

Title: Nurses' experiences of pain management in end of life dementia care: a literature review.

Abstract

Background: Nurses play an important role in pain management in end of life dementia care. However, this is often poorly managed in practice.

Aim: To explore nurses' experiences of pain management in end of life dementia care.

Method and search strategy: Using the Preferred Reporting Items for Systematic reviews and Meta- Analyses (PRISMA) guidelines, a systematic narrative review of research papers published in English between 2008-2018 was conducted. Data sources were CINAHL, Medline, PsycINFO, ScienceDirect and SocIndex. Articles focused on nursing at end of life and pain management in people with dementia.

Findings: Eight articles were retrieved that met the search criteria. Four studies used qualitative methodology, two quantitative and two mixed methods. Studies from the United Kingdom dominated ($n = 5$), the remainder from Sweden, Norway and United States of America. Following thematic analysis, three themes were identified: training and education in pain management at end-of-life for people with dementia; challenges in identifying pain; and pain assessment tool use.

Conclusion: The review revealed inadequate education for nurses concerning end of life care for people living with dementia, notably concerning pain recognition and use of assessment tools. It is recommended that specialist education is mandated for all nurses working with this client group to improve care delivery.

Key words: dementia; end-of-life; pain management; nursing; education

Key points:

- End-of-life dementia care represents a significant nursing challenge.

- People with dementia are at greater risk of experiencing pain due to their inability to communicate their needs.
- The management of pain predominantly utilises general palliative care guidelines not sufficiently tailored to the complex needs of those living with dementia.
- A person-centred approach facilitates identification of pain cues and associated interventions.
- Undergraduate pre-registration nurse education and continuous professional development around pain assessment and management in end of life dementia care should be mandated, implemented and evaluated.

Reflective questions:

1. The UK Nurses code (NMC 2018) states we must 'prioritise patients'; for people with cognitive impairments, what are the challenges in understanding their needs as an individual?
2. How might pain be apparent in patients with cognitive impairments such as dementia?
3. What specific knowledge and skills do I need to respond effectively to pain and distress in people living with dementia?

Background

Dementia is described by Barker and Board (2012) as an umbrella term for a collection of diseases of the brain that are progressive and terminal in nature. Symptoms include memory loss, problems with reasoning, perception and communication skills (Public Health England, 2018). There are many types including vascular dementia, Alzheimer's disease, dementia with Lewy bodies and frontotemporal dementia (NIHR 2019). Globally there are 50 million individuals diagnosed with dementia, expected to increase to 152 million by 2050 (Patterson 2018). In the UK, 850,000 people live with dementia of which 810,000 are over the age of

65; this number is predicted to rise to over 2 million by 2051 (NIHR 2019). In 2014, 59,199 people died in England and Wales due to dementia; this is expected to quadruple to 219,409 by 2040 (Etkind et al. 2017). Whilst research into cures for the diseases causing dementia is on-going, given the scale of its incidence, end-of-life care represents a significant healthcare challenge.

End of life care is defined as the physical, emotional, social and spiritual support given to people in the last months of life (National Cancer Institute 2019). A key goal as the Department of Health (DH 2008) stipulates is that a 'good death' is being without pain. However, people with dementia are at greater risk of experiencing pain due to their inability to communicate their needs (Marie Curie 2019). The use of general palliative care guidelines to manage pain may therefore have limitations in end of life dementia care (Hendriks et al. 2014) because of difficulties in interpreting pain and discomfort in the presence of other behavioural and psychological symptoms associated with the condition. It is essential that nurses are able to recognise when someone with dementia is in pain during end-of-life care and provide effective management to facilitate a pain-free death (Buchanan et al. 2014). Nurses have a key role in providing individualised and holistic care (Department of Health (DoH) 2012), including the delivery of end-of-life care based on of appropriate pain assessment (National Institute for Health and Care Excellence (NICE) 2015). This is only possible if they have knowledge, skills and understanding around pain management for this challenging client group (Burns and McIlfatrick 2015).

The Leadership Alliance for the Care of Dying people (2014) developed an advisory document following the independent review of the Liverpool Care Pathway for the dying patient (LCP), which outlined significant variation in the quality of care provided. Examples

of excellent as well as inappropriate pain management were found particularly around the use of opiates and tranquillisers being given on a routinised basis rather than on individualised need, based on pain assessment. Clearly therefore this is a challenge in all end of life care but where dying people have a diagnosis of dementia and may be unable to effectively explain their pain, NICE (2015) advocate the use of a validated behavioural pain assessment tool. However, it is essential health professionals have adequate time, education and training to ensure this is delivered effectively (NHS England 2014). Unrecognised or untreated pain by health professionals can aggravate the behavioural and psychological symptoms of dementia (BPSD) which include a range of inappropriate behaviours as well as agitation, depression, apathy, psychosis, aggression and sleep problems (Kales et al. 2015). One or more of these symptoms will affect nearly all people with dementia complicating end of life care.

In summary policy and research findings indicate that many living with dementia receive poor quality end of life care (NHS England 2014).

Burns and McIlfatrick (2015) in their review of literature concerning nurses' knowledge and attitudes towards pain assessment in older people with dementia published between 2000-2014, recommended appropriate training and a standardised approach to pain assessment with this client group. Our systematic narrative literature review updates these findings but focuses specifically on nurses' experiences of pain management in end of life dementia care.

Method and Search Strategy

A systematic narrative review was conducted using the Preferred Reporting Items for Systematic reviews and Meta- Analyses (PRISMA) guidelines as described by Tricco et al.

(2018); the process is outlined below. The literature search question was first developed using the PEO (Patient, Exposure and Outcome) framework (Bettany-Saltiko 2012) – see table 1.

[Insert table 1 here]

In December 2018 the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsycINFO, Science Direct, Science Citation Index (SocINDEX) databases were searched by author 1 using the following keywords: Pain Management, Pain Relief, Pain, Control, Pain Reduction, Analgesia, End of Life, Dying, Terminal, Terminally Ill. 'Dementia' was a limiter put in place to ensure the search was focused to this area of interest. Using two logical operators 'AND' and 'OR', boolean logic was applied to ensure the search was focused on the specific key terms. The inclusion criteria were: (a) research studies referring to patients diagnosed with dementia; (b) receiving end-of-life care (c) published in English between 2008-2018; (d) quantitative, qualitative or mixed methods. A timeframe of 2008-2018 was chosen in order to update previous reviews but not duplicate them. A focus on people over 65 years was selected as dementia affects this age group more than any other; the exclusion of those under 65 is acknowledged therefore as a limitation.

Records retrieved that did not meet these criteria were excluded. The search process is summarised in the PRISMA flow chart in Diagram 1 which shows the number of records retrieved and reasons for inclusion and exclusion (Moher et al. 2009).

[Insert diagram 1 here]

328 records were retrieved from the initial database search once all duplicates were removed. The title and abstracts of these articles were then screened against the inclusion criteria and 291 articles were rejected. The remaining 36 articles were read in full by author 1 and 2 to assess their relevance to answer the search question. A further 28 were removed based on the content. Five studies from the database search met the inclusion criteria and a further three

articles were manually retrieved by scrutinising retrieved article reference lists. A total of eight articles were identified for inclusion within this review.

Findings

This review includes qualitative, quantitative, and mixed method studies. Sample sizes varied, ranging from 7 to 96 participants and were health care professionals, particularly nurses as well as carers. Data were collected mainly via interviews and to a lesser extent questionnaires and retrospective chart audits. The retrieved studies-originate from the United Kingdom (UK) (5), Norway (1), United States of America (USA) (1) and Sweden (1).

The PRISMA guidelines (Tricco et al., 2018) do not require the use of critical appraisal tools and therefore the quality of the research was appraised using the inclusion and exclusion criteria.

The eight studies included within this review are summarised in table 2. Results are described by study characteristics and findings. Both authors used a process of content analysis (Greenheim & Lundman, 2004) to independently review the final selection of papers. Following comparison and discussion, results were grouped into three inter-related themes: Training and education in pain management in end-of-life care for people living with dementia; 2) challenges in identifying pain; 3) use of pain assessment tools.

[Insert table 2 here]

Training and education in pain management

Knowledge of pain assessment, pain relief and side effects are important aspects of caring effectively for people living with dementia at end-of-life (De Witt Jansen et al. 2016; De Witt Jansen et al. 2018; Lichtner et al. 2016). However, the review revealed perceived

inadequacies in the provision of education for health care professionals in this specialist area. Brorson et al. (2014) revealed nurses felt anxiety with regards to misdiagnosing pain, over-medication and managing the side effect of medication with this client group.

Monroe et al. (2012) recommended that staff education on pain behaviours in people with dementia was vital to overcome staff fears of medication side effects preventing administration of appropriate pain treatment. Similar findings were reflected by Barry et al. (2012) who found concerns about the use of opioids with residents with dementia. Only 60% of those surveyed used pain treatment guidelines and this was linked to a lack of consistent standards to guide practice and inadequate staff education.

The review indicates that staff clearly perceive the need for specialist education in this area, but its provision varies considerably. De Witt Jansen et al. (2016) compared hospice, acute care and nursing home nurses' experiences of pain management with this client group. They found that hospice nurses received more dementia care education compared with nursing home and acute care nurses. Heavier workloads and constraints on staff time in these latter settings resulted in some staff receiving no training in end-of-life pain management or dementia care. All participants recognised the importance of education, noting in particular a lack of pharmacological education resulting in poor understanding of the regimens they administer. In addition, Midtbust et al (2018) highlights the need for knowledge around non-pharmacological pain relief; their phenomenological study within Norwegian nursing homes focused on interpreting suffering in people with advanced dementia and highlighted staff anxiety around manifestations of pain, indicating the need for education around holistic pain management approaches for this vulnerable group.

In a further study by De Witts Jansen et al. (2018) across primary, secondary and hospice care sectors they highlight the importance of upskilling staff as a critical element of managing end-of-life pain in patients with dementia, particularly around the use specialist observational pain assessment tools to inform pain assessment and management.

Challenges in identifying pain in people living with dementia

Identification of pain in end-of-life dementia care is problematic predominantly as the ability to self-report pain is impaired, due to memory and cognition difficulties. Lichtner et al. (2016), Brorson et al. (2014) and De Witt Jansen et al. (2018) report that health professionals tend to rely on clients self-reporting pain, but this was hindered by communication difficulties. Whilst Brorson et al. (2014) reported that nurses believed they had enough experience to observe patients with dementia and interpret their individual signals of pain, this finding is not supported by others. Lichtner et al. (2016) study focused on pain assessment and management in England and Scotland; they found that nurses looked at physical and behavioural signs to understand patients' pain; this included interpretation of various body movements, postures, expressions and gestures for signs of distress. Experienced nurses used simpler language when trying to assess pain as well as behavioural prompts to stimulate response and became skilled at interpreting metaphorical expressions used by patients to describe discomfort such as 'red hot'. However care observations revealed that 'as required' prescribed medication (PRN) were often given on an *ad hoc* basis to patients with dementia unable to request additional pain relief as opposed to following a pain assessment process. Monroe et al. (2012) found that clinicians advised caution when administering PRN medication to individuals unable to report pain verbally or behaviourally due to the danger of over sedation, advising that administering scheduled analgesics at appropriate times is more effective.

Whilst practitioner education is important, a number of studies indicate that knowing the person in order to authentically connect with them is as important to understanding their pain experience. Midtbust et al (2018) studied health professionals experiences of providing palliative care for people living with dementia in Norwegian nursing homes. They described their distress at being unable to manage pain well, citing lack of time and care continuity which limited a building of understanding of patients' pain expressions. Nurses reported that although some patients showed small signs of behavioural changes, only those who knew the patient well were able to realise they were in pain. This issue becomes more complex given the trajectory of the disease process. Monroe et al. (2012) found that people with Alzheimer's disease have fewer observable pain behaviours and they diminish as the disease progresses, which means that assessing pain using behavioural indications presents challenges. Both Brorson et al. (2014) and Midtbust et al. (2018) acknowledge the value of relatives/carers to help assess patients and manage pain in people living with dementia. Midtbust et al. (2018) also highlights the importance to advanced care planning to document pain expressions earlier in the illness trajectory.

Pain assessment tool use

As previously identified, assessing end-of-life pain of individuals who are cognitively impaired and unable to self-report pain is challenging. A number of studies focused on the use of pain assessment tools. The study by Barry et al. (2012) with nursing home managers found ambiguities in pain assessment practices due to a lack of standardisation in the sector. The evidence retrieved indicates inconsistency in this area. De Witt Jansen et al. (2016) found no evidence of nurses using any form of pain assessment tool. Similarly Lichtner et al. (2016) observed no use of pain assessment tools with clients; although the Abbey Pain Scale

was recommended within some settings, this was not seen to be used. Likewise, De Witt Jansen et al. (2018) found that only 13 out of 47 participants (nurses and physicians) routinely used Observational Pain Assessment Tools (OPT) in patients with dementia nearing end-of-life. This was due to perceived limitations of these tools but also a lack of understanding of their value. This is consistent with research by Brorson et al. (2014) which found only one nurse used a pain assessment tool, the Doloplus 2. Moreover the tools themselves have limitations; for example Monroe et al. (2012) found that the Discomfort Behavioural Scale (DBS) was not able to identify all pain behaviours as direct observational behaviours diminish as Alzheimer's Disease worsens.

Assessment is vital as is its link to pain control interventions. Cohen-Mansfield (2014) reports a study that examined the implementation of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). Six nurses were observed working with 22 residents in a nursing home in the USA. The data revealed that half of the staff who identified pain failed to implement pain control measures due to fear that they had misinterpreted pain cues. However compliancy with recording was also problematic. All the studies that focused on pain assessment indicate that health professionals tend to rely on behavioural observations when using pain assessment tools. To be effective, they require sufficient training and education in pain behaviours in people living with dementia.

Discussion

Whilst effective pain management is a key outcome for a good death (DH 2008) this literature review highlights significant limitations in the provision of holistic end-of-life care for people living with dementia. Our literature review indicates that nurses play a key role in the management of pain in this situation, but the findings indicate that largely due to

inadequate education and training about end of life in dementia, pain in particular is inadequately identified which undermines assessment and care management. Our review updates and supports the findings of the review by Burns and McIlpatrick (2015), indicating that these challenges persist and still need to be addressed.

The NMC Code (NMC 2018) obliges Registered nurses to undertake all necessary education in order to ensure competence in any area of practice with which they are engaged. Generally nurse education about dementia care is improving (Hendriks et al. 2014) but this review indicates that knowledge and training around care of people with dementia at end of life remains poor (De Witt et al. 2016)). A key goal of the Liverpool Care Pathway was to expand practitioner knowledge and thereby improve quality of care in the last hours or days of life (Ellershaw and Wilkinson 2011). This is also reflected in the current End of Life Strategy for England (DH 2018). Our review identifies that whilst nurses are aware of the importance of recognising and managing pain at end-of-life care in individuals with dementia, pain management was not consistently provided as nurses had reservations about giving pain medication. This was due to a lack of pharmacological knowledge concerning medication use in dementia as well difficulties in identifying and therefore assessing pain. This is supported by Barber and Murphy (2011) and Peacock (2008) who found that health care providers lacked specialist training in pain management with this client group, with fears associated with potential side-effects inhibiting effective pain management. The administration of analgesia on a PRN basis in conjunction with analgesia administered at regular intervals caused considerable uncertainty due to anxieties about misdiagnosing need and inappropriate over medicating. The World Health Organisation (WHO 2019) advocates that for optimal pain relief, medication should be given 'by the clock', rather than on demand.

Pain management education needs to draw upon a strong evidence-base. For example the WHO (2019) three step analgesic ladder was developed to maintain freedom from pain; this provides guidelines for practitioners from the use of non-opioids and non-pharmaceutical measures at the lowest level up to opioids and adjuvant therapy. Clearly however intervention needs to arise from accurate pain assessment but as the review indicated, this was found to be challenging in patients with dementia. Burns and McIlfatrick (2015) recommended the use of a pain assessment tool specifically designed for patients with dementia to facilitate better pain management during end-of-life care. Herr et al. (2010) recommend Pain Assessment in Advanced Dementia (PAINAD) as a useful tool for daily assessment which includes a follow up evaluation of pain intervention. Other observational pain assessment tools available to use in end-of-life dementia care include the Abbey Pain Scale, and Doloplus 2 (Schofield 2018).

However our review found that assessment tools were inconsistently used in practice due to a lack of standardised guidelines on use, being available in some care settings or insufficient staff education on how to use the tools. This issue is recognised by the British Geriatric Society (2019) who recommend that all health professionals have education and training on the use of pain assessment tools. Embedding this in everyday practice in all care settings is a challenge requiring interventions at several levels: end of life policy is important but changes in practice are enacted through the implementation of specific care standards in this area, leadership and role modelling by experienced staff supported by specialised education for all levels of care staff. Further our review indicates it is a priority that undergraduate pre-registration education and continuous professional development dementia related pain assessment and management sessions are mandated, implemented and evaluated.

A common definition of pain within health care is 'pain is what the experiencing person says it is' (McCaffery 1968 cited by Clark and 2008 Iphofen). Unfortunately in end-of-life care of patients with dementia, verbal communication is often very limited which represents a considerable challenge. Our review found that nurses lacked knowledge and confidence in diagnosing pain behaviour from other behaviour disturbances. Central to effective pain assessment is recognition of behavioural cues as signs of pain in people living with dementia (American Geriatric Society (2002). Marie Curie (2019) highlights the importance of responding to non-verbal communication and behaviour to express pain; Zwakhalen et al. (2007) and Husebo et al. (2008) advocate the need for staff education to identify behavioural changes which may be associated with pain. Our review found that more experienced nurses were more successful in identifying and responding to pain cues. Chang et al. (2011) adds that identification of pain predominantly relies on behavioural observations learned through clinical experience. This indicates the need for mentoring by experienced nurses in the workplace to support staff new to end of life care in people with dementia.

Whilst it is vital that all nurses have a better understanding of dementia and how it can affect people regardless of their experience (Wilson 2013), at the very least the use of a person-centred approach can make a positive difference (Marie Curie 2019). Knowing the person living with dementia can be facilitated through the use of support tools such as 'This is Me' which provides information regarding the person's normal preferences and behaviours, including pain indicators, enabling health care professionals to deliver person-centred care tailored around individual needs, despite communication limitations (Alzheimer's Society 2019). Consequently, this helps to reduce distress for individuals by helping to overcome communication barriers as health professionals can read the document to identify pain indicators.

Limitations

This review drew upon research studies and excluded 'grey literature' which is therefore a limitation. The search was conducted using mySearch, Bournemouth University's iteration of the comprehensive and well-used EBSCO Discovery Service (EDS) tool which has the option to limit the search to full text papers; this was selected due to the time resources available. The research papers retrieved centred mainly on pain management during end-of-life for people with a diagnosis of dementia but in one case concerned those in receipt of palliative care. The reviewed articles used mainly qualitative methodology with small sample sizes; whilst they revealed rich data, these findings cannot be generalised. The most common data collection method was interviews; this method is useful for gaining an understanding from participants lived experiences and perspectives (Ellis 2016). Generalisability is therefore not possible but the rich insights gained were very valuable.

Conclusion

This literature review highlights that pain management during end-of-life care for people living with dementia both in the UK and internationally remains largely unmet by health professionals. All the studies reviewed highlighted the need for more knowledge and training around dementia care, particularly concerning pain assessment, medication administration and side effects. Further, although end-of-life care guidelines stipulate pain management is paramount, this does not appear to be effectively embedded as a norm for practitioners working with this vulnerable group. Further research is needed to develop and test specialised pain assessment tools for people with dementia linked with effective practitioner education programmes. It is essential nurses' practice person-centred approaches to care as knowing the person by speaking with relatives perhaps using tools to record details about a

person with dementia who may have difficulty sharing this themselves. A person-centred approach may significantly improve identification of pain and therefore positively impact on pain management.

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