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## **“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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