

Pain in people with dementia is often undertreated. Nurses should use recognised assessment tools and tailor pain management to patients' needs

Barriers to the management of pain in dementia care

In this article...

- › **Barriers to effective treatment of pain in people with dementia**
- › **How these barriers could be addressed**
- › **Why more research is needed**

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Pain in people with dementia is increasingly recognised as both under-assessed and undertreated. This review discusses the main barriers to effective assessment and management of pain in this population, strategies to overcome these barriers, and the implications of such strategies for practitioners and researchers. There appear to be gaps in nursing knowledge and inaccurate beliefs about pain in dementia, and further education may address these. More research is necessary to explore barriers and develop further evidence-based strategies to tackle them. Nurses need to be aware of these barriers and become active in overcoming them.

Essentially a condition of older people, dementia affects more than 35 million people worldwide, and it is estimated it will affect 115 million people by 2050 (Alzheimer's Disease International, 2013).

The growing number of older people, particularly those with dementia, places pressure on healthcare providers and services to meet their treatment and care needs as pain is a significant care need and presents a challenge to treatment in dementia (Achterberg et al, 2013). The prevalence of pain is estimated to be in the range of 25-50% in older people living in the community and of 30-49% in those living in nursing homes (Chodosh et al,

2004; Won et al, 2004; McClean and Higginbotham, 2002).

Older people with cognitive impairment, particularly those with dementia, are especially vulnerable to unmanaged pain due to communication problems (Regnard et al, 2003), as they may not always be able to report their pain. As a result, despite being equally susceptible to painful conditions, people with dementia receive fewer analgesics than their cognitively intact counterparts (McLachlan et al, 2011; Horgas and Tsai, 1998).

Self-reporting is essential to both assessment and management of pain and, while older people's inability to communicate they are in pain is a significant barrier, research suggests additional barriers are present (Kenefick and Schulman-Green, 2004). Knowledge of these barriers is limited due to the paucity of research in this area (McAuliffe et al, 2009) but the most commonly cited emerging from existing empirical studies and those most pertinent to nurses and healthcare researchers, are discussed below. These barriers do not exist in isolation and can interact, further hindering accurate pain assessment and delivery of adequate pain management.

Barriers

Barriers identified relate to dementia, organisational factors and to individual patients and healthcare providers.

Dementia-related barriers

Lack of recognition: Weiner and Rudy (2002) demonstrated that pain can go unrecognised, unheard or ignored by nursing home staff and is frequently undocumented, particularly for cognitively impaired residents.

5 key points

- 1** An estimated 115 million people could be affected by dementia by 2050
- 2** The prevalence of pain in older people is estimated to be 25-50%
- 3** People with dementia receive fewer analgesics than their counterparts who are cognitively intact
- 4** One study found three quarters of nursing homes did not use standardised pain assessment tools
- 5** Attitudes and beliefs among patients and nurses can be substantial barriers to effective pain management



Staff training with an emphasis on empathy could address barriers to pain control

Misdiagnosis of behavioural manifestations: behavioural manifestations of pain or verbalisations in people with dementia may be unrecognised or misdiagnosed; this is attributed to difficulties in interpreting the meaning of altered or challenging behaviour (Kovach et al, 2000). Behavioural changes or disturbance in dementia are primarily considered to be a psychological or psychiatric problem, and pain is only considered as the underlying cause as a last resort (Kaasalainen et al, 2007). Confusion and ambiguity around deciphering the meaning of behavioural disturbance can lead to purposely delayed pain management or no treatment at all (Gilmore-Bykovskyi and Bowers, 2013). The ability to read pain cues and behavioural symptoms is further hindered by perceived difficulty connecting with people with dementia (Brorson et al, 2014).

Use of psychotropic drugs: as a result of behavioural disturbance, psychotropic drugs are administered as a first response (Kovach et al, 2000); this may serve as a barrier as they can mask pain symptoms and have adverse side-effects (Frampton, 2003). Kovach et al (2000) indicate that when psychotropic drugs are unsuccessful in reducing behavioural disturbance, analgesics are often administered. The delay in the use of analgesics can impede timely and effective pain management.

Organisational barriers

Lack of training and education: a lack of training and/or education has been cited as a barrier to pain assessment and management by both researchers and nurses (Ghandehari et al, 2013; Kaasalainen et al, 2007). Ghandehari et al (2013) found gaps in nurses' understanding and knowledge of pain in dementia, alongside inaccurate beliefs about pain relief such as those around the regular use of analgesics. Cohen-Mansfield (2014) demonstrated that when nurses are given a choice, they prefer to use non-pharmacological interventions. Poor or dated education is associated with poor recognition of behavioural expressions of pain and an endorsement of unhelpful pain attitudes (Zwakhaleh et al, 2007).

Poor or non-use of guidelines and assessment tools: guidelines on the assessment and management of pain, such as those from the British Pain Society (Box 1), are not consistently used and, in some cases, they are not used at all (Barry et al, 2012). Allcock et al (2002) found 75% of nursing homes in their study did not use standardised assessment tools, with 84% relying on self-reports or observations.

BOX 1. BRITISH PAIN SOCIETY GUIDELINES

Pain assessment tools, particularly observational or behavioural tools, help to identify pain-related behaviour. A combination of methodological pain observation and self-reporting is recommended in mild and moderate dementia.

British Pain Society guidance offers evidence-based guidelines for clinical management including pain assessment tools. It can be found at tinyurl.com/BPS-Pain-Older

Self-reports are important contributions to the assessment of pain (Chatterjee, 2012) and, even though it might not be possible to obtain such contributions from people with severe dementia (Scherder and Plooij, 2012), the consensus is that these reports should always be considered. However, given the ambiguity surrounding behavioural manifestations of pain, their use is a concern. In addition, it is possible the non-use of pain assessment tools relates to concerns raised about their trustworthiness, appropriateness and effectiveness in dementia care (Barry et al, 2012).

Lack of resources: these include inadequate time, insufficient dosage or availability of pain relief, workload demands, poor pain-related communication between healthcare providers, high staff turnover and limited patient/nurse ratios (Brorson et al, 2014; Kaasalainen et al, 2007; Weiner and Rudy, 2002). Lack of resources can hinder nurses' ability to complete pain assessments and administer appropriate pain relief.

Patient and provider barriers

Attitudes and beliefs: older people, including those with dementia, can be stoic and accepting of their pain. They often express hopelessness about being relieved of pain, have fears relating to addiction and are at times labelled "bad patients" for disturbing staff (Chatterjee, 2012). Nurses may also have unhelpful beliefs such as that people with dementia cannot reliably report pain or that there is change to pain processing; they may be uncertain about pain relief, rely on physical pathology and believe that their personal judgment should primarily inform a decision to treat pain (Kenefick and Schulman-Green, 2004). Patients and healthcare providers also have their own cultural attitudes to the meaning and

communication of the pain experience, affecting patients' pain expression and nurses' response to pain (Lovering, 2006).

Provider concerns about use of analgesia: nurses express concerns about the risks of pain relief drugs, particularly those of narcotic opioids. Concerns raised include fears about addiction, drug interactions, tolerance and the suitability of drugs for people with dementia (Kaasalainen et al, 2007; Auret and Schug, 2005). While side-effects and risks are a reality that nurses should be cautious of, concerns about them may relate to inadequate or non-use of pain management (Horgas and Tsai, 1998).

Barriers relating to research: research involving people with dementia is sparse, yet is critical to informing and developing best practices (Monroe et al, 2013). The obstacles to their inclusion in research reflect both ethical and legal issues, and research frequently excludes those with cognitive impairment (Verbeek et al, 2013). There is a lack of research and consensus relating to a number of issues in dementia, such as use of analgesics, pain processing and validation of existing pain assessment tools (Achterberg et al, 2013). The repercussions of such inconsistency and scarcity in research manifest in deficits of knowledge and misinformed attitudes (Barry et al, 2012; Zwakhaleh et al, 2007). In addition, evidence-based innovations in research are sparsely implemented in care settings such as nursing homes, resulting in a gap between scientific knowledge and practice (Verbeek et al, 2013).

Recommendations and strategies

The literature suggests a number of strategies to overcome the barriers cited above. The main strategies are discussed below.

Knowing the person with dementia

Kenefick and Schulman-Green (2004) argue that knowing a person with dementia can improve the recognition of pain and the interpretation of pain behaviours. Familiarity and an emotional connection with the person with dementia assist in detecting changes in personal habits and deciphering the symbolic meaning of pain-related behavioural changes without the use of pain assessment tools (Kovach et al, 2000).

Use of assessment tools and guidelines

The use of guidelines and pain assessment tools, particularly observational or behavioural tools, assists in identifying pain-related behaviours (Zwakhaleh et al, 2006).

Increasing the use of assessment tools would also assist recognition of pain more

generally, in particular for those suspected of having pain or perceived to be susceptible to pain. The combined use of methodological pain observation and self-report, particularly in mild and moderate dementia, is also recommended (Scherder and Plooij, 2012).

Education for staff

The development and implementation of education and training, with an emphasis on empathy, could address many of the barriers discussed above (McAuliffe et al, 2009). However, while some studies have attempted to develop educational initiatives in nursing homes (for example Ghandehari et al, 2013), evidence-based educational and training initiatives in all care settings are yet to be successfully implemented.

Standardised approaches

Barry et al (2012) and Zwakhalen et al (2007) suggested that increasing research, developing standardised approaches to pain assessment and management, and increasing dissemination of existing research could address many of the barriers discussed above. Such an approach would promote evidence-based practice and improve nurses' knowledge and attitudes.

QUICK FACT
30-49%
Prevalence of pain in people living in nursing homes

Better resources

Research recommends that resources need to be improved, including increasing teamwork and communication between staff and providers, assessing pain during daily care so it does not take additional time and improving staff retention (Brorson et al, 2014; Cohen-Mansfield and Mintzer, 2005; Weiner and Rudy, 2002).

Discussion

This review has discussed barriers to the effective assessment and management of pain in dementia, and highlighted strategies to overcome them. Although this review is not exhaustive, the barriers and strategies identified could provide a foundation for improving the recognition and management of pain in adults with dementia.

The barriers highlighted include organisational, dementia-specific, research-related, and patient- and provider-based barriers. These are similar to those identified in reviews from more than a decade ago

TABLE 1. BARRIERS AND WAYS TO OVERCOME THEM

Barriers to pain assessment and management in people with dementia	Ways to overcome them
<ul style="list-style-type: none"> ● Lack of recognition ● Misdiagnosis of behavioural manifestations ● Use of psychotropic drugs ● Lack of training and education ● Poor or non-use of guidelines and pain assessment tools ● Lack of resources ● Attitudes and beliefs ● Provider concerns about use of analgesia ● Lack of research 	<ul style="list-style-type: none"> ● Knowing a person with dementia ● Use of pain assessment tools and guidelines ● Education for staff ● Development and dissemination of standardised approaches ● Increasing resources ● More research

such as that by Gibson (1998). This demonstrates not only the pervasiveness of these barriers but also the inefficacy or absence of strategies to overcome them.

The strategies suggested to overcome barriers range from improving education and training to knowing the person with dementia closely. Such strategies seem intuitive; familiarity with the person with dementia seems to be a valid and appropriate mechanism by which to improve pain recognition. The feasibility of this recommendation depends on the climate of care provision and, with nurses citing lacking time and understaffing, might not be easily achieved. Education, believed to be at the root of many barriers, also appears to be an appropriate course of action, as not all education provided has been effective (Jones et al, 2004).

The literature suggests some nurses informally do assess pain, and are aware that behavioural symptoms can be an expression of pain and that psychotropic medication can be inappropriately used (Kaasalainen et al, 2007; Kovach et al, 2000). Nurses are also aware and concerned about the undermanagement of pain in people with cognitive impairment (Kaasalainen et al, 2007). This, combined with affirmation that they are willing to learn and do more (Schofield, 2006), seems to indicate nurses are open to and in a position to work on the barriers and strategies cited in this review.

The research and recommendations discussed in this review have implications for both practitioners and researchers.

Implications for practice

Nurses should implement validated pain assessment tools where available, conducting baseline and follow-up assessments, while individualising the process to meet the unique needs of individuals with dementia (McAuliffe et al, 2009). In

this approach, self-reports should not be overlooked.

Consistent contact and care with the same patients is also advisable to foster familiarity. Care delivery should be structured to facilitate this, and therefore improve recognition and diagnosis of behavioural disturbance (Kovach et al, 2000). Nurses need to be mindful of their colleagues' and their own attitudes and knowledge deficits, and raise concerns about education. Participating in and collaborating with research would increase the amount of relevant and useful research, and increase evidence-based practice.

Implications for research

Literature on the process of pain assessment and management needs further exploration, particularly on knowledge, attitudes, validation of existing pain assessment tools and the successful development of evidence-based strategies (McAuliffe et al, 2009; Zwakhalen et al, 2007). The lack of research in this area is particularly worrying, given the projected increase in diagnoses of dementia. This shortfall in research could be filled by collaboration with practitioners in varying care contexts.

Conclusion

This review has highlighted the main barriers to the effective assessment and management of pain in people with dementia; other barriers may exist. Its findings point to further research and evidence-based strategies achievable through a collaborative approach by nurses and researchers. When this approach is adopted, the care of vulnerable people with dementia is likely to improve. **NT**

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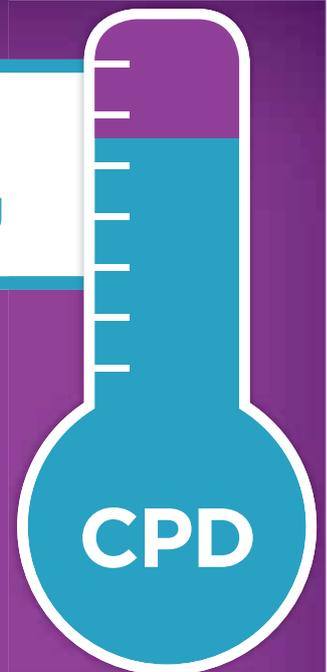
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