



“There’s a Catch-22”. The complexities of pain management for people with advanced dementia nearing the end of life: a qualitative exploration of physicians’ perspectives

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1 **“There’s a Catch-22”. The complexities of pain management for people with**
2 **advanced dementia nearing the end of life: a qualitative exploration of physicians’**
3 **perspectives**

4

5 **Pain management at end of life in dementia**

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34

35 **What is already known about this topic?**

36 • Pain is prevalent among people with advanced dementia approaching the end of life
37 but is challenging to identify and treat in patients with profound loss of
38 communication who are unable to report the presence, nature and intensity of their
39 pain.

40 • People with advanced dementia are at risk of under-treatment or suboptimal treatment
41 of pain as they approach the end of life.

42 • Untreated pain, or suboptimal treatment of pain, often have deleterious effects on
43 people with advanced dementia including: delirium, sleep disturbance, increased
44 confusion and exacerbation of neuropsychiatric symptoms.

45

46

47 **What this paper adds?**

48 • This study is the first to explore and describe the complexities and challenges
49 experienced by physicians when prescribing for and managing pain in people with
50 advanced dementia who are approaching the end of life, the impact of these challenges
51 on prescribing and treatment approaches, and the strategies used by physicians to
52 overcome these challenges.

53 • Physicians' prescribing and treatment decisions were shaped by patients'
54 comorbidities, ageing physiology, existing medication regimens, physical and
55 cognitive impairments and health status.

56 • Physicians from primary, secondary and hospice care settings made use of knowledge
57 networks across specialties (e.g. palliative care, psychiatry etc.) to inform prescribing
58 and treatment approaches and to overcome the challenges of pain management in this
59 vulnerable patient population.

60

61

62

63 **Implications for practice, theory or policy?**

64 • Physicians' goals in end of life care for people with dementia included optimal pain
65 management. However, the complexity of the patient population can make optimal
66 pain management challenging to achieve in practice.

67 • Physicians' narratives revealed an interactive interface across primary, secondary and
68 hospice care settings and across medical specialties through which knowledge and
69 expertise were exchanged to allow palliative and non-palliative doctors to overcome
70 the challenges of pain management.

- 71 • Promoting cross-specialty knowledge exchange and mentoring can empower non-
72 palliative care physicians to confidently and effectively manage complex palliative
73 care patients in their respective settings.

74

75 **Abstract**

76 **Background:** Pain management is a cornerstone of palliative care. The clinical issues
77 encountered by physicians when managing pain in patients dying with advanced
78 dementia, and how these may impact on prescribing and treatment, are unknown. **Aim:**
79 To explore physicians' experiences of pain management for patients nearing the end of
80 life, the impact of these on prescribing and treatment approaches, and the methods
81 employed to overcome these challenges. **Design:** Qualitative, semi-structured interview
82 study exploring: barriers to and facilitators of pain management, prescribing and
83 treatment decisions, and training needs. Thematic analysis was used to elicit key themes.
84 **Settings/Participants:** Twenty-three physicians, responsible for treating patients with
85 advanced dementia approaching the end of life, were recruited from primary care (**n=9**),
86 psychiatry (**n=7**) and hospice care (**n=7**). **Results:** Six themes emerged: diagnosing pain,
87 complex prescribing and treatment approaches, side-effects and adverse events, route of
88 administration, importance of sharing knowledge and training needs. Knowledge
89 exchange was often practised through liaison with physicians from other specialties.
90 Cross-specialty mentoring, and the creation of knowledge networks were believed to

91 improve pain management in this patient population. **Conclusions:** Pain management in
92 end-stage dementia is complex, requiring cross-population of knowledge between
93 palliative care specialists and non-specialists, in addition to collateral information
94 provided by other health professionals and patients' families. Regular, cost- and time-
95 effective mentoring and ongoing professional development are perceived to be essential
96 in empowering physicians to meet clinical challenges in this area.

97

98 **Keywords:** Dementia; Pain; Pain Management; Physicians; Palliative Care; Frail Elderly

99

100 **Introduction**

101 Dementia is an increasingly challenging global public health concern (1). Worldwide
102 prevalence has reached 46.8 million (2), and projections estimate 74.4 million people
103 living with dementia by 2030 (3). In the United Kingdom (UK), 850,000 people are living
104 with dementia, 19,765 of whom reside in Northern Ireland (NI) (4). The need for
105 appropriate palliative care to manage symptoms, including pain, for people living and
106 dying with dementia is a focus of dementia care strategy in public health policy and is a
107 recognised human right (5-7).

108 Pain is commonly experienced by people with dementia towards the end of life and is
109 predominantly due to the prevalence of age-associated conditions (e.g. osteo- and
110 rheumatoid arthritis, joint disorders, infection), chronic comorbidities (e.g. heart disease,
111 cancer, diabetes) and distressing symptoms including: nausea, dehydration, dysphagia
112 and dyspnoea (8-12). The deleterious impact of undetected, unresolved or untreated pain
113 in people with moderate and advanced dementia has been reported to result in: delirium,
114 sleep disturbance, increased confusion and exacerbation of neuropsychiatric symptoms
115 (13-20). Previous studies have reported inconsistent approaches to pain management for
116 people with dementia (21-24), primarily due to difficulty assessing and diagnosing pain,
117 and lack of clinical data to guide prescribing for patients approaching the end of life (12,
118 25-27). The under-representation of older adults in clinical trials of analgesics may mean
119 that key outcome measures including toxicity and drug action do not accurately reflect
120 their use in patients with multiple comorbidities and significant physical frailty, and can
121 lead to variability in treatment outcomes (28-33). The inclusion of older, comorbid adults
122 in clinical drug trials is attracting increasing research interest (34-36). Little is known
123 about the challenges encountered by physicians when managing pain in people with
124 advanced dementia nearing the end of life; even less is known about the strategies and
125 resources used to overcome these challenges. This study aimed to elucidate this
126 information as part of a wider programme of research into assessing and managing pain
127 in this complex patient group.

128 **Aim**

129 To explore physicians' perspectives of the barriers to managing pain in patients nearing
130 the end of life, the impact of these on patient outcomes and the methods employed to
131 overcome these challenges.

132

133 **Methods**

134

135 *Setting/Participants*

136 Physicians from primary, secondary and hospice care settings were recruited from general
137 practice surgeries (n=5), hospices (n=4) and hospitals (n=4) across four Health and Social
138 Care (HSC) Trusts in NI. Eligible participants were physicians with responsibility for
139 managing pain in patients with advanced dementia who had died or who were
140 approaching the end of life.

141

142 *Sampling and recruitment*

143 A pragmatic approach to sampling was taken in light of the number of practising
144 physicians in NI and the range of medical specialities, departments and care settings in

145 which people with dementia at end of life may be managed, and following a review of
146 sampling frames used in similar studies (37).

147 Seven General Practitioners (GPs) who participated in previous research with members
148 of the research team (Project Management Group [PMG]) were asked to disseminate
149 study information to colleagues in a process of onward referral. In acute care, four
150 consultants (each within a different HSC Trust region) from geriatric medicine (n=2),
151 palliative medicine (n=1) and psychiatry (n=1) disseminated study information to eligible
152 hospital physicians within their HSC catchment area. Four Medical Directors (one in each
153 of the participating hospices) circulated study information to hospice physicians. All
154 physicians who contacted the first author regarding participation were recruited to the
155 study. Physicians who assisted with dissemination of study information did not participate
156 in the study.

157

158 *Ethical approval*

159 The Office for Research Ethics Committees Northern Ireland (ORECNI) granted ethical
160 approval for the study (14/NI/0013). The study protocol and supporting materials were
161 also approved by hospice ethics committees and HSC Trusts.

162

163 *Study design and data collection*

164 Semi-structured, in-person interviews were conducted using an interview guide which
165 allowed flexible exploration of individual experiences within an overarching structure by
166 which commonalities of experience could be identified (38). Interview questions were
167 developed following review of relevant literature and refined in an iterative process of
168 consultation and revision with the PMG which included primary, secondary and hospice
169 care physicians and academics from nursing, palliative care, geriatric medicine and
170 pharmacy. Questions covered: approaches to pain management in people with advanced
171 dementia approaching the end of life, barriers to and facilitators of prescribing for pain
172 and administering analgesics, and training and education needs. The topic guide is
173 presented in Table 1.

174 Physicians were interviewed in their workplace and received Continuing Professional
175 Development (CPD) certificates for participation. Interviews began with a brief
176 exposition of the study aims and objectives, and explanations of ethical approval and the
177 interview process. Each participant provided written, informed consent. Recruitment
178 continued until no further novel data were identified in interviews.

179

180 *Data analysis and validation*

181 Data were collected between June 2014 and September 2015. Interviews were conducted,
182 digitally recorded, transcribed verbatim and analysed by the first author, a researcher with
183 five years' prior training in and experience of designing and conducting qualitative
184 research. Interview duration was on average 18 minutes. Transcripts were checked for
185 accuracy against recordings by KB and HB. Braun and Clarke's paradigm of thematic
186 analysis formed the analytical approach (39). Transcripts were reread several times and
187 line-by-line coding performed to identify recurrent ideas, statements, feelings/sentiments,
188 topics and key words. The first ten scripts were reviewed to ensure that coding uniformly
189 expressed the same ideas, concepts or topics, and a coding frame was developed. Codes
190 from all transcripts were categorised into themes expressing their core concepts. NVivo
191 10 (QSR International (UK) Ltd, Cheshire, UK) software was used to facilitate analysis.
192 Data were independently analysed and verified by KB and CP. Final themes and findings
193 were discussed by the PMG.

194

195 **Results**

196 Twenty-three physicians participated. Physicians' average age was 42.5 years (range 28
197 to 58 years), and they had an average of 17.5 years' clinical experience (range 5 years to
198 31 years). Most were female (n=16; 69.6%). Six (26.1%) had additional postgraduate
199 qualifications. Participant characteristics are presented in Table 2.

200 Six key themes emerged from the interviews: (1) diagnosing pain, (2) complex
201 prescribing and treatment approaches, (3) side-effects and adverse events, (4) route of
202 administration, (5) sharing knowledge and (6) training needs.

203

204 *Diagnosing pain*

205 Difficulty diagnosing pain was the most commonly reported barrier to managing pain
206 appropriately in people with advanced dementia approaching the end of life. Loss of the
207 critical patient-physician pain dialogue and the absence of any obvious physical cause of
208 pain (e.g. fracture, wounds) or painful comorbid condition (e.g. cancer) made it difficult
209 to identify and characterise pain.

210

211 In a patient with dementia, if you have no history or communication from the
212 patient, it's impossible to get an accurate history to be able to identify the character
213 of pain in the way you would be with a patient who could communicate and had
214 understanding. (PHYS011, GP)

215

216 In the absence of patient report, respondents observed for, and interpreted, behavioural
217 and nonverbal signs. All respondents were acutely aware of the limitations of this

218 approach, recognising that many of these indicators could also be expressions of fear,
219 anxiety and other non-pain related distress. Most expressed concern regarding potential
220 misinterpretation of these cues and advocated caution in relying on this information.

221

222 The signs of pain in this particular patient group could be signs of something else
223 as well, and that's where you have to be very careful to recognise what is their
224 normal behaviour and what has changed or what can we link to pain. (PHYS012,
225 Consultant in Palliative Care, Hospice)

226

227 The presence of neuropsychiatric symptoms in these patients further complicated pain
228 diagnosis. Some participants highlighted the potential for misinterpretation of these cues
229 to result in inappropriate treatment, for example, pain relief for emotional distress, whilst
230 others reported uncertainty in decisions to treat the patient for (presumed) pain or for the
231 manifested psychiatric symptoms.

232

233 Saw a patient yesterday or two days ago who appeared to be in pain, she had
234 advanced dementia, I felt she was in the last days of her life and she was lying on

235 the bed occasionally agitated, throwing her arm up around her head. Hard to know
236 if that's pain or not. So do I treat her for pain in that scenario? (PHYS019, GP)

237

238 ***Complex prescribing and treatment approaches***

239 The impact of complex comorbidity profiles, neurodegenerative disease, low body mass
240 index and ageing physiology on the pharmacodynamics and pharmacokinetics of many
241 analgesics were key considerations for physicians.

242

243 In the very severe stages we get people who can be very, very, physically failed
244 and frail, very low body mass, really no musculature, usually sort of dehydrated,
245 usually with sort of poor cardiac output. Often we're not actually sure how much
246 pain relief is getting in to somebody. Often the difference between what you think
247 the analgesic's going to be and what it actually does to a patient in that kind of
248 stage—the difference is quite substantial. (PHYS03, Consultant Psychiatrist,
249 Secondary Care)

250

251 Participants described past experiences in which analgesic effects had been highly
252 unpredictable, resulting in over-treatment for some patients, poor pain control in others
253 and adverse events for a minority.

254 I've had it where I've given one big fellow a very strong painkiller and it floored
255 him; I've seen a wee lady half the size and very frail and actually it wasn't working
256 on her at all. So although I assumed little old ladies need less, it actually went the
257 opposite way. It's really very individual, like with everything, everybody's
258 different (PHYS011, GP).

259

260 Most respondents therefore exercised caution in prescribing, particularly when treating
261 new patients, and many followed the principle 'start low and go slow' using paracetamol
262 (acetaminophen) as the preferred first-line treatment, particularly in cases where pain
263 diagnosis was ambiguous.

264

265 I would start off with maybe a trial of analgesia but I would start off with the
266 mildest form like paracetamol or something just to see if it made a difference. If
267 they seemed to be responding, I suppose I would use the WHO analgesia ladder
268 and just come up very, very cautiously. (PHYS04, GP)

269

270 Pain management was often described as a ‘trial and error’ process in which pain relief
271 was titrated in response to changes in behaviour, nonverbal cues, vocalisation and levels
272 of consciousness. Psychiatrists and GPs found the World Health Organisation (WHO)
273 Analgesic Ladder (40) helpful in guiding upwards titration; hospice physicians relied on
274 their own previous clinical experience and consultation with colleagues and preferred the
275 national Palliative Adult Network Guidelines (PANG) (41). All physicians regularly
276 prescribed a wide range of analgesics including opioid and compound opioid preparations
277 in a variety of formulations including transdermal patches, intramuscular injections and
278 syringe drivers. GPs and psychiatrists often sought advice or confirmation from
279 specialists such as community hospice, palliative medicine and psychogeriatric
280 practitioners when titrating to higher doses.

281

282 If these patients are already on medication for pain it’s like where do you go to
283 augment and increase it? So having input from people who are specialists is always
284 appreciated. (PHSY014, Psychiatrist, Secondary Care)

285

286 *Side-effects and adverse events*

287 Participants described the challenge of prescribing for patients with advanced dementia
288 nearing the end of life as a ‘catch-22’ situation in which multiple symptom control
289 (including pain), was required, with minimal polypharmacy and avoiding drug
290 interactions and adverse and/or side-effects.

291

292 There’s a catch twenty-two, there’s potential for a lot of interactions with the other
293 medication that they are on, then you face the difficulty with the side effects of
294 medications. So it’s really about hitting the balance of making sure that you’re
295 doing the patient no harm and treating their pain. It’s finding that fine line
296 (PHYS07, Psychiatrist, Secondary Care)

297

298 Many patients required a greater degree of pain control than could be provided by
299 paracetamol and other simple analgesics, however; codeine and other opioid-based
300 preparations were deemed to carry a high risk of respiratory depression, sedation,
301 constipation and falls, whilst non-steroidal anti-inflammatory drugs (NSAIDs) were
302 associated with risk of gastric bleeding, cardiovascular and stroke events. Side-effects
303 such as constipation (a trigger for onset of acute delirium) and nausea (difficult to detect
304 in the absence of patient self-report), respiratory depression and sedation were considered
305 highly detrimental to patients and contravened participants’ goals of care.

306

307 The likes of the more codeine-based [preparations], it's the risk of them becoming
308 constipated and making things worse and then I suppose the more heavy
309 morphines and so on, it can just floor them, really wipe them off their feet, more
310 prone to more falls, makes them more drowsy. (PHYS06, Psychiatrist, Secondary
311 Care)

312

313 Most participants reported that these factors restricted choice of suitable analgesics and
314 often resulted in off-label prescribing. Many GPs and psychiatrists found this challenging
315 due to unfamiliarity with off-label uses for palliative purposes, requiring guidance from
316 palliative care specialists.

317

318 [Palliative care] has taught me things about using certain agents, midazolam, for
319 example ... something that isn't used widely in my world but it's used widely in
320 [the] palliative world. (PHYS09, Consultant Psychiatrist, Secondary Care)

321

322 ***Route of administration***

323 All participants reported challenges with routes of administration for patients with
324 dementia approaching the end of life. Oral administration was compromised in patients
325 with significant swallowing difficulties, poor gut absorption, nausea and/or vomiting,
326 impaired consciousness (sedation, coma, sleep or drowsiness), or who refused to take
327 medication.

328

329 ... so perhaps liquids might be refused, tablets may not be taken, they may not be
330 able to take anything orally and they may need medication by a different route.

331 (PHYS015, Consultant in Palliative Care, Hospice)

332

333 Many respondents described difficulty encouraging compliance in patients who lacked
334 capacity to engage in discussion regarding the need for symptom control. Syringe drivers,
335 normally considered when oral administration is not viable, presented a number of
336 complications including: forceful removal by agitated patients, lack of available staff
337 experienced in their set-up and use; and in some cases, lack of access to necessary
338 equipment or resources.

339

340 Intravenous [administration] I would have to say we actually rarely use. The
341 problems being that maintaining venous access in somebody who's failing is a
342 problem, it's often painful and distressing for patient and we open up then risks of
343 infection and so on as well. So we often try and go for, for subcuts if we can, or
344 patches. (PHYS03, Consultant Psychiatrist, Secondary Care)

345

346 Transdermal patches were a preferred route for overcoming the challenges posed by oral
347 and syringe driver routes.

348

349 We're maybe more likely to use medications administered by patch through the
350 skin rather than tablets because it's felt to override the challenges of patients being
351 able to take their oral medication reliably. (PHYS017, Consultant in Palliative
352 Care, Hospice)

353

354 Transdermal patches were considered particularly suitable for agitated patients due to their
355 unobtrusive and non-invasive nature and for avoiding difficulties associated with *pro-re-*
356 *nata* (PRN) prescribing in non-verbal patients.

357

358 We would try and use patches sometimes because they're less noticeable to the
359 patient, and if the pain is more stable that can be a way around it. (PHYS015
360 Consultant in Palliative Care, Hospice)

361

362 Physicians, particularly GPs, highlighted the importance of selecting a route of
363 administration appropriate to a patient's health status and needs, and the need to ensure
364 the availability of healthcare staff appropriately trained to administer and monitor
365 medication via that route.

366

367 You've an issue with trying to select the type of medication you're going to use
368 and you've an issue then with what way you're going to administer it to them and
369 then who's going to manage that and monitor it as well. (PHYS022, GP)

370

371 *Sharing knowledge*

372 All respondents strongly believed that the care of people with dementia approaching the
373 end of life, including pain management, required input from families and healthcare
374 professionals across disciplines. Physicians believed their key responsibility was to
375 provide optimal care for their patients, which included recognising and addressing their

376 own limitations. Narratives revealed an interactive interface across primary, secondary
377 and hospice care settings and medical specialties through which knowledge and expertise
378 were exchanged.

379

380 When it comes to end of life then, we're sharing knowledge, we're the experts in
381 antipsychotic medications and they [palliative medicine physicians] are finding
382 that with people with challenging behaviour, they may need to go that route so
383 we're sharing in terms of cross-populating our knowledge base. (PHYS09,
384 Consultant Psychiatrist, Secondary Care)

385

386 GPs and psychiatrists sought advice from palliative and hospice care physicians and
387 psychogeriatricians regarding: off-label use of analgesics; titration for patients already
388 receiving pain relief; use of opioid preparations; combining pain-relieving agents;
389 combining analgesics with mild sedation; managing background or breakthrough pain;
390 and routes of administration. Hospice physicians sought guidance for particularly
391 complex patients from neurology, psychogeriatrics, palliative pharmacy and psychiatry.
392 In many cases, participants wanted confirmation of their proposed treatment; receiving
393 support from other specialties and knowing they were 'on the right track' with prescribing

394 and treatment increased confidence and job satisfaction. Many enjoyed learning from and
395 sharing their expertise with other doctors outside their care setting and medical specialty.

396

397 I would ring, for example, [the hospice] and speak to one of the consultants and I
398 would ask “This is what I’m thinking of doing, do you think this sounds okay?”
399 And then I would get that advice. It just gives me that bit more confidence that the
400 patient’s getting maybe the best they could get; because I don’t think I’m the best,
401 I think I’m a GP and I think a palliative care consultant would be the best.

402 (PHYS08, GP)

403

404 Families were perceived to hold key collateral information such as patients’ former beliefs
405 about medications, previous pain thresholds, whether they were likely to report pain or
406 ‘suffer in silence’, drug tolerance and allergies, behavioural and nonverbal indicators of
407 pain, and preferred methods of medication delivery.

408

409 We very much work with the families because the families usually know this
410 person to the point that they know what they maybe would have wanted or how

411 they are going to respond so we try and get everybody in on the decision-making.
412 (PHYS012, Consultant in Palliative Care, Hospice)

413

414 Physicians used this knowledge to inform prescribing decisions and to assess treatment
415 response.

416

417 One thing is us giving the families information but the other thing is asking them
418 their perception of whether they perceive that something has helped or not and
419 whether they have noticed any signs of side-effects. They're just better placed—if
420 they're with the person a lot, to identify whether or not the medication has made
421 them confused or that kind of thing. (PHYS017, Consultant in Palliative Care,
422 Hospice)

423

424 ***Training needs***

425 Physicians were dedicated to providing optimal care for patients often within multiple
426 organisational constraints. All respondents believed that the knowledge, skills and
427 expertise required to optimally manage pain in this complex patient population existed
428 within the health professions but were highly dispersed across medical and other

429 disciplines and care-settings. Physicians considered pharmacology,
430 pharmacotherapeutics, managing pain in patients with challenging behaviours, and
431 distinguishing between pain-related and non-pain related behavioural and psychological
432 symptoms of dementia (BSPD), to be key areas for further training. The majority
433 described physician-to-physician mentoring, in the form of regular meetings of an
434 established network of practitioners from across care settings and disciplines to discuss
435 anonymised real patient cases, as an ideal approach to ongoing professional development.

436

437 The best would be experiential learning where you can go on a ward round, discuss
438 a case, ask questions, that's the gold standard. (PHYS012, Consultant in Palliative
439 Care, Hospice)

440

441 Physicians widely believed that this approach would have greater clinical utility and
442 impact than workshops, training days or didactic lectures.

443

444 I think that case-based learning is useful because I think it gets people to think
445 about what they do themselves and how they would manage a particular problem.

446 I think that has more relevance and power in terms of changing what people do for
447 the better. (PHYS015, Consultant in Palliative Care, Hospice)

448

449 **Discussion**

450 To our knowledge this is the first comprehensive exploration of the challenges in pain
451 management for people with advanced dementia approaching the end of life, from
452 physicians' perspectives. People with advanced dementia require the same vigilance in
453 pain management as patients dying with terminal cancer; however, available guidelines
454 offer little advice on how this may be achieved (42-43). Pain control in this patient
455 population can be difficult to achieve and the findings presented here offer greater insight
456 into these challenges from the perspectives of those primarily responsible for this aspect
457 of patient management (44).

458 The gold standard in diagnosing pain is self-report. In advanced dementia, this is rarely
459 available; much of the critical information required to accurately assess, diagnose and
460 target treatment is lost (45). The findings of this study indicate that in the absence of
461 patient report, collateral history from patients' families and other health professionals,
462 along with clinical investigation and interpretation of changes in mood, behaviour, and
463 other nonverbal cues, become important (45-46). However, participants widely
464 acknowledged that many well-recognised behavioural indicators of pain, such as distress,

465 agitation, wailing, screaming, frowning and apathy, are identical to those expressed
466 through anxiety, boredom, frustration and emotional distress (47). Behavioural
467 interpretation leaves room for misinterpretation and potentially inappropriate treatment
468 (47). Physicians' prescribing decisions were also shaped by patients' comorbidities,
469 ageing physiology, existing medication regimens, physical and cognitive impairments and
470 health status, which were perceived to restrict the range and strengths of analgesics that
471 may be safely tolerated (48). Changes in drug pharmacokinetics and pharmacodynamics,
472 and variation in gut absorption and body fat index may result in over-treatment, delayed
473 effects of pain relief and increased risk of side-effects and adverse events, making
474 management complex and uncertain (48). Most physicians adopted a cautious approach
475 to management. Route of administration was reported as problematic in severely
476 cognitively impaired, dying patients. Loss of swallow, patient refusal and altered
477 consciousness often precluded oral administration, whilst syringe driver use was
478 problematic due to forceful removal by agitated or distressed patients and issues regarding
479 availability of appropriately experienced nursing staff to set up and monitor the
480 equipment. Medication delivery via the transdermal route was considered a better
481 alternative.

482 Physicians across specialties and care settings often sought and shared advice and
483 approaches to pain management. Most respondents strongly believed ongoing CPD via
484 mentoring and knowledge exchange using real-patient cases would empower non-

485 palliative specialists to effectively manage patients approaching the end of life. Previous
486 studies have identified a need for further training for healthcare professionals in
487 pharmacology and the use of nonpharmacological treatments, and in discriminating
488 between behavioural and psychological symptoms caused by pain and those which are not
489 pain-related in origin (44,49). The present findings corroborate these suggestions, and
490 provide additional insight into physicians' training preferences.

491 Sharing knowledge extended beyond health professionals; most participants found
492 collateral history provided by families to be helpful in assessing pain and interpreting
493 nonverbal cues. This echoes other studies which report that good communication, shared
494 knowledge and a mutually respectful relationship between the healthcare team and family
495 carers are critical if treatment is to reflect the interests of the dying patient and achieve
496 clinical goals of care (50-51). Some of the above findings echo those reported in the
497 nursing literature, indicating that medical, nursing and other healthcare staff experience
498 similar challenges in assessment and management of pain for patients with dementia and
499 emphasising the need for effective multidisciplinary working and open communication
500 between healthcare professionals (52-55).

501 There are some limitations with this study. The sampling approach may have resulted in
502 a skewed sample of physicians with an interest in, or past experience of, research
503 participation, who felt comfortable talking about professional challenges. We aimed to
504 recruit physicians across acute specialties; the low participation by physicians outside

505 psychiatry (possibly due to staffing pressures and workloads) is an acknowledged
506 limitation. Future studies might consider exploring physicians' approaches to pain
507 management for people with advanced dementia with a broader sample of acute
508 physicians. The findings of this study are being used to develop and pilot an intervention
509 aimed at bringing together physicians and other health professionals to engage in
510 interactive real patient case-based learning. It is hoped these findings may encourage
511 further development of strategies to support and empower physicians to provide a gold
512 standard in managing pain for people living and dying with dementia.

513

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523 **References**

- 524 1. World Health Organization and Alzheimer's Disease International. Dementia: a public
525 health priority. 2012. Available from: [http://www.who.int/mental_health/publications/
526 dementia_report_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/). Accessed October 2015.
- 527 2. Luengo-Fernandez R, Leal J, Gray A. Dementia 2010: the economic burden of
528 dementia and associated research funding in the United Kingdom. 2010. Available
529 from:[http://www.alzheimersresearchuk.org/wp-
530 content/uploads/2015/01/Dementia2010Full.pdf](http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/Dementia2010Full.pdf) Accessed October 2015.
- 531 3. Prince M, Wimo A, Guerchet M, Ali G, Wu Y, Prina M. World Alzheimer Report
532 2015: The Global Impact of Dementia An analysis of prevalence, incidence, cost and
533 trends. 2015. Available from: <http://www.alz.co.uk/research/world-report-2015>.
534 Accessed October 2015.
- 535 4. Prince M, Knapp M, Guerchet M, et al. Dementia UK: Update. 2014. Available from:
536 https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2759.
537 Accessed October 2015.
- 538 5. Department of Health. Living well with dementia: a National Dementia Strategy. 2009.
539 Available from:
540 [https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/d
541 h_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf). Accessed October 2015.

- 542 6. Department of Health, Social Services and Public Safety. Improving dementia services
543 in Northern Ireland: a regional strategy. 2011. Available from:
544 [https://www.dhsspsni.gov.uk/publications/improving-dementia-services-northern-](https://www.dhsspsni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy)
545 [ireland-regional-strategy](https://www.dhsspsni.gov.uk/publications/improving-dementia-services-northern-ireland-regional-strategy). Accessed October 2015.
- 546 7. van der Steen JT, Radbruch L, Hertogh CM et al. White paper defining optimal
547 palliative care in older people with dementia: A Delphi study and recommendations from
548 the European Association for Palliative Care. *Palliat Med* 2014; 28: 197-209.
- 549 8. Husebo BS, Strand LI, Moe-Nilssen R et al. Who Suffers Most? Dementia and Pain in
550 Nursing Home Patients: A Cross-sectional Study. *J Am Med Dir Assoc* 2008; 9: 427-433.
551 doi:<http://dx.doi.org/10.1016/j.jamda.2008.03.001>.
- 552 9. Bunn F, Burn A-M, Goodman C et al. Comorbidity and dementia: A scoping review
553 of the literature. *BMC Med* 2014; 192. doi:10.1186/s12916-014-0192-4.
- 554 10. Klapwijk MS, Caljouw MAA, Van Soest-Poortvliet MC, Van Der Steen JT,
555 Achterberg WP. Symptoms and treatment when death is expected in dementia patients in
556 long-term care facilities. *BMC Geriatr* 2014; 14:99. doi:10.1186/1471-2318-14-99.
- 557 11. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN et al. The clinical course of
558 advanced dementia. *N Engl J Med* 2009; 361: 1529-1538.

- 559 12. Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CPM, van der Steen JT.
560 From Admission to Death: prevalence and course of pain, agitation, and shortness of
561 breath, and treatment of these symptoms in nursing home residents with dementia. *J Am*
562 *Med Dir Assoc* 2015; 16: 475-481. doi:10.1016/j.jamda.2014.12.016.
- 563 13. Pieper MJC, van Dalen-Kok AH, Francke AL et al. Interventions targeting pain or
564 behavior in dementia: A systematic review. *Ageing Res Rev* 2013; 12: 1042-1055.
565 doi:10.1016/j.arr.2013.05.002.
- 566 14. Ahn H, Garvan C, Lyon D. Pain and aggression in nursing home residents with
567 dementia: Minimum data set 3.0 analysis. *Nurs Res* 2015; 64: 256-263.
- 568 15. Cipher DJ, Clifford PA. Dementia, pain, depression, behavioral disturbances, and
569 ADLs: Toward a comprehensive conceptualization of quality of life in long-term care. *Int*
570 *J Geriatr Psychiatry* 2004; 19: 741-748.
- 571 16. Hadjistavropoulos T, Voyer P, Sharpe D, Verreault R, Aubin M. Assessing Pain in
572 Dementia Patients with Comorbid Delirium and/or Depression. *Pain Manage Nurs* 2008;
573 9: 48-54. doi:10.1016/j.pmn.2007.12.004.
- 574 17. Deschenes CL, McCurry SM. Current treatments for sleep disturbances in individuals
575 with dementia. *Curr Psychiatry Rep* 2009; 11: 20-26.

- 576 18. Passmore P, Cunningham E. Pain assessment in cognitive impairment. *J Pain*
577 *Palliative Care Pharmacother* 2014; 28: 305-307. doi:10.3109/15360288.2014.941136.
- 578 19. Khachiyants N, Trinkle D, Son SJ, Kim KY. Sundown syndrome in persons with
579 dementia: An update. *Psychiatry Investig* 2011; 8: 275-287. doi:10.4306/pi.2011.8.4.275.
- 580 20. Lin P-C, Lin L-C, Shyu Y-L, Hua M-S. Predictors of pain in nursing home residents
581 with dementia: A cross-sectional study. *J Clin Nurs* 2011; 20: 1849-1857.
582 doi:10.1111/j.1365-2702.2010.03695.
- 583 21. De Souto Barreto P, Lapeyre-Mestre M, Vellas B, Rolland Y. Potential underuse of
584 analgesics for recognized pain in nursing home residents with dementia: A cross-sectional
585 study. *Pain* 2013; 154: 2427-2431. doi:10.1016/j.pain.2013.07.017.
- 586 22. Tan EC, Jokanovic N, Koponen MP et al. Prevalence of analgesic use and pain in
587 people with and without dementia or cognitive impairment in aged care facilities: A
588 systematic review and meta-analysis. *Curr Clin Pharmacol* 2015; 10: 194-203.
- 589 23. Bell ML. Postoperative pain management for the cognitively impaired older adult.
590 *Semin Perioper Nurs* 1997; 6: 37-41.

- 591 24. Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia
592 and cognitively intact patients with hip fracture. *J Pain Symptom Manage* 2000; 19: 240-
593 248.
- 594 25. Bruneau B. Barriers to the management of pain in dementia care. *Nurs Times* 2014;
595 110: 12-15.
- 596 26. Krumm N, Larkin P, Connolly M, Rode P, Elsner F. Improving dementia care in
597 nursing homes: Experiences with a palliative care symptom-assessment tool (MIDOS).
598 *Int J Palliative Nurs* 2014; 20: 187-192.
- 599 27. Borgsteede SD, Deliens L, Zuurmond WWA et al. Prescribing of pain medication in
600 palliative care. A survey in general practice. *Pharmacoepidemiol Drug Saf* 2009; 18: 16-
601 23. doi:10.1002/pds.1678.
- 602 28. Lövheim H, Karlsson S, Gustafson Y. The use of central nervous system drugs and
603 analgesics among very old people with and without dementia. *Pharmacoepidemiol Drug*
604 *Saf* 2008; 17: 912-918. doi:10.1002/pds.1600.
- 605 29. Husebo BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. Efficacy of treating pain
606 to reduce behavioral disturbances in residents of nursing homes with dementia: Cluster
607 randomised clinical trial. *BMJ* 2011; 343: d4065.

- 608 30. McLachlan AJ, Bath S, Naganathan V et al. Clinical pharmacology of analgesic
609 medicines in older people: Impact of frailty and cognitive impairment. *Br J Clin*
610 *Pharmacol* 2011; 71: 351-364. doi:10.1111/j.1365-2125.2010.03847.
- 611 31. Mallet L, Spinewine A, Huang A. The challenge of managing drug interactions in
612 elderly people. *Lancet* 2007; 370: 185-191.
- 613 32. McLachlan AJ, Hilmer SN, Le Couteur DG. Variability in response to medicines in
614 older people: Phenotypic and genotypic factors. *Clin Pharmacol Ther* 2009; 85(4): 431-
615 433. doi: 10.1038/clpt.2009.
- 616 33. Brenes-Salazar JA, Alshawabkeh L, Schmader KE, Hanlon JT, Forman DE. Clinical
617 pharmacology relevant to older adults with cardiovascular disease. *J Geriatr Cardiol*
618 2015; 12(3): 192-195. doi:10.11909/j.issn.1671-5411.2015.03.018.
- 619 34. Crome P, Lally F, Cherubini A. et al. Exclusion of older people from clinical trials:
620 professional views from nine European countries participating in the PREDICT study.
621 *Drugs Aging* 2011; 28: 667-77. doi:10.2165/11591990-000000000-00000.
- 622 35. Crome P, Cherubini A, Oristrell J. The PREDICT (increasing the participation of the
623 elderly in clinical trials) study: the charter and beyond. *Expert Rev Clin Pharmacol* 2014;
624 7: 457-468. doi:10.1586/17512433.2014.922864.

- 625 36. Watts G. Why the exclusion of older people from clinical research must stop.
626 BMJ 2012; 344: e3445. doi:<http://dx.doi.org/10.1136/bmj.e3445>.
- 627 37. Johnston S, Liddy C, Hogg W et al. Barriers and facilitators to recruitment of
628 physicians and practices for primary care health services research at one centre. BMC
629 Med Res Methodol 2010; 10: 109. doi:10.1186/1471-2288-10-109.
- 630 38. Britten N. Qualitative interviews in healthcare. In: Pope C, Mays N, eds. Qualitative
631 research in health care. London: BMJ Books, 1999: 11-19.
- 632 39. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;
633 3: 77-101. doi:10.1191/1478088706qp063oa.
- 634 40. World Health Organisation. WHO's Pain Relief Ladder. Available at:
635 <http://www.who.int/cancer/palliative/painladder/en/>. Accessed December 2015.
- 636 41. Watson M, Lucas C, Hoy A, Back I, Armstrong P. Palliative Adult Network
637 Guidelines. Available at: <http://book.pallcare.info/>. Accessed October 2015.
- 638 42. Scott S, Sampson EL, Jones L. The Compassion programme: Looking at improving
639 end-of-life care for people with advanced dementia. Int J Palliative Nurs 2012; 18: 212-
640 216.

- 641 43. National Institute for Health and Care Excellence. Dementia: supporting people with
642 dementia and their carers in health and social care. 2006. Available from:
643 <https://www.nice.org.uk/guidance/cg42>. Accessed October 2015.
- 644 44. Achterberg WP, Pieper MJC, van Dalen-Kok AH et al. Pain management in patients
645 with dementia. *Clin Interv Aging* 2013; 8: 1471–1482. doi:10.2147/CIA.S36739.
- 646 45. McAuliffe L, Brown D, Fetherstonhaugh D. Pain and dementia: an overview of the
647 literature. *Int J Older People Nurs* 2012; 7: 219-226. doi:10.1111/j.1748-
648 3743.2012.00331.
- 649 46. American Geriatrics Society. Panel on persistent pain in older persons: The
650 management of persistent pain in older persons. *J Am Geriatr Soc* 2002; 50: S205-S224.
- 651 47. Ballard C, Creese B, Corbett A, Aarsland D. Atypical antipsychotics for the treatment
652 of behavioral and psychological symptoms in dementia, with a particular focus on longer
653 term outcomes and mortality. *Expert Opin Drug Saf* 2011; 10: 35-43.
- 654 48. McLachlan AJ, Bath S, Naganathan V et al. Clinical pharmacology of analgesic
655 medicines in older people: impact of frailty and cognitive impairment. *Br J Clin*
656 *Pharmacol* 2011; 71: 351-64.

- 657 49. Tousignant-Laflamme Y, Tousignant M, Lussier D et al. Educational needs of health
658 care providers working in long-term care facilities with regard to pain management. *Pain*
659 *Res Manage* 2012; 17: 341-346.
- 660 50. Dening KH, Jones L, Sampson EL. Preferences for end-of-life care: A nominal group
661 study of people with dementia and their family carers. *Palliat Med* 2013; 27: 409-417.
- 662 51. Lopez RP, Mazor KM, Mitchell SL, Givens JL. What is family-centered care for
663 nursing home residents with advanced dementia? *Am J Alzheimers Dis Other Demen*
664 2013; 28: 763-768. doi:10.1177/1533317513504613.
- 665 52. Burns M, McIlpatrick S. Nurses' knowledge and attitudes towards pain assessment for
666 people with dementia in a nursing home setting. *Int J Palliat Nurs* 2015; 21: 479-487
- 667 53. Burns M, McIlpatrick S. Palliative care in dementia: literature review of nurses'
668 knowledge and attitudes towards pain assessment. *Int J Palliat Nurs* 2015; 21: 400-407
- 669 54. Fry M, Chenoweth L, Arendts G. Assessment and management of acute pain in the
670 older person with cognitive impairment: a qualitative study. *Int Emerg Nurs* 2016; 24:
671 54-60
- 672 55. Birch D, Draper J. A critical literature review exploring the challenges of delivering
673 effective palliative care to older people with dementia. *J Clin Nurs* 2008; 9: 1144-1163
674