**DEMENTIA: A FACTOR LEADING TO SUB-OPTIMAL PAIN MANAGEMENT IN ACUTE CARE?**

**Abstract**

**Aim**

To explore the factors influencing pain management in those with dementia within the acute care setting, from the Emergency Department (ED) through to the acute ward environments, in the context of international literature.

**Method**

Five databases were searched using the PICO framework (Population, Intervention, Control and Outcomes) to focus the search terms and to set inclusion and exclusion criteria.

**Findings**

Fourteen research papers from six countries were included in this review (see table 1). The main themes identified were: pain management; pain assessment tools and the need for education; communication and family involvement; culture and context.

**Conclusion**

While there is a dearth of literature available on pain management for the person living with dementia within acute care, what is known is that these patients are receiving suboptimal management. Therefore, there is a need for further exploration of the barriers to pain assessment and management practices from the ED through to the acute ward environments.

**Introduction**

Every three seconds someone in the world develops dementia. Current figures estimate that globally 50 million people are living with this disease (World Alzheimer Report, 2018). It is estimated that a quarter of all hospital beds are occupied by patients who are affected by dementia (Alzheimer’s Society, 2009). The most common reasons for their admission being falls, fractured neck of femur, urinary tract infections or chest infections (Alzheimer’s Society, 2009). The need to manage acute pain for these patients is becoming more prevalent (Corbettet al*.,* 2014). Although dementia has no age boundaries, it is more common in older people (Gaglieseet al*.,* 2017). Therefore, it is likely the person will have other co-morbidities (Dewing and Dijk, 2016) and as a result may already be living with chronic pain (Huseboet al*.,* 2016).

The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage (IASP, 2017). The Declaration of Montreal, which was developed during the first International Pain Summit in 2010, states that access to pain management is a fundamental human right (Cousins and Lynch, 2011). However, for individuals living with dementia and admitted to acute care, pain management remains inadequate (Lichtneret al*.,* 2014; Timmonset al*.,* 2016; Allioneet al*.,* 2017). Research suggests that hospital admissions can be detrimental to these patients, resulting in longer stays with poorer outcomes (Paulsonet al*.,* 2014; Griffiths et al*.,* 2015; Dewing and Dijk, 2016). This indicates a loss of independence for the person and may also add a further burden of cost on the National Health Service (NHS) (Walsh, 2012).

To improve pain management, the British Geriatrics Society and British Pain Society have collaborated to develop United Kingdom (UK) guidelines on the management of pain in older people, including those who have dementia. Patients with dementia and pain offer unique challenges for those working in acute care settings. In particular, the American Society for Pain Management Nursing noted that when a person is unable to self-report their pain, healthcare staff must find other ways to assess it, such as involving the family and utilising behavioural pain assessments (Hadjistavropouloset al*.,* 2014). Each person has a right to adequate pain management, however for the person with dementia this goal is more difficult to achieve (Reganet al*.*, 2015).

**Aim**

To explore the factors influencing pain management in those with dementia within the acute care setting, from the Emergency Department (ED) through to the acute ward environments, in the context of international literature.

**Search Strategy**

Early indications from searching the available literature suggested that exploring issues of pain management in older people who were also living with dementia, in acute care settings, was scant. Therefore, in order to gain a broad, comprehensive and critical overview of the literature, a narrative review is used. Ferrari (2005) claims that to reduce bias, the quality of a narrative review may be improved by following the systematic review methodologies. Therefore, to provide rigour the following methods were used. Five databases were searched: Cinahl Plus; Medline; PsycINFO; Cochrane library and; Embase using the key words shown in Table 2. The PICO framework (Population, Intervention, Control and Outcomes) was used to guide the search. This helped to focus the search terms and to set inclusion and exclusion criteria (Methleyet al*.,* 2014). The inclusion period was from 2013 to 2018, generating 263 results. Hand searching resulted in a further 28 papers, giving a total of 291 papers (see table 3). All papers were reviewed by title, abstract and then full text for inclusion. Duplicates were removed and only papers that pertained to acute care were selected. Fourteen papers were subsequently included in this review. Of the 14 papers reviewed, 4 related to a singular study (Lichtneret al*.,* 2014; Lichtneret al*.,* 2015; Dowdinget al*.,* 2016; Closset al*.,* 2016). However, as they all referenced different aspects of a larger study, they have all been included. It was interesting to note that while ‘nurse’ was not used as a key search term, much of the literature in this area focused on nurses as opposed to other healthcare professionals. Thus, to support the literature, additional pain management documents were used. Four themes from the literature were identified for discussion: pain management; pain assessment tools and the need for education; communication and family involvement; culture and context.

**Pain management**

Pain management should start with an assessment of pain through to appropriate prescription of analgesia, its administration and monitoring of care (Gregory, 2017). It begins when the person enters hospital, including through ED and continuing throughout their hospital stay. The British Pain Society (2017) describes pain as a feeling experienced in the brain, unlike any of our other senses. It can be acute, where the pain lasts less than twelve weeks, or chronic with the pain lasting beyond this timespan (The British Pain Society, 2017). Typically, it is acute pain that alerts the person or carer to seek help, with pain being a significant factor in helping healthcare professionals to diagnose conditions, highlight potential problems or concerns and take appropriate action to treat it (Achterberget al*.,* 2013). However, as many patients living with dementia have chronic or neuropathic pain from a pre-existing co-morbidity (Wright 2014), it is vital that the pain management they receive in acute care takes into consideration the whole person including their previous pain history (Achterberg et al*.,* 2013).

One example from the literature can be found in Van de Rijt et al.,’s (2018) study in which two UK hospitals reviewed the occurrence of orofacial pain in 101 patients who were admitted into an acute medical unit. The study identified that orofacial pain was present in 11.9% of patients at rest and 21.9% whilst chewing. This area of pain may have previously gone unnoticed, therefore the study concluded that admission to acute care could be used as an opportunity to address any oral health issues, in turn helping to reduce the patient’s pain.

Although treatment of a person’s pain is a fundamental human right (The British Pain Society, 2017) pain management for the patient with dementia remains a challenge for healthcare staff (Achterberget al*.,* 2013; Johnson and Karlawish, 2015; Huseboet al., 2016). This has been borne out through recent studies which have highlighted that people with a bone fracture and dementia were less likely to receive analgesia than a person who had the same fracture, but no dementia (Green et al., 2016; McCorkell et al*.,* 2017). Green et al., (2016) collected retrospective data from the medical records of 10 patients with and 10 patients without dementia who were admitted to hospital with a bone fracture. The aim was to explore the differences, if any, in the administration of analgesia. Results showed that the 10 patients with dementia received significantly less ‘Pro Re Nata’ (PRN) analgesia than those without during the first three days of their admission. However, the small sample size is a limitation of this study.

Where analgesia was given, Rantala et al., (2014) stated that the most common postoperative analgesia administered to patients with dementia were strong opioids and paracetamol. The study analysed data from questionnaires completed by 269 orthopaedic nurses, in seventeen hospitals in Finland. However, these findings were reported from the nurses’ recollections and therefore may not be an accurate account. With untreated pain having a profound effect on the patients’ quality of life (Lichtner et al., 2014), Closs et al., (2016) advised that a more renewed and rigorous approach to managing pain in patients with dementia is needed. Additionally, Feast et al., (2018) demonstrated that the person living with dementia, who had pain at rest, was more likely to develop delirium and remain in pain for most of their stay in hospital. This study recommends the regular use of pain and delirium assessments for the person living with dementia within acute care.

**Pain assessment tools and the need for education.**

Assessing the patient’s pain is seen as essential to treating it effectively and is often referred to as the fifth vital sign (Wright, 2014). Mirroring Feast et al.,’s (2018) findings, recommendations from an audit of dementia care in Northern Ireland acute hospitals, emphasised that an appropriate pain assessment tool is needed for improving the person living with dementia’s pain management (Timmons et al., 2016). Moreover, the UK National Guidelines: The Assessment of Pain in Older Adults (2018) recognised the difficulties experienced when managing pain for the person living with dementia. They advised that the patient’s pain should be measured regularly, using an appropriate assessment tool, whilst encompassing a multidisciplinary approach (Schofield and Abdulla, 2018). When assessing pain, verbal description is perceived as the ideal (Brown, 2011; Wright, 2014). This is the same for the person living with dementia (Cunningham et al*.,* 2010), but will depend on each individual or current stage of their disease. Various tools are available for self-reporting pain (Guerriero et al., 2016), however the choice of tool should be based on the patients’ ability (Schofield and Abdulla, 2018).

Ngu et al*.,* (2015) evaluated the performance of self-reported pain, nurse reported pain and observational pain tools, amongst 152 older patients with cognitive impairment. The authors highlighted the potential for lack of reliability in self-report and recommended using self-report and observational pain tools concurrently. As assessing pain is not always straightforward, multiple pain assessment methods may be necessary. Pinson, (2015) highlights that poor pain assessment and staff shortages, particularly in ED’s, impact negatively on patients’ receiving adequate pain relief.

Using an observational pain tool will help improve pain management for the person who is unable to self-report their pain (Lichtner et al., 2015; Jones et al., 2017). Employing an exploratory ethnographic approach, Lichtner et al., (2016) identified that when assessing the patient’s pain, some staff looked beyond the pain assessment tool, observing for behavioural clues. This view was also supported by Jones et al., (2017) in a recent narrative review. However, not all staff assess pain in this way, mainly due to their level of knowledge and experience (Lichtner et al., 2016). A meta-review of systematic reviews regarding observational pain assessment tools examined what tools are available for the person living with dementia and in what settings they are being used, taking into consideration their validity and reliability (Lichtneret al., 2014). The authors concluded that although there are many different pain tools available, one could not be identified as superior to any other. Moreover, this study calls for further research involving not only the testing of tools but also the exploration of the contextual elements that may influence their use.

A review undertaken for The Assessment of Pain in Older People: UK National Guidelines (2018) identified several behavioural pain scales. They recognised the Abbey pain scale (1999) as popular in the UK, but acknowledged its lack of validation, since the previous UK National Guidelines in 2007. More recently the guidelines recognised the ongoing validation of the Bolton Pain Assessment Tool (BPAT) within different clinical settings (Schofieldet al., 2018). Gregory (2017) tested the BPAT within four trauma units in the UK. The BPAT not only identifies pain behaviours but also allows for family or carers to be involved in the assessment. However, like Lichtner et al*.,* (2014), the UK National Guidelines (2018) also recognise the need for further testing of existing pain assessment tools.

Emergency nurses’ views on the feasibility and utility of the Pain Assessment in Advanced Dementia (PAINAD) tool in people with a cognitive impairment over age of 65 were reviewed by Fry et al., (2016). The nurses identified the PAINAD tool as the most appropriate tool for these patients within the ED context, stating how it gave structure and acted as a prompt to pain assessment. Although not encompassed within the PAINAD tool, the value of having a multidisciplinary approach to pain management that involves the family/carer within a person-centred environment was recognised in Fry et al,’sstudy. This study suggested several factors responsible for the lack of pain assessment such as the nurse’s experience and the working environment.

An integrative review of the literature by Tsai et al., (2018) discussing the implications for nurses and their practice in relation to pain management for older people with dementia in hospital settings found the observational PAINAD tool to be widely used. Whereas the visual analogue scale (VAS), horizontal VAS and Faces scale were used more for self-reported pain in patients with dementia. Still, there are a number of similarities between the findings in this review and the study by Fry et al., (2016). Tsai et al., (2018) endorsed the importance of pain assessment tools in effective pain management for the person with dementia within acute care, calling for future research to employ novel approaches to help encourage staff to engage in pain assessment.

McCorkell et al., (2017) described the introduction of such a novel approach with the introduction of a ‘Purple Toolkit’ to a trauma orthopaedic unit (TOU), through an action research approach. This Toolkit is a purple folder that raises awareness amongst staff that the person has dementia. Inside are components to help care for the person living with dementia, including an adaptation of the BPAT (Gregory, 2012). This study demonstrated that enhancing a more person-centred approach resulted in improvements to the patients’ pain management.

Gregory (2017) stated that the use of an appropriate pain assessment tool can help standardise the patients’ pain assessment. However, Lichtner et al., (2016) argued that pain information is often gathered in a disjointed way, by different members of staff, at various times. Nevertheless, while pain tools offer guidance, it could be argued that a tool alone is insufficient *per se* to assess pain, and to successfully assess pain the knowledge of healthcare staff and their ability to view the whole older person must be considered (Brown and McCormack, 2011; de Witt Jansen, 2017).

Exploring this further, Tsai et al., (2018) stated that nurses find it challenging to assess pain holistically for people living with dementia, often relying solely on the their clinical judgement. To enhance practice and assist staff assessing pain in individuals with advanced dementia, it has been recommended that further dementia and pain focused education are essential (De Witt Jansen et al., 2017). This is a recurring theme in the literature (Brown, 2011; Gandesha et al., 2012; McAuliffe et al., 2012; Schofield and Abdulla, 2018).

Education is required because at times a person’s behavioural responses to untreated pain may mimic the complex behavioural symptoms often associated with dementia, thereby creating a situation where the person in pain may be misunderstood (Ballard et al., 2011; Sampson et al., 2015). Healthcare staff are therefore required to be knowledgeable in both dementia and pain (van Kooten et al., 2015; Sampson et al., 2015) and to be proficient in pain management (Tracy and Morrison, 2013; Green et al., 2016; De Witt Jansen et al., 2017). In line with this, The UK National Guidelines on the assessment of pain in older people (2018) recommend staff should be provided with the necessary training and education (Guerriero et al., 2016).

Nevertheless, Brown and McCormack (2011) state that education alone is insufficient to improve pain management practices with older people. For education to be successfully sustained in practice there is a need for good communication across the team, strong leadership (Guerriero et al., 2016) and change of culture to transform the care of people with dementia in acute hospitals. Staff and clinical leaders along with other members of the multi-disciplinary teams require the support found in psychologically safe spaces (Brown and McCormack, 2016), if they are to be enabled to make the necessary changes (Evans et al., 2015).

**Communication and family involvement**

One of the barriers to effective pain management for the person living with dementia within acute care is poor communication (Guerriero et al., 2016; Schofield and Abdulla, 2018). Staff need to be skilled in communicating with patients who have lost the ability to communicate verbally (Fry et al., 2016; Tsai et al., 2018). It is also important that staff have knowledge of the patient’s pain history (Gregory, 2015; Dowding et al., 2016), as people with dementia often have underlying painful conditions (Wright, 2014). The patients’ inability to communicate effectively may result in the under assessment and treatment of their pain (Tsai et al., 2018). In these instances families can provide valuable information to assist with the patient’s pain management (Adams, 2007; Fry et al., 2015; Scotland, 2016).

In a descriptive qualitative study by Fry et al., (2015), 80 ED nurses discuss their views on the importance of involving family and carers within ED, to facilitate communication of pain. One example given in the study related to a female patient who did not speak clearly enough for staff to understand; however, the patient’s carer was able to understand and have full conversations with her. Fry et al., (2015) stressed the importance of clear two-way communication. Thompson (2015) advised that the patients’ care may also be compromised due to their inability to communicate at the same pace as those caring for them. Further research is therefore required to help nurses find a way to communicate and work better with families (Fry et al., 2015).

Drawing on the importance of including family/carers, Dowding et al., (2016) highlighted the need for pain management to encompass a biopsychosocial approach. This approach places the person living with dementia at the centre of care (Dowding et al., 2016) and actively includes the family. The effects of these holistic approaches are supported by McCorkell et al., (2017) and Schofield et al., (2018), suggesting that there is a requirement for healthcare staff to enhance their understanding of pain assessment practices alongside a need for further research, that is inclusive of family perceptions of pain management for the person living with dementia within acute care.

**The influence of culture on pain**

While pain management, assessment, education and communication are all vital to enhancing pain management practices in acute care settings, culture and context are also important considerations, if pain management practices are to be sustainably achieved (Brown and McCormack 2011). Ongoing work in this field contends that culture is complex and impacted upon by the different contexts in which care is provided (McCance et al., 2013). Dowding et al., (2016) determined how the busy acute hospital ward, with its many cultures and routines, may be a disorienting and distressing environment for a person with dementia. Dewing and Dijk (2016) suggested that ongoing organisational targets, shorter stays and risk management in a setting where culture remains driven by a bio-medical approach are barriers to pain assessment and management practices. This is further supported with the State of Care report (2015/16) claiming that the challenges faced by staff within acute care are a mix of economic pressures and rising demands, with the greatest task being the flow of patients through the acute care setting (Quality Commission, 2015).

Porock et al., (2015) explored the experience of hospitalisation from the perspectives of the older person with dementia, their family/carer and other patients sharing the ward. The results suggested that taking a person living with dementia out of their usual routine affects family and staff as well as person with dementia. Likewise, Mc Connell (2015) stated that, for staff working in the ED, care is influenced by their working environment. Clevenger et al., (2012) suggested that dementia and the emergency department do not work well together due to staff feeling burdened due to time constraint and lack of resources.

The above findings suggest several different factors that may influence the management of pain for the person living with dementia, such as culture and context within the hospital setting (McAuliffe et al., 2012; Dowding et al., 2016). Brown and McCormack (2011) demonstrated that ward cultures played an instrumental role in the pain management received by older patients. Therefore, to improve this area of care attention should be focused on ward/ unit/ departmental cultures. Evidence for this can be derived from the previously discussed study by McCorkell et al., (2017) where it could be argued that facilitation and change of culture created alongside the implementation of the Purple Toolkit was critical to its success (Kitson et al., 1998).

However creating change in a target driven, task orientated culture may be challenging (Tan et al., 2015). This is echoed by Thomas (2015) who contends that to create a change in culture there is a need for careful consideration of resources within acute care settings, such as staffing numbers, skill mix and support to deliver care that is individualised to the person. Evidence suggests that there is a need for a change of culture within acute care, to one that focuses on valuing the psychosocial needs of the person living with dementia (Clissett et al., 2013; Surr et al., 2016; Dewing and Dijk, 2016) consequently providing better pain management.

**Conclusion**

This review synthesised evidence in relation to dementia and pain management within the acute care setting to discover what is known about the subject. It is evident from the available literature that there are gaps in service provision due to factors such as inadequate pain assessment, lack of communication and professional education. However, this review is limited as so few papers were found relating to the role of the whole healthcare team in managing pain in this patient group. Pain assessment and management is not solely the domain of nurses and this needs to be addressed if real changes in practice are to be realised. To robustly inform future provision there is a need for further research, to improve the multidisciplinary evidence base for pain management for the person living with dementia within acute care.

**Implications for practice**

* Be more aware of the impact that poor pain management has on the patient living with dementia, their family, healthcare staff and the NHS
* Consider involving the family in helping to manage pain
* When the person is unable to verbalise pain, use an observational assessment pain tool
* Pay attention to any pre-existing chronic pain the person may have
* Consider prescribing regular analgesia alongside PRN analgesia

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| Author & DateTable 1 | Aim | Design | Setting |
| Green, E., Bernoth, M., and Nielsen, S., (2016) | To examine if patients with a diagnosis of dementia are less likely to receive pro re nata (PRN) analgesia when they are admitted to an acute care with a bone fracture than patients without a diagnosis of dementia. | Pilot Study using correlation design | Australia |
| Rantala, M., Hartikainen, S., Kvist, T., and Kankkunen, P., (2014) | To describe analgesia, use in dementia patients with a hip fracture during the first two days postoperative as reported by nurses. | Cross sectional descriptive questionnaire  | Finland |
| McCorkell, G., Harkin, D., McCrory, V., Lafferty, M., and Coates, V., (2016) | To increase awareness of the needs of patients with dementia in the trauma and orthopaedics unit of one acute hospital, and to identify ways of improving the care. | Action Research | Northern Ireland |
| Lichtner, V., Dowding, D., Allcock, N., Keady, J., Sampson E.L., Briggs, M., Corbett, A., James, K., Lasrado, R., Swarbrick, C., and Closs, S.J., (2016) | To investigate how pain is recognised, assessed and managed in patients with dementia in a range of acute hospital wards, to inform the development of a decision support tool. | A qualitative, multi-site exploratory case study. | England & Scotland |
| Lichtner, V., Dowding, P., and Closs, S.J., (2015) | To understand current pain assessment practices, in order to later inform the development of a decision support tool.  | An exploratory study  | England & Scotland |
| Fry, M., Arendts, G., and Chenoweth, L., (2016) | To explore emergency nurses' perceptions of the feasibility and utility of Pain Assessment in Advanced Dementia tool in people over 65 with cognitive impairment and then compare it with other pain tools. | Multicentre exploratory qualitative study conducted within a constructivist paradigm | Australia |
| Fry, M., Chenoweth, L., MacGrefor, C., and Arendts, G., (2015) | To understand emergency nurses' perceptions of the role of family/carers in caring for the older cognitively impaired person experiencing pain. | A descriptive qualitative study. Focus Groups using semi structured interviews | Australia |
| Gregory, J., (2016) | To present the findings of initial testing of BPAT | Testing of a behavioural pain assessment tool within trauma units | England |
| Tsai, I., Jeong, S.,Y. and Hunter, S., (2018) | To synthesise evidence about pain assessment and management for older people with dementia in hospital settings and implications for nursing practice. | Integrative literature review | Australia |
| Dowing, D., Lichtner, V., Allcock, N., Briggs, M., James, K., Keady, J., Lasrado, R., Sampson, E.L., Swarbrick, C., and Closs, S.J., (2016) | To provide a revised conceptual model of pain recognition, assessment and management based on sense-making theories of decision making. | Exploratory ethnographic study using nested case sites | England & Scotland |
| Lichtner, V., Dowding, P., Esterhuizen, P., Closs, S.J., Long, A.F., Corbett, A. and Briggs, M., (2014) | To find tools that are available to assess pain for the patient with dementia throughout different care settings and to test their reliability, validity and clinical utility. | A systematic review of systematic reviews of pain assessment tools | England |
| Sampson, E. L., White, N., Lord, K., Leurent, B., Vickerstaff, V., Scott, S., and Jones, L., (2015) | To investigate the prevalence of pain in people with dementia admitted to general hospitals and explore the association between pain and behavioural and psychiatric symptoms of dementia. | Longitudinal cohort study | England |
| Feast, A.R., White, N., Lord, K., Kupeli, N., Vickerstaff, V., and Sampson, E.J., (2018) | To investigate the relationship between pain and delirium in people with dementia, on admission and throughout a hospital admission. | Exploratory secondary analysis of observational prospective longitudinal cohort data | England |
| Ngu, S.J., Tan, M.P., Subramanian, P., Rahman, R.A., Kamaruzzaman, S., Chin, A., Tan, K.M., and Poi, P.J., (2015) | To evaluate the performance of self-reported pain, nurse-reported pain, and observational pain tools among older patients with cognitive impairment. | Prospective observational design. | Malaysia |

Table 2

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| Dementia or cognitive impairment or Alzheimer’s |
| AND |
| Pain or pain management or pain assessment or pain tools |
| AND |
| Acute care or hospital or emergency department or ED |

Table 3

Five databases were searched: Cinahl Plus; Medline; PsycINFO; Cochrane library and; Embase

Additional records identified through hand searching
(n = 28)

Records identified through database searching
(n = 263)

Total records
(n = 291)

Records excluded
(n =276)

Records screened
(n =291)

Full-text articles assessed for eligibility
(n =14)

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