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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

Pain management at end of life in dementia

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What is already known about this topic?

- Pain is prevalent among people with advanced dementia approaching the end of life but is challenging to identify and treat in patients with profound loss of communication who are unable to report the presence, nature and intensity of their pain.
- People with advanced dementia are at risk of under-treatment or suboptimal treatment of pain as they approach the end of life.
- Untreated pain, or suboptimal treatment of pain, often have deleterious effects on people with advanced dementia including: delirium, sleep disturbance, increased confusion and exacerbation of neuropsychiatric symptoms.

What this paper adds?

- This study is the first to explore and describe the complexities and challenges experienced by physicians when prescribing for and managing pain in people with advanced dementia who are approaching the end of life, the impact of these challenges on prescribing and treatment approaches, and the strategies used by physicians to overcome these challenges.
• Physicians’ prescribing and treatment decisions were shaped by patients’ comorbidities, ageing physiology, existing medication regimens, physical and cognitive impairments and health status.

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

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

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

• Physicians’ narratives revealed an interactive interface across primary, secondary and hospice care settings and across medical specialties through which knowledge and expertise were exchanged to allow palliative and non-palliative doctors to overcome the challenges of pain management.
• Promoting cross-specialty knowledge exchange and mentoring can empower non-palliative care physicians to confidently and effectively manage complex palliative care patients in their respective settings.

Abstract

Background: Pain management is a cornerstone of palliative care. The clinical issues encountered by physicians when managing pain in patients dying with advanced dementia, and how these may impact on prescribing and treatment, are unknown. Aim: To explore physicians’ experiences of pain management for patients nearing the end of life, the impact of these on prescribing and treatment approaches, and the methods employed to overcome these challenges. Design: Qualitative, semi-structured interview study exploring: barriers to and facilitators of pain management, prescribing and treatment decisions, and training needs. Thematic analysis was used to elicit key themes. Settings/Participants: Twenty-three physicians, responsible for treating patients with advanced dementia approaching the end of life, were recruited from primary care (n=9), psychiatry (n=7) and hospice care (n=7). Results: Six themes emerged: diagnosing pain, complex prescribing and treatment approaches, side-effects and adverse events, route of administration, importance of sharing knowledge and training needs. Knowledge exchange was often practised through liaison with physicians from other specialties. Cross-specialty mentoring, and the creation of knowledge networks were believed to
improve pain management in this patient population. **Conclusions:** Pain management in end-stage dementia is complex, requiring cross-population of knowledge between palliative care specialists and non-specialists, in addition to collateral information provided by other health professionals and patients’ families. Regular, cost- and time-effective mentoring and ongoing professional development are perceived to be essential in empowering physicians to meet clinical challenges in this area.

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

**Introduction**

Dementia is an increasingly challenging global public health concern (1). Worldwide prevalence has reached 46.8 million (2), and projections estimate 74.4 million people living with dementia by 2030 (3). In the United Kingdom (UK), 850,000 people are living with dementia, 19,765 of whom reside in Northern Ireland (NI) (4). The need for appropriate palliative care to manage symptoms, including pain, for people living and dying with dementia is a focus of dementia care strategy in public health policy and is a recognised human right (5-7).
Pain is commonly experienced by people with dementia towards the end of life and is predominantly due to the prevalence of age-associated conditions (e.g. osteo- and rheumatoid arthritis, joint disorders, infection), chronic comorbidities (e.g. heart disease, cancer, diabetes) and distressing symptoms including: nausea, dehydration, dysphagia and dyspnoea (8-12). The deleterious impact of undetected, unresolved or untreated pain in people with moderate and advanced dementia has been reported to result in: delirium, sleep disturbance, increased confusion and exacerbation of neuropsychiatric symptoms (13-20). Previous studies have reported inconsistent approaches to pain management for people with dementia (21-24), primarily due to difficulty assessing and diagnosing pain, and lack of clinical data to guide prescribing for patients approaching the end of life (12, 25-27). The under-representation of older adults in clinical trials of analgesics may mean that key outcome measures including toxicity and drug action do not accurately reflect their use in patients with multiple comorbidities and significant physical frailty, and can lead to variability in treatment outcomes (28-33). The inclusion of older, comorbid adults in clinical drug trials is attracting increasing research interest (34-36). Little is known about the challenges encountered by physicians when managing pain in people with advanced dementia nearing the end of life; even less is known about the strategies and resources used to overcome these challenges. This study aimed to elucidate this information as part of a wider programme of research into assessing and managing pain in this complex patient group.
Aim

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

Methods

Setting/Participants

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

Sampling and recruitment

A pragmatic approach to sampling was taken in light of the number of practising physicians in NI and the range of medical specialities, departments and care settings in
which people with dementia at end of life may be managed, and following a review of sampling frames used in similar studies (37).

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

Ethical approval

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

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

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

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

**Results**

Twenty-three physicians participated. Physicians’ average age was 42.5 years (range 28 to 58 years), and they had an average of 17.5 years’ clinical experience (range 5 years to 31 years). Most were female (n=16; 69.6%). Six (26.1%) had additional postgraduate qualifications. Participant characteristics are presented in Table 2.
Six key themes emerged from the interviews: (1) diagnosing pain, (2) complex prescribing and treatment approaches, (3) side-effects and adverse events, (4) route of administration, (5) sharing knowledge and (6) training needs.

**Diagnosing pain**

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

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

In the absence of patient report, respondents observed for, and interpreted, behavioural and nonverbal signs. All respondents were acutely aware of the limitations of this
approach, recognising that many of these indicators could also be expressions of fear, anxiety and other non-pain related distress. Most expressed concern regarding potential misinterpretation of these cues and advocated caution in relying on this information.

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

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

Saw a patient yesterday or two days ago who appeared to be in pain, she had advanced dementia, I felt she was in the last days of her life and she was lying on
the bed occasionally agitated, throwing her arm up around her head. Hard to know if that’s pain or not. So do I treat her for pain in that scenario? (PHYS019, GP)

Complex prescribing and treatment approaches

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

In the very severe stages we get people who can be very, very, physically failed and frail, very low body mass, really no musculature, usually sort of dehydrated, usually with sort of poor cardiac output. Often we’re not actually sure how much pain relief is getting in to somebody. Often the difference between what you think the analgesic’s going to be and what it actually does to a patient in that kind of stage—the difference is quite substantial. (PHYS03, Consultant Psychiatrist, Secondary Care)
Participants described past experiences in which analgesic effects had been highly unpredictable, resulting in over-treatment for some patients, poor pain control in others and adverse events for a minority.

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

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

I would start off with maybe a trial of analgesia but I would start off with the mildest form like paracetamol or something just to see if it made a difference. If they seemed to be responding, I suppose I would use the WHO analgesia ladder and just come up very, very cautiously. (PHYS04, GP)
Pain management was often described as a ‘trial and error’ process in which pain relief was titrated in response to changes in behaviour, nonverbal cues, vocalisation and levels of consciousness. Psychiatrists and GPs found the World Health Organisation (WHO) Analgesic Ladder (40) helpful in guiding upwards titration; hospice physicians relied on their own previous clinical experience and consultation with colleagues and preferred the national Palliative Adult Network Guidelines (PANG) (41). All physicians regularly prescribed a wide range of analgesics including opioid and compound opioid preparations in a variety of formulations including transdermal patches, intramuscular injections and syringe drivers. GPs and psychiatrists often sought advice or confirmation from specialists such as community hospice, palliative medicine and psychogeriatric practitioners when titrating to higher doses.

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

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

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

(PHYS07, Psychiatrist, Secondary Care)

Many patients required a greater degree of pain control than could be provided by paracetamol and other simple analgesics, however; codeine and other opioid-based preparations were deemed to carry a high risk of respiratory depression, sedation, constipation and falls, whilst non-steroidal anti-inflammatory drugs (NSAIDs) were associated with risk of gastric bleeding, cardiovascular and stroke events. Side-effects such as constipation (a trigger for onset of acute delirium) and nausea (difficult to detect in the absence of patient self-report), respiratory depression and sedation were considered highly detrimental to patients and contravened participants’ goals of care.
The likes of the more codeine-based [preparations], it’s the risk of them becoming constipated and making things worse and then I suppose the more heavy morphines and so on, it can just floor them, really wipe them off their feet, more prone to more falls, makes them more drowsy. (PHYS06, Psychiatrist, Secondary Care)

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

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

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

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

(PHYS015, Consultant in Palliative Care, Hospice)

Many respondents described difficulty encouraging compliance in patients who lacked capacity to engage in discussion regarding the need for symptom control. Syringe drivers, normally considered when oral administration is not viable, presented a number of complications including: forceful removal by agitated patients, lack of available staff experienced in their set-up and use; and in some cases, lack of access to necessary equipment or resources.
Intravenous [administration] I would have to say we actually rarely use. The problems being that maintaining venous access in somebody who’s failing is a problem, it’s often painful and distressing for patient and we open up then risks of infection and so on as well. So we often try and go for, for subcuts if we can, or patches. (PHYS03, Consultant Psychiatrist, Secondary Care)

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

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

Transdermal patches were considered particularly suitable for agitated patients due to their unobtrusive and non-invasive nature and for avoiding difficulties associated with pro-re-nata (PRN) prescribing in non-verbal patients.
We would try and use patches sometimes because they’re less noticeable to the patient, and if the pain is more stable that can be a way around it. (PHYS015 Consultant in Palliative Care, Hospice)

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

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

**Sharing knowledge**

All respondents strongly believed that the care of people with dementia approaching the end of life, including pain management, required input from families and healthcare professionals across disciplines. Physicians believed their key responsibility was to provide optimal care for their patients, which included recognising and addressing their
own limitations. Narratives revealed an interactive interface across primary, secondary and hospice care settings and medical specialties through which knowledge and expertise were exchanged.

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

GPs and psychiatrists sought advice from palliative and hospice care physicians and psychogeriatricians regarding: off-label use of analgesics; titration for patients already receiving pain relief; use of opioid preparations; combining pain-relieving agents; combining analgesics with mild sedation; managing background or breakthrough pain; and routes of administration. Hospice physicians sought guidance for particularly complex patients from neurology, psychogeriatrics, palliative pharmacy and psychiatry. In many cases, participants wanted confirmation of their proposed treatment; receiving support from other specialties and knowing they were ‘on the right track’ with prescribing
and treatment increased confidence and job satisfaction. Many enjoyed learning from and sharing their expertise with other doctors outside their care setting and medical specialty.

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

(FPHS08, GP)

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

We very much work with the families because the families usually know this person to the point that they know what they maybe would have wanted or how
they are going to respond so we try and get everybody in on the decision-making.

(PHYS012, Consultant in Palliative Care, Hospice)

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

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

Training needs

Physicians were dedicated to providing optimal care for patients often within multiple organisational constraints. All respondents believed that the knowledge, skills and expertise required to optimally manage pain in this complex patient population existed within the health professions but were highly dispersed across medical and other
disciplines and care-settings. Physicians considered pharmacology, pharmacotherapeutics, managing pain in patients with challenging behaviours, and distinguishing between pain-related and non-pain related behavioural and psychological symptoms of dementia (BSPD), to be key areas for further training. The majority described physician-to-physician mentoring, in the form of regular meetings of an established network of practitioners from across care settings and disciplines to discuss anonymised real patient cases, as an ideal approach to ongoing professional development.

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

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

I think that case-based learning is useful because I think it gets people to think about what they do themselves and how they would manage a particular problem.
I think that has more relevance and power in terms of changing what people do for
the better. (PHYS015, Consultant in Palliative Care, Hospice)

Discussion

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

The gold standard in diagnosing pain is self-report. In advanced dementia, this is rarely
available; much of the critical information required to accurately assess, diagnose and
target treatment is lost (45). The findings of this study indicate that in the absence of
patient report, collateral history from patients’ families and other health professionals,
along with clinical investigation and interpretation of changes in mood, behaviour, and
other nonverbal cues, become important (45-46). However, participants widely
acknowledged that many well-recognised behavioural indicators of pain, such as distress,
agitation, wailing, screaming, frowning and apathy, are identical to those expressed through anxiety, boredom, frustration and emotional distress (47). Behavioural interpretation leaves room for misinterpretation and potentially inappropriate treatment (47). Physicians’ prescribing decisions were also shaped by patients’ comorbidities, ageing physiology, existing medication regimens, physical and cognitive impairments and health status, which were perceived to restrict the range and strengths of analgesics that may be safely tolerated (48). Changes in drug pharmacokinetics and pharmacodynamics, and variation in gut absorption and body fat index may result in over-treatment, delayed effects of pain relief and increased risk of side-effects and adverse events, making management complex and uncertain (48). Most physicians adopted a cautious approach to management. Route of administration was reported as problematic in severely cognitively impaired, dying patients. Loss of swallow, patient refusal and altered consciousness often precluded oral administration, whilst syringe driver use was problematic due to forceful removal by agitated or distressed patients and issues regarding availability of appropriately experienced nursing staff to set up and monitor the equipment. Medication delivery via the transdermal route was considered a better alternative.

Physicians across specialties and care settings often sought and shared advice and approaches to pain management. Most respondents strongly believed ongoing CPD via mentoring and knowledge exchange using real-patient cases would empower non-
palliative specialists to effectively manage patients approaching the end of life. Previous studies have identified a need for further training for healthcare professionals in pharmacology and the use of nonpharmacological treatments, and in discriminating between behavioural and psychological symptoms caused by pain and those which are not pain-related in origin (44,49). The present findings corroborate these suggestions, and provide additional insight into physicians’ training preferences.

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

There are some limitations with this study. The sampling approach may have resulted in a skewed sample of physicians with an interest in, or past experience of, research participation, who felt comfortable talking about professional challenges. We aimed to recruit physicians across acute specialties; the low participation by physicians outside
psychiatry (possibly due to staffing pressures and workloads) is an acknowledged limitation. Future studies might consider exploring physicians’ approaches to pain management for people with advanced dementia with a broader sample of acute physicians. The findings of this study are being used to develop and pilot an intervention aimed at bringing together physicians and other health professionals to engage in interactive real patient case-based learning. It is hoped these findings may encourage further development of strategies to support and empower physicians to provide a gold standard in managing pain for people living and dying with dementia.

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