed in collaboration with subject specialists, and underwent a plain English review. Consultation with those the resources were aimed at also took place.

The Care&Inform hub contains 6 sections: Resources for Healthcare Professionals; Caring for Others; Grief and Loss; Planning Ahead; Latest Research and Information and Bereavement Support Line information.

Resources are available via PDF, videos, and webinar.

**Results:** To date (July 2020) there have been more than 200,000 views of the Care&Inform hub.

Qualitative feedback: Hospital Group DON: 'I was assured that I was assisting the staff at the front line to ensure that their patients were receiving a high standard of care in difficult times'.

**Conclusion:** The need for clear, evidence-based information quickly became apparent at the onset of COVID-19. Working with partners, it was possible to identify areas where support was required, and as a result respond rapidly. Through co-ordination with other national agencies, dissemination has taken place and continues to be progressed.

## Abstract 18

### Exploring Change in a Series of Workshops About End-of-Life Conversations Among Elder Care Staff in Sweden

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**Background:** Conversations between residents, their relatives, and care staff about values and preferences for the end-of-life (EoL) can aid preparation and planning for future EoL care. Still, EoL conversations remain rare in elder care and staff may avoid addressing the EoL altogether, indicating a need to build staff competence for discussing EoL-related matters.

**Aim:** This study explores changes in discussions about EoL conversations during a workshop series designed to promote and explore EoL communication in elder care.

**Method:** Series of 4 consecutive workshops were conducted with 5 groups of 38 staff from 6 Swedish elder care services. Workshops integrated individual reflection with group discussions and knowledge exchange and were analysed using longitudinal qualitative analysis.

**Results:** Three thematic continuums were constructed to illustrate changes in participants' discussions throughout the workshops. Over time, we found that: staff expressed more openness to discuss EoL; conceptualizations of quality EoL care extended to include, and emphasise, individual values; and staff's role in EoL decision-making became increasingly perceived in terms of facilitating preparation for future care. In addition, reflective exercises prompted emotional and cognitive mechanisms influencing change, for example, through relating personally to, and imagining others' views of, EoL care.

**Conclusion:** Using reflection and knowledge exchange to learn both about themselves and from others gave participants opportunity to build interest and confidence for EoL conversations but also highlighted issues of contention and areas of development where the organisational context is central. The change continuums in our findings point out key facets to consider in staff EoL competence-building efforts, while the mechanisms provide insight into ways in which such competence might be fostered.

**Keywords:** End-of-life care, elder care, reflection, communication, staff competence

## Abstract 19

### The Representation of Palliative Care by Practice, Policy and Advocacy Organisations: Definitional Variations and Discursive Tensions

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**Background:** Evidence suggests that a lack of clarity surrounding the meaning of palliative care persists as a potential obstacle for those in need of palliative care.

**Aims:** To examine the representations of palliative care within the online information spread by palliative care policy, advocacy, and practice organisations in Flanders, to detect elements of congruence, ambivalence, and tension within and between these representations and to identify and interpret the discourses at play.

**Methods:** In collaboration with a multidisciplinary research team of 7 people, an inventory of organisations, divided into 7 different sectors, was made. Through the purposive sampling technique of maximum variation, websites were explored in cycles of 7 organisations (one per sector) until theoretical saturation was obtained. In total, 56 organisations were analysed using the qualitative technique of discourse-theoretical analysis.

**Results:** Discrepancies were found in the way palliative care was defined in relation to curative, end-of-life, terminal, and supportive care. Yet, beyond these definitional variations, meaning was also generated through the representation of palliative care as a culture, connected to a holistic ontology externalised in the practice of 'total care', the values of compassion and openness and the positioning of the palliative patient as firmly embedded within a social context. However,

tensions arose around the concepts of autonomy, a natural death and an emphasis on the quality of life away from death and dying.

**Conclusion:** These discursive tensions, together and in relation with the definitional variations, suggest that the online information of palliative care can be seen as a potential source of confusion for the public. This analysis provides insights that may help to improve clarity towards the public.

**Keywords:** Online information, palliative care, discourse-theoretical analysis

### Funding

This study is part of the project ‘CAPACITY: Flanders Project to Develop Capacity in Palliative Care Across Society’, a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. This study is supported by a grant from the Research Foundation – Flanders, file number S002219N.

### Abstract 20

#### Compassionate Communities – From Frailty to Community Resilience

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**Aim:** To ensure social inclusion and integrated community membership that supports people to live well within our communities to the very end of our lives.

**Approach:** • Increase ‘Community Engagement and Development’ through relationship building, raising awareness, and grassroots initiatives. • Improve ‘Public Education’ aimed at increasing ‘death literacy’ and ‘health literacy’. • Enable ‘Social Change’ through collaboration and adoption of the Compassionate Cities Charter (CCC).

**Results:** • Befriending scheme supporting 40 matches annually, 200 trained befrienders. • Active citizenship produces well-being benefits for recipients of support and those providing it. • Feelings of loneliness impacted with just ‘tea and a chat’. • 88 events with 14,036 engaged. • Awareness and education develop change agents through transference of knowledge and

experience. • The CCC facilitates collaboration with schools and businesses. • Project Board with 13 members from palliative and end-of-life care, older people’s care and social services; community services, housing, and education.

**Lessons Learned:** Impact within deprived areas can be increased. Health inequalities data and research have influenced future plans to focus on areas of social housing.

Our challenge is to further facilitate ways people can reach out to others by connecting resources, removing obstacles, educating and developing resilience. Taking the learning forward, a ‘Compassionate Watch’ model has been developed.

Opening the dialogue on death through ‘Death Cafés’ has been rebranded as ‘Dying to Talk Cafés’ to encourage increased participation.

COVID has brought into sharp focus the importance of palliative care and end-of-life care and empowered deployment of local resources and collaborative working. The learning has potential to accelerate community development to support people during times of health crisis and loss.

**Keywords:** Compassionate communities, public education, social change, community development

### Abstract 21

#### Bereavement Care After In-Hospital Death: A Systematic Review

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**Background:** In 2017, around 27,900 persons (45%) died in hospitals located in Flanders (Belgium). A hospital is characterised with different dying trajectories; some unexpected while others are anticipated.

**Aim(s):** To synthesise current evidence regarding bereavement care for relatives of patients who died in a hospital.

**Methods:** A mixed-method review was completed using standard procedures followed by a process of data extraction and synthesis. Using predefined search terms, literature was searched from 4 electronic databases (PubMed, Web of Science, CINAHL, and Embase) between January 2011 and April 2020. Reference lists from relevant articles were cross-checked and pertinent journals hand searched for articles.

**Results:** In total, 15 studies were included uncovering a range of practices, individual, and system-related barriers and facilitators. Most bereavement care was offered at the time immediately after the death, though, the follow-up of bereaved relatives was less routinely offered. Furthermore, the practices varied in approach, were not evidence-based, and poorly evaluated; therefore, creating a void for those most in need.

**Discussion/conclusion:** This review identified that largely as a result of study design, our knowledge on bereavement care in a hospital setting remains limited. In-hospital bereavement care is unsatisfactory and a 'best practice' model has not been determined yet. Further research is needed to investigate the type of bereavement care desired by bereaved relatives. In addition, the effectiveness of bereavement care services must be evaluated and a reevaluation of the current workforce model is suggested.

**Keywords:** Bereavement care, hospital, relatives, risk assessment, systematic review, Belgium

### Funding

This research received funding from 'Kom op tegen Kanker'.

### Abstract 22

#### The Impact of Poverty on End of Life and Bereavement Experiences: Lived Experience of Bereaved Individuals and Professionals Working in Low-Income Communities in the United Kingdom

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**Background:** Research shows that people living with severe economic disadvantage are less likely

to access palliative care services in the United Kingdom and that funeral poverty is growing. However, little is understood about the ways in which the structural, social, and economic aspects of poverty impact upon preparing for end of life, and experiences of dying and bereavement. While public health approaches to palliative care and 'death awareness' initiatives encourage wider acceptance of the need to prepare for end of life, there is a need to examine the relevance of these approaches to people struggling to live well.

**Aims:** This study examines the notion of 'a good death' within low-income communities, and the ways in which poverty affects attitudes towards, and experiences of, death and dying.

**Methods:** Taking a qualitative and engaged approach, exploratory workshops were held bringing together health care professionals, voluntary organisations, and community groups to share existing knowledge and identify research priorities. Qualitative interviews were then carried out with 10 professionals supporting individuals through end-of-life and bereavement in low-income communities (e.g. funeral directors, faith leaders, advice workers) and 10 bereaved individuals with experience of funeral poverty. Interviews were conducted via phone/video call and data include experiences of end of life and bereavement both before and during the pandemic.

**Results:** This article will present early findings and provide evidence of the impact of poverty on experiences of death and dying at different stages of the life course; including concerns around preparing for death, experiences of end of life, and bereavement.

**Discussion:** This paper will consider whether some public health approaches to palliative care might inadvertently increase inequalities in access to care and support, and whether specific approaches may be needed to address the concerns of people on a low income in relation to a 'good death'.

**Keywords:** Poverty, end of life, public health, palliative care, death awareness, community

### Funding

This research is being conducted as part of a fellowship funded by the Wellcome Trust.



## Abstract 23

### A Framework for Adult Bereavement Care in Ireland. Policy and Planning Response in a COVID and Post-COVID-19 Ireland

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**Aims/goal of the work:** The COVID-19 pandemic has challenged how we address bereavement and grieving in Ireland. Understanding how grief impacts in the intermediate and long-term is an issue of national importance. Planning will be required to meet emergent needs and to support communities. This project aimed to develop a national public health framework for Bereavement Care

**Design, methods, and approach taken:** The framework was based on literature and developed through a national collaborative process with organisations and people at all levels of bereavement care, including state and voluntary sectors across Ireland. A working group of 16 representatives of organisations drafted the framework and supporting materials. The 4-level public health framework sets out needs and responses for *All, Some & Few* bereaved people. A national consultation was held.

**Results:** The national consultation received 56 responses from a wide range of professionals working in bereavement care in Ireland. An overwhelmingly positive response was received; 96% to 100% of respondents reported that they understood the framework and 94% could place their service within the tiered framework.

**Conclusion/lessons learned:** This national framework provides a structure for planning short-term and more long-term responses and services to meet bereaved people's needs in a COVID and post-COVID-19 Ireland. However, we need a whole of government response to coordinate, progress, and embed innovative, evidence-based solutions to issues which arise. Specific to the COVID experience there are opportunities for public grief education and first-line services (Level 1). Based on predictions for difficulties in grief through lack of social support and other complexity there is also a requirement for investment in skills training and services at Levels 2, 3, and 4 of the bereavement model.

The IHF has set out 7 policy pillars to shape an approach to policy on end of life and bereavement issues in Ireland. They advocate for the development of a new robust strategy taking into consideration the views of the public, the State, and those dealing professionally with end of life in all care settings, in palliative and bereavement care.

**Keywords:** Bereavement care, public health approach, framework

## Abstract 24

### Responding to Covid-19 Bereavement in Southern Ireland: An Approach for the Whole Population

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**Background:** The IHF Bereavement Support Line (BSL) was set up in April 2020 with the HSE to meet anticipated needs of people bereaved by Covid-19 losses.

Social support is a strong determinant of psychosocial adjustment following bereavement.<sup>1</sup> In a recent study of bereaved people in Australia and Ireland, the majority of respondents (94-80%) reported that family and friends were their main source of support.<sup>2</sup> Only between 5% and 19% sought support from professional services. A public health approach to loss recognises that the normal resources of family, friends, and community are adequate to support the majority of bereaved people in normal circumstances.<sup>3</sup>

Bereavement guidance recommends a tiered approach to service development.<sup>4,5</sup> Level 1/ Universal corresponds to an approach that educates and strengthens public knowledge of bereavement and signposts those in need of intervention to assessment and treatment services. The BSL was designed as an innovative, level 1 service based on Psychological First Aid principles and knowledge of bereavement theory and reactions.<sup>6</sup> Its aim was to provide a supportive compassionate listening service, education advice, and signposting to practical, community, and mental health resources.

**Aim:** The aim was to evaluate the pilot phase of the BSL.

**Method:** A reflective learning mixed-methods approach was used. Service data were analysed. All stake holders were interviewed: IHF board members, managers, and staff. Volunteers were surveyed and interviewed to provide insight into their experience of training, supervision, knowledge of models used, skills, personal attitudes, and the cognitive and emotional impact of being a volunteer on the line. A thematic analysis was applied to the qualitative data.

**Results:** Preliminary evidence to date is that the BSL meets a national need, and PFA provides a useful framework for training and delivery. Volunteers find the work challenging but are using supervision and are continuing to volunteer. Full results will be available by November 2020.

**Keywords:** Bereavement, loss, Covid-19

## Abstract 25

### Wellness Together Project

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**Introduction:** There are many things that can pull us away from the ‘solid self’, daily in a palliative care environment, where families and patients are going through the most stressful time of their lives – the ‘solid self’ being the self that is resilient, grounded, and works well through a busy day.

**Aims:** The aim of Wellness Together is to assist staff to access a solid self.

#### Objectives:

- To build awareness among staff about their well-being.
- To provide staff with a common language to discuss well-being.
- To empower staff to return to the solid self when ‘pulled away’.

Design, method, and approaches taken: Wellness is introduced using artwork – the image is a mature tree, with various parts of the tree having significance to our emotional wellness. Feedback from staff has indicated how the image of a tree supports

them to recognise where they are in their own process of wellness. For example, solid like the trunk or stressed and triggered like the branches.

**Method and Approaches:** The trunk represents the solid or resilient part of us. The branches represent the triggering thoughts we may have. The leaves represent the feelings that arise. Finally, the roots represent the ‘5-minute practice’ that staff do each day to bring them back to the solid self.

There are 10 different daily practices (of 5-min duration). Each is practised for 5 weeks. Every practice has an audio piece that you can follow at home or at work.

**Results:** This Wellness Together project started in 2018 mainly in small groups and individually. Results thus far demonstrate that the more stress a staff member is under, the more they identify, engage, and benefit from this process.

When staff have engaged in this process, it has very quickly given us a shared language to easily and informally discuss and practice well-being.

**Conclusion:** Change in the practice of well-being is recognised as slow and this project is part of a long-term plan to move from information to the integration of the process of well-being. Wellness together acts as a reminder to come back again and again to the practices that keeps us well.

## Abstract 26

### Co-design and Implementation of an Exercise Intervention for Women With Ovarian Cancer

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**Background:** Ovarian cancer is the leading cause of mortality among gynaecologic cancers in developed countries and the seventh most common cancer worldwide with nearly 240,000 women diagnosed each year. Although it is recognised that engaging in exercise results in positive health care

outcomes, women with ovarian cancer are reluctant to participate. No evidence currently exists focusing on how to successfully implement an exercise intervention programme for patients with ovarian cancer, using a co-design approach. There is a requirement for the implementation of such programmes within the health care setting as engagement in such interventions has positive health care outcomes for women with ovarian cancer both during and following treatment.

**Aim:** To implement and evaluate a co-designed exercise intervention for women with ovarian cancer.

**Methods:** The Medical Research Council guidelines for developing complex interventions were used to guide the development and implementation of the intervention. This single-centre study employed a mixed-methods research design and consisted of Stage 1-A realist literature review; Stage 2 – co-design of the implementation of an exercise intervention with women following treatment for ovarian cancer, their carer's and health care professionals; Stage 3 – the feasibility of implementation and evaluation of the co-designed exercise intervention; and Stage 4 – an economic costing of the intervention.

**Results:** This study will highlight key issues in relation to the implementation of an exercise intervention within this patient population.

**Conclusions:** This study will inform future research on the implementation of exercise interventions for this patient population. It is anticipated that this intervention will be implemented into practice as part of standard care for this group of patients.

## Abstract 27

### A Public Health Hazard: If in Jurisdictions Permitting Assisted Dying (AD) Palliative Care (PC) Rejects AD, all End-of-Life Care May Suffer

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**Background:** For international palliative care (PC) organisations, euthanasia and/or assisted suicide (EAS) are 'incompatible with the very foundations of PC'. Yet, 250 million people worldwide now live in EAS-permissive jurisdictions and in many others EAS is on the societal agenda. In current or future EAS-permissive environments, PC organisations have 3 options: (1) keep excluding EAS from PC, (2) as in the Netherlands, leave involvement in EAS to individual caregivers who may act themselves or call in the Expertisecentrum Euthanasie, or (3) as in Belgium, embed EAS in PC.

**Aim:** To explore the public health issues raised by the controversial PC/EAS relationship.

**Methods:** Reviewing: (1) the essentialist (epistemological, historical, doctrinal, conceptual, and ethical) arguments to exclude EAS from PC; (2) the factual PC/EAS relationship in EAS-permissive jurisdictions.

**Results:** (1) Intellectually, several essentialist objections to PC accepting EAS are problematic. (2) Empirically, in Flanders (Belgium), EAS occurs 3 times more after a PC pathway than after nonspecialised end-of-life (EOL) care and, as in Oregon and Washington, more than 70% of EAS are preceded by professional PC. In the Netherlands, no precise epidemiological data are extant, but studies report that PC workers are usually associated with EAS cases.

**Conclusions:** (1) EAS seamlessly following conventional PC serves the continuity of care and the primacy of patient values. (2) Pragmatically, if in future EAS-permissive jurisdictions PC excludes EAS, EAS will be practised only by caregivers who are likely less professionally competent for EOL care. This would logically have 2 adverse consequences: (1) patients who demand the option of EAS will be nudged to shun professional PC and may thus not receive optimal EOL care and (2) EAS will likely be less practised in a PC spirit of 'total care'. Thus, the quality of *all* EOL care is likely to decline. PC organisations must confront these ethical and practical issues with open minds.

**Keywords:** Public health, palliative care, euthanasia

**Abstract 28****Improving End-of-Life Care in the Hospital Setting****Author:** *Mary O'Kane*<sup>1\*</sup><sup>1</sup>Macmillan End of Life Care Facilitator, Northern Health & Social Care Trust, Antrim, UK\*Correspondence should be addressed to: [Mary.OKane@northerntrust.hscni.net](mailto:Mary.OKane@northerntrust.hscni.net)

**Background:** Evidence shows that the majority of people with advanced progressive illness would rather die at home. However, 47% of people are still dying in acute hospitals, which highlights the need to improve early identification of end-of-life (EoL) care. This bespoke EoL care model impacts positively on patients, those people important to them, staff and the wider organisation.

**Aim:** The aim within the acute hospital setting is to identify and improve the quality of person-centred care of people who may be in the last year of life, including those in the dying phase. These patients will have an end-of-life management plan in place to optimise the right care in the right place, at the right time and 'live well until they die'.

**Method:** The EoL care model has 4 steps:

1. Identifying those patients who may be in the last year of life.
2. Ensuring the care of the dying is compliant with national guidance.
3. Capturing the experience of bereaved relatives through audit.
4. Enhancing knowledge of multidisciplinary staff on EoL care through education and training.

**Results:** We are making this happen by . . .

1. Identifying patients with EoL care needs once admitted to an acute hospital bed.
2. On discharge, these identified patients are referred to the Primary Health Care Team, for a palliative care holistic assessment, and to consider inclusion on the Palliative Care Register.
3. Ensuring those patients dying in hospital receive high-quality care as the NICE NG31 is operationalized through the end-of-life care medical and nursing management plans.
4. Improving what we do in the future, by capturing through audit the experience of bereaved relatives whose loved ones have died in hospital.

This work is supported by an implementation plan, measurement plan, and an on-line resource pack including supporting tools.

**Conclusion:** Since January 2018, the EoL care model has been scaled and spread across acute 10 wards. Using best practice tools, on average 26 patients per month are identified as having end-of-life care needs.

These patients have an average length of stay of 5.0 days, and an average cost of care of £2,577 per patient. This is compared to 7.2 days length of stay and £4,829 cost of care per patient for those patients who have not been identified through the EoL care model.

The average monthly avoided bed days and costs are as a result of implementation of the EoL care model, respectively, are – 57.2 days and £58,552. Per annum, this equates to 686 days and £702,624

**Keywords:** End-of-life care model, improving outcomes, early identification, bereaved relatives experience

**Abstract 29****Rehabilitative Palliative Care as a Health-Promoting Approach***Dr Karen Clarke, Chief Executive, St Michael's Hospice, East Sussex, UK*Correspondence should be addressed to: [kclarke@stmichaelsghospice.com](mailto:kclarke@stmichaelsghospice.com)

**Background:** Hospices face significant shifts in demography and illness and need to find innovative and sustainable ways to respond. Health-promoting palliative care (HPPC) and rehabilitative palliative care (RPC) call for a paradigm shift in palliative care provision to empower both the individuals living with serious, life-limiting illness, and the communities that support them.

**Aims:** Assess whether RPC offers an opportunity to integrate HPPC in a UK hospice in-patient setting.

**Methods:** Three inquiries were undertaken using a participatory worldview perspective:

1. Participatory action research: a co-operative inquiry group (CIG) planned and implemented ways to integrate RPC.

2. Thematic analysis: to examine the facilitators and barriers to implementation of RPC.
3. Literature review: assessed whether these factors were present in other studies.

The alignment and dissonance between HPPC and RPC were also examined.

**Results:** A postintervention review indicated that RPC had been implemented, but there was conflict, also identified in the literature, between a model perceived to be focused on caring (palliative), and one based on enabling (rehabilitation).

Rosenberg and Yates' (2010) model was expanded to illustrate how the components of health promotion are also applicable to RPC.

Alignment between HPPC and RPC was presented:

- Democratic, empowering, participatory.
- Focused on enablement, control, choice, and independence.
- Emphasising social interaction.
- Encouraging individuals to become active participants in their care.
- Interdisciplinary and inclusive: professionals, patients, families, communities, and volunteers.

Discord between the 2 approaches was examined and alternative perspectives presented.

**Conclusion:** Despite its close associations with community initiatives, the principles of HPPC can be integrated in a hospice in-patient setting using RPC.

**Keywords:** Health-promoting palliative care, rehabilitative palliative care, participatory action research, co-operative inquiry group

### Abstract 30

#### Reflections From Children and Older Adults Participating in Community-Based Arts Initiatives About Dying, Death, and Loss in Sweden

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**Background:** Sweden's end-of-life (EoL) care is increasingly professionalised and specialised, with little community engagement. Although an ageing society, Sweden has few intergenerational meeting places. To support community engagement with EoL-issues and create opportunities for intergenerational interaction, a community-based initiative called Studio DöBra, was developed in which children (9 years old) and older adults (mostly 80+) engaged with topics related to dying, death, and loss through shared arts activities.

**Aim:** Based on analysis of empirical data, we discuss how children and older adults motivated their Studio DöBra participation, their experiences of participating, and ways in which they were affected by participation.

**Methods:** Two Studio DöBra iterations were developed (2016, 2018) in different Swedish cities, by project groups comprised of the first author and representatives from relevant community organisations, using a community-based participatory research approach. Each iteration engaged 8 children and 8 older adults in a series of 5 2-hour workshops. Older adults, children, and their parents were interviewed after each iteration. Data were analysed inductively, guided by interpretive description.

**Results:** Participants acted with agency in connecting across generations and in creating spaces for engaging with EoL-issues in the initiative and also in their social networks. Participants reflected on a changing sense of community through new intergenerational connections, and expressed a desire to maintain these.

**Conclusion:** Although findings are in line with the goals of the initiative, sustainability challenges remain. Children and older adults rely on support from community organisations to maintain intergenerational meeting places and support engagement with EoL issues.

**Keywords:** EoL engagement, intergenerational interaction, community-based participatory research

#### Funding

FORTE 2014-4071; Investor AB 2-2314/2013; Stockholm City Elder Care Bureau 243-662/2015

**Abstract 31****Using Elements of Play in Arts Activities to Engage Communities With End-of-Life Issues**

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**Background:** End-of-life (EoL) issues can be difficult to talk about and arts have been found to offer alternative ways of engaging with them. However, little is known about the mechanisms through which this occurs. In *Studio DöBra*, a Swedish community-based intergenerational initiative, children (9 year old) and older adults (mostly 80+) engaged with EoL-issues through arts activities in a series of 5 2-hour workshops. Studio DöBra was developed through participatory action research in a collaboration between first author and partners from community organisations. Initial analysis indicated that play elements were central in arts activities.

**Aim:** We used abductive analysis, moving between empirical data and existing play theories, to investigate how partners and participants used play elements in arts activities to engage with EoL-issues.

**Methods:** Two Studio DöBra iterations were held (2016, 2018) in different communities. Qualitative data were generated through participant observations of arts activities, partners' reflective meetings, and follow-up interviews with partners, children, and older adults.

**Results:** We found 4 distinct play-dynamics: (1) participants moved in and out of playful modes in engaging with EoL-issues in arts activities; (2) partners tried to balance restrictions and freedoms in, for example, topics and arts processes, to stimulate participants to independently execute arts activities and engage with EoL-issues; (3) the definite and abstract nature of death was approached through a combination of imagination and sharing personal experiences; (4) Collective arts processes and products contributed to a sense of community which continued after Studio DöBra.

**Conclusion:** This study contributes insight into the underlying dynamics through which arts activities support or inhibit engagement with EoL-issues in community contexts.

**Keywords:** EoL engagement, intergenerational, arts, play

**Funding**

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**Abstract 32****Maintaining Palliative Care Through COVID by Resourcing Doctors**

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**Aim:** To ensure high-quality palliative care during COVID-19 by equipping junior doctors.

**Design:** Maximising public health and delivery of palliative care requires professional awareness among doctors.

COVID-related service disruption led to a greater proportion of specialist palliative care being undertaken in the acute hospital. Medical staff managed an increased volume and complexity of palliative care patients; therefore, remote teaching programme was initiated for newly started interimFY1 doctors (iFY1s).

They completed online learning resources in palliative care including symptom control, emergencies, and COVID-19. Doctors undertook ward-based experience and were offered a small group Zoom session with the Specialist Palliative Care Team (SPCT).

Online questionnaires were completed and results analysed.

**Results:** Doctors experienced improved confidence in managing palliative patients. Prior to starting 88% felt not so confident 12% somewhat confident, whereas afterwards 76% somewhat confident and 24% very confident.

Main areas of improvement were prescribing, managing symptoms at EOL, accessing resources and the role of the SPCT in addition to managing emergencies.

**Lessons:** The challenges of accessing resources and remote learning were balanced with benefits of personal experience in the practice and ethos of palliative care through individual encounters, promoting knowledge, and compassion. Signposting of resources and experience in establishing and communicating ceilings of care provided a framework and tools for quality care.

Doctors maximised their exposure in a protected setting and learned to treat as well as advocate for their patients, particularly in the absence of family members. Palliative care comes into its own in adversity and the lessons learned early shape a doctors' future practice. Using opportunities to instil professional awareness around palliative care benefits patients and improves overall delivery of the service.

**Keywords:** COVID, education

### Abstract 33

#### Evaluating the Availability, Quality, and Feasibility of Death Certificate Data to Study Place of Death in Latin America: a Study of 19 Countries

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**Background:** Developing countries face many challenges in end-of-life care in people with serious or life-threatening illnesses and in relatively few Latin American countries place of death (PoD) has been studied. Previous death certificate studies in Europe have shown the value of using death certificates for studying PoD. This article aims to describe the availability of death certificate data and evaluate their feasibility to study PoD in Latin America (LA).

**Methods:** Death certificate forms were collected in 19 LA countries and studied regarding how

PoD is recorded. In addition, if possible, the digital data files containing all deaths of 1 year for all these countries were collected. The quality of the data was assessed using completeness, number of ill-defined causes of death and timeliness. If completeness is above 90% and percentage of ill-defined causes of death is below 10%, the data were considered of high quality (below 70% or above 20%, respectively, were classified as low quality). The availability of variables possibly associated with PoD such as civil status, age, gender, education level, cause of death and region of death, and/or residence, was studied.

**Results:** All 19 countries provided death certificate forms and 18 registered PoD on the certificate. A distinction between 'Hospital/Healthcare institution', 'Home' and 'Other place' is possible in all countries. Digital data files with death certificate data were available in 13 countries. No fees had to be paid to obtain the data files. The data are considered of high quality for 3 countries, medium quality for 7 countries, and low quality for 3 countries. Place of death categories and most of the predetermined factors possibly associated to PoD are included in the available data files.

**Conclusion:** Death certificate data are available in most LA countries and provide a good opportunity to study PoD and associated factors.

**Keywords:** Place of death, death certificate data, Latin America, developing countries, palliative care, end-of-life care

### Abstract 34

#### Exploring Young Adults Understanding of Palliative Care: A Mixed-Methods Study Employing an Integrated Theoretical Model

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**Background/Aim:** Despite global recognition of palliative care as an exigent societal issue

warranting consideration within a wider public health context, young adults understanding of palliative care has not been gauged. The aim of this study was to gain insight into what influences young adult's understanding of palliative care and explore inhibiting and facilitating factors for future engagement.

**Methods:** An integrated theoretical model comprising the socio ecological model (SEM) and the theory of planned behaviour (TPB) guided the research. The inclusion of the TPB at the individual levels of the SEM provided a framework for the measurement of knowledge attitudes and perceptions via an online cross-sectional survey of young adults. Contextual influences relating to the outer layers of the SEM were explored through one-to-one interviews with inferences developed from the integration of both data sets. Statistical analysis of the survey data ( $n=859$ ) preceded thematic analysis of the interviews ( $n=24$ ) using a Framework Approach.

**Results:** Knowledge deficits were identified demonstrating an uninformed rather than misinformed group. The absence of a firm knowledge base to inform decisions, skills to navigate social situations, and opportunity to connect within communities allowed a cultural norm to prevail that placed palliative care outside of participants' relevance and reach. They wanted to know more about palliative care albeit as an unexplored issue. They suggested this could be enabled by targeting layers of influence relating to social networks, educational systems, and cultural taboos surrounding death, dying, and loss.

**Conclusion:** The use of an integrated theoretical model enabled the identification of key determinants that explain and predict young adults understanding and engagement with palliative care. The mixed-methods provided specificity to the outer layers of the SEM informing a public health approach to extending the reach of palliative care.

**Keywords:** Palliative care, public health, young adults, knowledge, attitude

### Funding

This study was funded by the Department for Employment and Learning in Northern Ireland as a PhD study.

### Abstract 35

#### Same, Same But Different? Changes in Community-Dwelling, Older Adults' End-of-Life Preferences Over Time

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**Background:** End-of-life (EoL) preferences may change over time due to, for example, illness progression or life events. Research on stability of EoL preferences has largely focused on life-sustaining treatments in seriously ill patients or medical decision-making based on hypothetical illness scenarios and possible treatment options.

**Aim:** To explore if and how community-dwelling, older adults' prioritizations and reasoning about preferences for future EoL care change over time.

**Methods:** This study focused on engaging older, community-dwelling adults without imminent EoL care needs in conversations about future EoL care. At 2 interview timepoints (T1 and T2) 6 to 12 months apart, 52 individuals were asked to reflect on what would be important to them at the EoL, both in an open conversation and while using the DöBra cards, a Swedish version of the GoWish cards. Mixed methods were used to compare rankings of card statements and reasoning about these choices at T1 and T2. Stability in ranking was calculated as number of card statements reoccurring in the top-10 priorities at both timepoints.

**Results:** Stability in the top-10 ranked cards ranged from 20% to 80%, median 60%. On a group level, the most frequently prioritised card items were most likely to reoccur, as were those most highly prioritised at T1. Demographic variables, change in health status, time elapsed or level of card use between interviews, were not related to stability in card rankings. Reoccurring card choices were not always explained by similar reasoning, and a change in card choices could be motivated in various ways.

**Discussion:** Combining longitudinal exploration of DöBra card rankings with underlying reasoning



about EoL preferences over time furthers knowledge on the dynamics between values and preferences in EoL decision-making. The importance of a conversation-based approach to advance care planning was illustrated as participants' values and underlying reasoning were sometimes stable even when card choices were not.

**Keywords:** End-of-life preferences, advance care planning, community-dwellers

### Funding

The main source of funding for this study was the Swedish Research Council for Health, Welfare, and Working Life.

### Abstract 36

#### Incorporating Virtual Reality Into a Physical Exercise Programme for Patients With Parkinson's Disease in an Outpatient Palliative Care Setting

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**Introduction:** Parkinson's is a neurological disorder that leads to progressive disability. Exercise programmes may be an effective strategy to delay or reverse functional decline for patients with Parkinson's. Virtual reality (VR) technology is proposed as a new rehabilitation tool with a possible added value to traditional physiotherapy exercise approaches.

**Aim:** To assess the feasibility and potential effectiveness of a VR intervention as part of a physiotherapy led exercise programme aimed at improving functional ability (balance and gait) in patients with Parkinson's.

**Methods:** A small-scale feasibility study with a single-patient cohort using a pretest-posttest design. The VR exercise programme ran for 8 weeks at Marie Curie Hospice Belfast. Participants completed timed tasks related to balance and gait and fed back on the acceptability of the programme. Artificial Intelligence was also integrated into the VR programme to ensure personalised rehabilitation training for each patient through automatic changes in levels of difficulty. The timing of tasks

was incorporated into the existing software to enable performance monitoring.

**Results:** Five patients with mild to moderate Parkinson's disease were invited to participate in the study (3:2 female: male; median age 55 years; Hoehn & Yahr stages 11 and 111). Four patients completed the programme. All 4 patients showed an improvement in functionality (range of improvement of timed tasks 3.95-57.27s), reported being fully immersed in the exercise programme and loved the fun element of the VR technology.

**Conclusions:** Findings suggest a VR exercise programme is feasible, with multiple potential benefits for patients with Parkinson's.

**Keywords:** Rehabilitation, VR technology, Parkinson's

### Abstract 37

#### Could Kinesiology Taping Help Mitigate Pain in Palliative Care Patients?

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**Background:** The global burden of cancer is growing as people generally live longer with cancer. Symptom management is challenging yet critically important in palliative care. Nonpharmacological alternatives have become important adjuncts to pharmacotherapy. Kinesiology taping (K-taping) is a nonpharmacological therapeutic technique that involves application of an elastic adhesive cotton-based tape to the skin. Current evidence suggests that K-taping may have a role as an adjunct in the management of pain in palliative care patients.

**Aim:** To assess the effectiveness of using K-tape as an adjunct for pain relief in palliative care patients.

**Methods:** A small-scale feasibility study with a single-patient cohort using a pretest-posttest design. Palliative care patients attending the hospice who presented with pain were offered K-tape application as appropriate. The visual analogue scale (VAS) pain score for each patient was assessed at baseline and following application of K-taping. Furthermore, changes in medication and function were also recorded following K-tape application.

**Results:** Nine patients were invited to participate in the study (6 male: 3 female, median age 69). Four patients reported a decrease in VAS for pain after initial application (range 2–4/10). Five patients reported no change in VAS; however, one of these patients reported an improvement symptomatically in ‘comfort’. Two patients reported a decrease in the use of their prescribed analgesia medication while wearing the *K*-tape and 2 patients reported an improvement in function.

**Conclusions:** Overall, the results of this feasibility study indicate that *K*-taping may be useful as an adjunct in the management of pain in palliative care patients. It offers advantages that include low-cost and over-the-counter availability. *K*-taping can be administered by carers or by patients themselves as this technique is relatively easy to learn. This empowers patients to self-manage their symptoms.

**Keywords:** Kinesiology tape, pain

### Abstract 38

#### Challenges in Qualitative Research With Adults With Migration Background at the End of Life

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**Background:** Research about the specific experiences, challenges, and needs of people with migration background at the end of their lives is important for health research in view of the increasing migration flows in recent decades. Qualitative research designs are particularly suitable – but challenging – for this purpose, as they promise to provide access to the subjective perspectives, relevance, and meanings of this vulnerable population.

**Aims:** A critical examination of the use of qualitative methods on the topic of adults with a migration background at the end of life.

**Methods:** Nineteen articles were identified through a systematic review approach using terms related to ‘end of life’, ‘migrants’, ‘perspectives’ in 3 electronic data bases up to Nov 2019. Included was qualitative research on adults with a migration background at the end of life. We

focused on the individual methodological decisions regarding sampling, analysis methods, and reflexivity of the researchers.

**Results:** We identified issues in 3 areas: the sampling of the migrant groups was determined solely in terms of their ascribed ethnicity. Reflexivity was focused to (1) acknowledgement of the need of asking open questions and/or (2) at least one member of the research team should belong to the studied ethnic group. The analysis method used was purely content-oriented thematic analysis, in which quotations stand ‘for themselves’ without further interpretation, the data were decontextualised and only manifest meanings were taken into account.

**Conclusion:** These methodological decisions lead (1) to a homogenising description of the migrant groups, (2) culture appears as fixed, static property, and (3) is blind to implicit but action-relevant aspects of culture. To dissolve these problematic aspects, greater flexibility and reflexivity will be required in the choice of individual methodological steps.

**Keywords:** People with migration background, end of life, qualitative research methods

### Abstract 39

#### Economic Analysis Shows Value of Volunteering in Palliative Care Day Services

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**Background:** Despite the growth of Day Services in recent years, evidence of their costs and effects is scarce. It is important to establish the value of such services so that health and care decision-makers can make evidence-based resource allocation decisions. Day Service offers supportive care to people with advanced progressive illness who may be approaching the end of life, who are able to remain living in their own home. Interested members of the public are often involved in assisting with transport and nonclinical aspects of service delivery

**Aim:** To establish the costs of Day Services with different service configurations in England, Scotland, and Northern Ireland.

**Methods:** Newly referred attendees to Day Services were recruited into a pragmatic before-and-after descriptive cohort study. Data on costs were collected on health and care use in the 4 weeks preceding attendance using adapted versions of the Client Service Receipt Inventory. Outcomes, cost per attendee/day, and volunteer contribution were also estimated.

**Results:** Thirty-eight participants were recruited and provided detailed follow-up data at both baseline and 4 weeks. The cost per attendee/day ranged from £121 to £190 (excluding volunteer contribution) to £172 to £264 (including volunteer contribution) across the 3 sites. Volunteering constituted between 28% and 38% of the total costs.

**Conclusions:** This study highlights the large contribution made by volunteers in Day Services provision and so demonstrates the value of involving the public in palliative care.

**Keywords:** Volunteer, day services, costs, health economics

### Funding

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### Abstract 40

#### Survey of Palliative Care Provision by Faith-Based Health Facilities in India and Nepal During Covid-19

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**Background:** Faith-based organisations (FBO) contribute substantially to healthcare in low- and middle-income countries (LMIC). WHO worked with FBOs to define the primary care approach in the Alma-Ata Declaration and promotes FBO contributions to care underpinned by values of compassion and altruism, particularly for marginalised communities. Indian and Nepalese FBOs provide palliative care (PC) alongside other services, developing appropriate evidence-based models for remote rural areas and excluded urban groups. Covid-19 poses substantial challenges for FBO services. Initially, lockdown affected more than Covid-19 itself. Patients with advanced illness were unable to access care, supply chains (e.g. for morphine) were disrupted and communities faced hunger because of interrupted food supplies. With cases rising new challenges are emerging. Exploring and recording FBO responses enables good palliative care to be identified. This can inform practice in Covid-19 and future pandemics in LMIC nationally and internationally.

**Aims:** To gain strategic understanding of PC provision by FBO in India and Nepal during the Covid-19 pandemic including:

- Effects of Covid-19 on patients and families with PC needs.
- FBO preparedness for responding to the crisis.
- Impact of the pandemic on PC provision, including challenges and solutions that strengthen PC interventions.

**Methods:** Mixed-method survey of PC provision by FBOs using: provider questionnaires, key informant interviews (KII), and patient questionnaires sent to all FBOs identified as providing PC. Questionnaire results will allow important findings to be explored in depth through KII.

**Results:** The study began with an expert advisory group of senior PC clinicians reviewing the

questionnaires and interview schedules. Field work will be completed by October 2020.

**Conclusions:** Understanding FBO responses and strategies for PC during Covid-19 can enable appropriate public health strategies for LMIC to be defined.

## Abstract 41

### Delivering Community Home-Based Palliative Care in Bangladesh During the Covid-19 Pandemic

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**Aim:** The aim was to understand how community home-based palliative care could be adapted in a pandemic and still address palliative care needs in poor areas of Narayanganj, Bangladesh.

**Design, methods and approach:** Using a case study approach, we gathered data through a survey and interviews with 20 people. Qualitative data were collected to understand lessons from adapting PC services during Covid-19 lockdown. Adaptations to services included training in Covid-19 precautions and communications skills. Home visits were replaced with weekly phone calls to patients by Palliative Care Assistants with doctor/nurse follow-up calls. Medicines were made available locally. Food parcel size was increased and was made available at local shops for patients/carers to collect. Community sensitisations moved online.

**Results:** In the first 3 months of lockdown, more than 1500 calls were made by PCAs to patients and more than 150 nurse/doctor follow-up calls made. One-hundred thirty food parcels and 100 prescriptions were dispensed. Six thousand people were reached with sensitisations. Patient feedback included: ‘Your service is not just a phone call; it is a beacon of hope. I have no one here . . . receiving phone call from you gives me a lot of courage. I believe, you will stand by us in this crisis period like before’. ‘In this lockdown, we had

nothing to eat. But you have distributed food. I am able to eat today only thanks to you’. The team relied on online groups to communicate, exchange information and to cope.

**Conclusion/lessons:** Providing PC support via telephone proved to be a good way to continue services during lockdown. Lessons learned: How to be flexible, adaptable and take on new challenges; Increased understanding of using technology effectively; Increased empathy – realising the difficulty faced by housebound patients; Partnerships with local businesses made access to food and medicine easier; Frequent virtual team meetings were key for the team to overcome their own fears.

**Keywords:** Community-based home care

## Funding

UKAID Direct funding.

## Abstract 42

### EAPC Research Network International Seminar

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**Background:** Refractory breathlessness is a complex and debilitating symptom, associated with a heightened risk of mortality, and greater need for health care intervention in the context of palliative care. Recognition of the role of the caregiver in supporting symptom management with the patient receiving palliative care is essential in achieving collaborative patient goals.

**Aims:** To evaluate a Multidisciplinary Breathlessness Support Service (MBSS), and its impact on breathlessness and self-management skills among individuals and their carers living with refractory breathlessness.

**Design:** Mixed-methods quasi-experimental sequential explanatory design.

**Methods:** People with refractory breathlessness and their carers engaged in a brief intervention (MBSS), service users completed longitudinal questionnaires ( $n=10$ ), medical record audit ( $n=14$ ), and a postdischarge interview ( $n=8$ ). Caregivers ( $n=1$ ) and health care professionals involved in referral to ( $n=2$ ) and delivery of ( $n=3$ ) the MBSS service participated in a cross-sectional interview.

**Results:** Statistically significant improvements in mastery of breathlessness were demonstrated by patient participants in addition to improvements in emotional well-being and self-perceived breathlessness and its impact upon their lives. Interviewees uniformly described positive impacts of service engagement on their functional and emotional well-being, and valued the holistic nature of the assessment and intervention. However, no statistically significant improvements in service users' breathlessness were identified on standardised breathlessness measures.

**Conclusions:** Engagement with this brief, multidisciplinary breathlessness support programme by service users and their carers has been shown to empower patients receiving palliative care to gain mastery over this debilitating symptom. Targeted, multidisciplinary intervention to address breathlessness in the palliative care setting using a holistic framework was valued by participants and their caregivers. Further exploration is needed to examine the scope of delivering this programme in a virtual capacity.

**Keywords:** Breathlessness management, health promotion, empowerment, palliative care

### Abstract 43

#### Psychosocial and Educational Interventions for People With Advanced Cancer and Their Informal Caregivers (Diadic): Protocol for a Phase III Randomized Controlled Trial

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**Background:** Worldwide, millions of people with advanced cancer and their family caregivers are at risk of severe physical and psychological distress. Psychosocial support and education can reduce distress and prevent avoidable healthcare resource use. To date, we lack knowledge on which interventions generate positive outcomes for people with cancer and their informal caregivers' quality of life. This protocol describes the DIAdIC study which will evaluate the effectiveness of 2 psychosocial and educational interventions aimed at improving patient-family caregiver dyads' quality of life.

**Methods:** International multicenter 3-arm randomised controlled trial in 6 European countries.

**Population:** in each country, 156 dyads (936 in total) of people with advanced cancer and their family caregiver will be randomised to one of the 3 study arms.

**Intervention:** the 2 interventions offer tailored psychosocial and educational support for the patient-family caregiver dyad: (1) nurse-led face-to-face intervention consisting of 2 home visits and one telephone session, and (2) web-based intervention, independently completed by the patient-family caregiver dyad in 4 sessions. Both interventions will be compared to standard care. The interventions are based on the American FOCUS intervention which consists of 5 components: family involvement, optimistic outlook, coping effectiveness, uncertainty reduction, and symptom management. The FOCUS intervention will be adapted to the European context.

**Outcome:** primary outcome is self-efficacy and social function of the patient and the family caregiver.

**Discussion:** DIAdIC aims to develop cost-effective interventions that integrate principles of early palliative care and salutogenesis into standard care. By focusing on empowerment of the person with cancer and family caregiver, pressure on professional care providers can be reduced. This project has received funding from the European Union's Horizon 2020 research and innovation programme.

**Abstract 44****The Impact of COVID-19 on an Inpatient Palliative Care Service in a Tertiary Referral Centre**

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**Background:** The COVID-19 global pandemic has resulted in many deaths and simultaneously altered delivery of many health care services.

**Aims:** To audit the impact of the COVID-19 pandemic upon the delivery of specialist palliative care (PC) in a large academic health centre.

**Methods:** Retrospective chart analysis was carried out on all patients on the PC service over a 6-week period (March/April 2020) and compared to the same period in 2019. Patient demographics, outcomes, and number of reviews were collected, and data were analysed using GraphPad Prism.

**Results:** Thirty-three patients with COVID-19 were referred to the PC service during this period. Total number of referrals to the PC service between 2020 and 2019 was similar. ( $n=92$  vs  $n=99$ ). Patients were reviewed on average twice as frequently in the COVID-19 period compared to the equivalent period in 2019. (0.6660 vs 0.3077 reviews per day on service,  $P<.0001$ ). There was no significant difference in the number of documented PC reviews in COVID-19 versus non-COVID-19 patients in 2020 (0.7084 vs 0.6250 reviews per day on service,  $P = .3163$ ). However, COVID-19 patients were reviewed in person 3 times less than non-COVID-19 patients (0.1940 vs 0.6000 reviews per day on service,  $P = .0002$ ). More patients referred during the pandemic period died in hospital compared to 2019 (60.4% vs 33.3%). The median number of days a PC referral was made prior to death was significantly shorter during the pandemic period (4.5 vs 13 days,  $P<.0001$ ).

**Conclusion:** Palliative care service was maintained throughout the pandemic period; however,

patients with COVID-19 had less in person reviews. The increase in total patient reviews during this period may reflect the role of PC in managing serious illness and augmenting communication at a time of patient isolation. However, in planning PC service provision in the ongoing pandemic, the benefit of early referral for all patients requiring specialist PC should be highlighted.

**Abstract 45****Evaluation of a Palliative Care Team Hospital Performance During the Pandemic**

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**Background:** Due to the COVID-19 pandemic, between March 23 and May 2, the government declared a state of emergency. To adjust the response to the expected incremental demand, our Palliative Care Team (PCT) adopted various policies. The PCT works in a suburban acute care hospital with 360 beds. It is the primary hospital for around 180,000 people, and it is the secondary reference for 300,000 people.

During this period, one of the main problems was the lack of health care professionals, as they were infected by the virus or because their primary focus was with COVID-19 patients. Another problem was the necessary use of personal protecting equipment and the need to avoid dissemination of the virus. Therefore, direct patient evaluation has decreased. Regarding the necessary deliver of palliative care the team has assessed and provided for the extra need of drugs and materials, provided electronic devices as an alternative method of communication, established protocols regarding prevalent symptoms, referenced a palliative care professional in the COVID wards, provided psychological support to all patients and families and provided 24-h palliative care consultation.

**Aims:** The aim of this work is to analyse how hospital doctors evaluated the support of the PCT.

**Methods:** Delivered an online survey to doctors working in the wards of the medical department,

questioning: the PCT protocols and if they have used it, the 24-h support of the PCT and if they have used it and how they evaluate the PCT performance.

**Results:** The survey was delivered to 80 doctors with 19 responses. Most doctors worked directly with COVID-19 patients. About 64.7% of respondents have acknowledged the protocols and 63.6% used it; 81.8% considered the protocols useful. Concerning the 24-h support, 53.8% knew about it and 30.8% used it. About 84.6% considered the performance of the PCT greater than 7/10.

**Conclusion:** During the emergency pandemic period, the policies adopted by the PCT seem successful.

**Keywords:** Palliative care, COVID-19, pandemic

### Abstract 46

#### Performance of a Palliative Care Team During the COVID-19 Emergency

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**Background:** Our Palliative Care Team (PCT) promotes integrated care between the hospital and home. Due to the COVID-19 pandemic, between the March 23 and May 2, the government declared a state of emergency.

**Aims:** To analyse how the emergency period affected the performance of the team.

**Methods:** Retrospective study comparing the delivery of care in hospital and at home during the emergency period and similar period in 2019. Statistical analysis used the SPSS programme, version 20.

**Results:** In 2020, there were 96 attended patients (31 in-hospital and 65 domiciliary). In 2019, 100 patients were attended to (43 in-hospital and 57 domiciliary).

**Results comparing 2019 to 2010:** In hospital, the average patient's age and the waiting time was similar (70.3 vs 70.6,  $P=.944$ ; 1.49 vs 1.35 respectively,  $P=.73$ ). Fewer women were attended (46.5% vs 25.8%,  $P=.057$ ). The main causes for referral were pain and guidance of care (23% & 46.5% vs 12% & 67%). Most had oncological diseases (76.7% vs 83.9%,  $P=.32$ ). Family conferences were similar (62.8% vs 64.5%,  $P=.53$ ), although only 25% were face-to-face in 2020 ( $P=.001$ ).

There are more teleconsultations (0% vs 32%,  $P=.001$ ) and psychological support (23% vs 51.6%,  $P=.012$ ). The change in rate of hospital deaths was not significant (48.8% vs 61%,  $P=.205$ ).

In domiciliary care, patient's average age was similar (75 vs 74,  $P=.595$ ) with no difference in gender ( $P=.289$ ). The main disease remains oncological (63.2% vs 66.2%,  $P=.438$ ). Teleconsultations increased (0% vs 27.7%,  $P=.003$ ) and there was a reduction in face-to-face consultations (47.4% vs 16.9%,  $P=.028$ ). Mortality rate was similar (15.8% vs 18.5%,  $P=.812$ ), but deaths at home decreased (66.7% vs 50%,  $P=.66$ ). The psychological support was similar (15.8% vs 12.3%,  $P=.885$ ).

**Conclusion:** The way of delivering care was modified mainly by the use of electronic communication, but did not have implications in the type or the number of patients attended.

**Keywords:** Palliative care, COVID-19, pandemic

### Abstract 47

#### COVID-19: Communities And Organisations: Strange Or Natural Bedfellows?

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How has COVID shown us communities can work in partnership with organisations? This paper will share reflections from a COVID project in a hospice in the United Kingdom that aimed to ensure that people in the community remained as connected as possible to others and

felt the ‘presence’ of care around them despite physical distancing measures.

In the paper, we will explore how necessity and restrictions presented by COVID actually offered us an opportunity to trial a new partnership approach to working together to ensure that people at home or shielding were connected to the community.

The challenges and speed of COVID measures and their impact on every day work meant certain principles of reciprocity and agency that underpin relationship building between organisations and community members became a default rather than were hard won. We will reflect on how the learning and opportunities arising from this project have helped us all learn about community action, including the challenges of innovating between communities and organisations.

**Aims or goal of the work:** To establish a community-based response to COVID-19 pandemic by working in partnership; to establish a learning and experimentation platform for innovation around social models of care; to ensure that at a time of physical distancing people felt supported and cared for by the surrounding community.

**Design, methods, and approach taken:** A community development/action approach was taken, emphasising working with community members, groups and colleagues in partnership, using a ‘learning and reflection’ approach rather than a training one. During this time, a looser programme management approach was taken to models and delivery systems, using volunteers in flexible roles and, rather than managing people, linking affiliated community members together with others whatever their need, skillset or experience. Working in partnership with other groups to share resources and knowledge, training, or liaising with community groups around COVID. Resourcing the response through funding applications so that to help people did not come with greater cost for community members.

**Results:** We have observed a growing confidence in community members associated with this initiative around death, dying and loss, and confidence to help others. Emphasising learning rather than training has introduced a reflective approach where community members support others and introduce new subjects to discuss. We have had a

rise in interest from colleagues in initiatives involving the community, with 4 new projects internally requesting community-based help within a couple of months. We have had a rise in community groups requesting support from us or partnership working with peer-peer bereavement, befriending, and other community-led initiatives around death, dying, and loss.

**Conclusion/lessons learned:** Working with a sense of shared purpose and simple ideas about compassionate care for others during COVID is a key element for changing the way that institutions and community members can work together. Emphasising that anyone who is part of an institution is also part of a community helps to value the lived experience of staff and community members. Having people involved in initiatives that help them make their own connections via ‘learning by doing’ and reflecting on their actions might be a more strategic way to introduce changes than to introduce ‘top-down changes’; relational approaches that emphasise community skillsets work well for emphasising trust and respect, and lead to a more networked approach in the community.

**Keywords:** Community action, partnerships, learning, reflection, community, social innovation, end-of-life care, death literacy, reciprocity

### Abstract 48 Conference Keynote Address

#### Public Health Approaches To Bereavement Care: Through the Lens of the Pandemic

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Until recently, we had surprisingly little data about bereavement as it is lived out in everyday life. We were well informed about the minority who seek support from professional services, but not about the majority who do not. Bereavement was understood as a problem to be solved rather than an experience to be engaged. Our perceptions/strategies for all were largely shaped by the complications that can arise for some, and we paid correspondingly less attention to the experience and resources used by the majority, those who learn to live with their loss.



The public health model of bereavement support has changed this landscape, in terms of knowing who needs bereavement support, who is perceived by bereaved people to have offered them support and was it helpful. Informal care is the bedrock, with formal services supplementing this support. This presentation describes this 'evidence-based' approach focusing on how the findings of a population-based survey has challenged conventional practices around bereavement care and provided evidence that supported public health strategies and policy in countries such as United Kingdom and Ireland and for a traumatic fast progressing terminal illness such as MND. Empirical indicators/directions have encouraged a compassionate community approach to future bereavement support practice and policy.

COVID-19 has brought the focus more acutely on grief, bereavement, and mental health. Many conventional memorialisation practices/rituals have been modified or taken away from the bereaved. However, they were replaced by creative and viable grieving strategies including improved grief literacy and death literacy. Nevertheless, many of the projections of increased complicated grief may be over-estimating the importance of professional support, and under-estimating what family, friends, and neighbours can provide.

Public health approaches to bereavement care are essential if we are to develop relevant, coherent, and comprehensive end-of-life care policies and practices.

**Keywords:** Grief, bereavement support, public health model, compassionate communities, memorialisation, COVID-19, pandemic

### Abstract 49 Conference Keynote Address

#### Public Health and Palliative Care: What do the Public Know and What Lessons can be Learnt?

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**Background:** Palliative care is becoming a public health issue, with global calls for earlier integration in wider health care systems. One way to enable this is to ascertain what the public know and understand about palliative care. International evidence would suggest that palliative care is poorly understood.

**Aim:** To examine public awareness, knowledge, and perceptions of palliative care and to draw on this evidence to examine wider theoretical, methodological, and awareness-raising issues.

**Methods:** A 2-phase, explanatory, sequential mixed-methods design including a cross-sectional survey and qualitative interviews with members of the public. The survey examined sociodemographic characteristics, public awareness, knowledge, and perceptions of palliative care using the PacKs 13-item tool, analysed by factor analysis and nonparametric statistics. Qualitative interviews explored strategies to raise awareness and were analysed thematically.

**Results:** A total of 1201 participants completed the survey (58.3% female, mean age 61 years) and 25 took part in focus groups/interviews. A fifth of participants (20.1%) had previously heard about palliative care and were accurate in their understanding of palliative care. Demographic factors such as being female, higher educated, married, and older, were associated with higher levels of awareness. The most common help misconception was that palliative care was exclusively for people in the last 6 months of life.

**Discussion:** There is a need for public education programmes to provide targeted, accurate, and consistent messages using a full range of media. It is important this is located within a wider socio ecological framework that moves beyond the individual and considers societal engagement across a range of stakeholders at organisational, community, and public policy perspectives. Further work is needed to enhance the evidence base when developing and testing interventions.

**Keywords:** Public health, palliative care

#### Funding

HSC R&D Office and Department of Health NI

## Abstract 50 Conference Keynote Address

### Promoting Palliative Care in Schools

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**Background:** In Scotland, 50.8% of 8 year olds have experienced a bereavement and it is estimated that, in each classroom, there are 2 children with caring responsibilities. Yet, despite the prominence of these experiences in schools, illness, death, and bereavement are not systematically addressed, and school staff report feeling uninformed and unconfident to engage with such issues. Moreover, given the prevalence of death in children's lives, their voices and experiences remain on the periphery of health-promoting palliative care, and this represents a significant gap in understanding associated approaches.

**Methods:** This paper draws on findings from an action research study in 2 Scottish primary schools that explored, implemented, and evaluated models of practice to promote education and

support around death, dying, and bereavement from a health promotion perspective. This involved working with children aged 9 to 12, parents/carers, school staff, and hospice staff in collaborative inquiry to engage in change processes.

**Findings:** The findings identified that children can/want to talk about death and that school communities viewed this as part of their role; yet a number of barriers existed that inhibited such work. As a result, practice innovations were identified that were relevant to the school curriculum and environment and the relationship between hospices and school communities more broadly. These innovations can be understood as health-promoting palliative care activities due to their focus on a whole schools approach that focuses on early intervention and harm reduction.

**Conclusion:** The research demonstrates that schools are in a unique position to engage with children around death, dying, and bereavement and that hospices have expertise to support and advocate for such work. Yet, the capacity of schools to engage in these activities is hampered by death denying curricula, policy and training focus that potentially limits systemic changes to practice.

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