Introduction

The literature suggests that pain is a common phenomenon in older people with dementia (e.g. MacDonald & Hilton, 2001; Pickering et al., 2006; McAuliffe et al., 2009). While the causes and incidence of pain in people with dementia are comparable to those for people without dementia, the former are at increased risk of having their pain underassessed and undertreated (Zwakhalen et al., 2009). The reasons for the underassessment and undertreatment of pain in older adults with dementia are numerous (McAuliffe et al., 2009). As older people frequently have more medical comorbidities than their younger counterparts (Hallingbye et al., 2011) and require more prescribed medications (McClean & Le Couteur, 2004), the challenges in improving pain-assessment and management practices are complex. Delivering adequate pain relief to people experiencing chronic, acute on chronic and acute pain across a variety of different community, long-term care and acute settings requires healthcare providers to consider an individualised approach when caring for older people with dementia. Improving pain assessment and management is therefore a key priority for healthcare providers to address.

Aims and objectives

The aim of this paper is to provide a brief overview of recent literature in the area of pain and dementia and, in doing so, highlight key areas that contribute to the underassessment of pain and implications for clinical practice.

Methods

The search strategy involved database searching for literature on pain and dementia published in the English language over
the past five years (2006–2011). Earlier works were also included if deemed relevant by the authors.

Databases searched included Medline, CINAHL, PsycINFO, AgeLine and The Cochrane Library. Search terms included the following keywords: pain, pain measurement, pain threshold, pain perception, chronic pain, neuropathic pain, dementia, vascular dementia, frontotemporal dementia and dementia with Lewy bodies.

Both empirical and literature-based papers were retrieved. All settings were included (e.g. residential care, acute and subacute care, dementia clinics and community settings). Papers that did not focus on older people with pain and dementia were excluded.

Results

Database searching yielded a total of 359 potentially relevant articles. Duplication of material between databases was noted and eliminated. A total of 178 articles were considered for inclusion in the review. The predominant focus of the published literature concerned pain-assessment tools; however, there were several other key themes highlighted by the articles. An overview of key themes is presented below.

Prevalence of pain in people with dementia

There is considerable variation in the prevalence estimates of pain in people with dementia, with this variance being attributed to differences in research methodology, setting and the characteristics of the sample studied. For example, in a study of 216 patients in long-term care, Bjorkman et al. (2008) found pain prevalence to range from 38.4% to as high as 83.8%, simply depending on the assessment tool used. Similarly, Chen et al. (2010) in their study of six long-term dementia care units found pain prevalence ranged from 18% to 30% and 34% to 48%, based on ratings derived from a self-report instrument and behavioural observational scale, respectively.

In the residential aged care (nursing home) setting, recent estimates of pain prevalence in people with dementia are somewhat lower than previously reported. For example, Sengupta et al. (2010) found that 17% of aged care residents with dementia reported or showed signs of pain, as compared with 29% of residents without dementia. The 18–48% prevalence estimate of Chen et al. (2010) reported above is also lower than earlier estimates for the residential aged care setting, which ranged from 48% to 75% (e.g. see Ferrell et al., 1990; Parmelee et al., 1993; Cohen-Mansfield, 2002; Fisher et al., 2002). In the community setting, 32–80% of people with dementia report pain (Shega et al., 2004). Chen et al. (2010) observed that early studies typically excluded those who could not respond verbally from pain prevalence statistics, suggesting that this explains the higher estimates previously reported.

Ascertaining an accurate rate of prevalence is further complicated by the finding that proxy ratings and self-report ratings are not always concordant. For example, a survey conducted in the United States found that 32% of people living with dementia self-reported pain at the time of the survey, whereas proxy ratings for the same sample estimated pain to be much higher at 52% (Shega et al., 2004). Conversely, Chen et al. (2010) found that institutional caregivers were less likely than people with dementia to give a rating of severe pain. Arguably, this is because pain assessment is not based exclusively upon subjective criteria (what the person says). Coincidently, a report of pain entails an objective measurement (how the person looks and acts) in which the healthcare professional tries to develop some understanding of the intensity, quality, location, duration, pattern and emotional impact of the pain being described. However, this approach to pain assessment can be problematic as social attitudes and cultural beliefs, of both the person in pain and the healthcare professional prevail, and may potentially act as a barrier to adequate pain management practices. Thus, it would appear that the choice of pain-assessment tool and how it is utilised is an important determinant as it is likely that many of the pain prevalence rates outlined above are underestimates.

In an alternative approach to using pain-assessment tools alone, a few studies have reported prevalence rates specific to the severity of dementia. A study of patients with severe dementia (MMSE median score + SD = 6.8 ± 3.0) found pain was reported by 44% of patients (Pautex et al., 2006). A study using an observational pain scale in aged care residents with dementia obtained similar results, with the 47% of residents with dementia who reported pain also tending to have severe (MMSE < 7) cognitive impairment (Zwakhalen et al., 2009). Given the complexity involved in detecting and assessing pain in the older person with dementia, researchers need to re-consider approaches to measuring pain if meaningful, accurate prevalence rates are to be obtained.

Causes of pain in people with dementia

Although dementia does not cause pain in itself (as far as has been ascertained by research), older people with dementia are susceptible to the same pain-causing conditions that affect older people without dementia. Pain in older people is associated with chronic underlying health disorders (e.g. arthritis, peripheral vascular disease) and acute pain condi-
tions such as cancer and surgical procedures. Nevertheless, the rates of chronic pain conditions in people with Alzheimer’s disease (AD) are comparable with the rates for older people who do not have cognitive impairment (Table 1).

Medical comorbidity has, however, been found to increase significantly with dementia severity (Doraiswamy et al., 2002; Black et al., 2006). As several pain-causing medical conditions (such as respiratory and urinary tract infections, pressure ulcers and fall-induced fractures) are specifically associated with advanced dementia, unrelieved pain can become problematic. Hampered further by the inability to communicate effectively, people with severe dementia may also be unable to report disease symptoms which in turn complicate the diagnosis of other pain-causing comorbid conditions (Black et al., 2006). This can cause physiological and psychological stress, resulting in an increase in disorientation and the emergence of behaviours that challenge carers and healthcare providers.

Pain processing in people with dementia

It is therefore essential that healthcare professionals have some understanding of the effect that dementia has on people and how this fits with pain and its management. Research suggests that people with dementia may experience pain differently than people without dementia. However, it is unclear whether the pain experience is altered as a result of pain-transmitting nerve fibre function decline (Hallingbye et al., 2011), progressive degeneration of brain regions involved in processing nociceptive information, or whether the difference in pain reporting is attributed to impaired communication and memory of pain.

Benedetti et al. (1999) found that patients with AD had an increased tolerance to pain and that tolerance was the highest amongst those with more severe cognitive impairment. Conversely, Cole et al. (2006) investigated fMRI pain-related brain activity and demonstrated that pain perception and processing were not diminished in Alzheimer’s disease, highlighting concerns about the current inadequate treatment of pain in people with dementia. These concerns are further emphasised by findings of another study that showed the placebo component of analgesic treatment to be disrupted in AD patients (Benedetti et al., 2006), raising the possibility that analgesic treatment may be less effective for some people with dementia and that revisions to analgesic treatment may be needed to compensate for this diminished effect (Scherder et al., 2009).

Dementia subtype and dementia severity are also considerations. Scherder et al. (2009) reviewed the neuropathological effects of dementia on the medial and lateral pain systems and argued that although subtypes of dementia may share common neuropathological features, the degree with which they occur and affect pain-related areas, determines the pattern of changes in pain experience. Support for dementia severity affecting pain also comes from other studies showing that patients with early-to-moderate AD, vascular dementia (VaD) and mixed dementia consistently rate weak stimuli similarly to controls (Gibson et al., 2001; Kunz et al., 2007).

Untreated pain has been observed across all three stages of AD (early, middle and final) and across dementia subtypes (Scherder & Bouma, 1997). It is possible that the risk of undertreatment of pain is particularly enhanced in patients with dementia who have white-matter lesions (which are characteristics of subcortical ischaemic vascular dementia), but may also occur in AD, frontotemporal dementia (FTD) and Parkinson’s disease (PD) as a result of possible increased suffering from pain caused by de-afferentation (Scherder et al., 2003). It would seem the more severe the cognitive impairment, the more pronounced the difference in pain experience between older populations with and without dementia (Scherder et al., 2009). This is potentially an area that requires further investigation.

Assessment and treatment of pain in people with dementia

Alongside the need for an enhanced understanding of pain mechanisms, there is also a requirement for healthcare professionals to gain the necessary skills, knowledge and expertise to enhance pain-assessment and management practices. This is of particular importance as it is well documented that pain assessment is the first most important step to any pain management process (Brown, 2011).

Pain-assessment tools

The literature advocates that the person’s description of their pain is the most reliable and accurate indicator. While the evidence suggests that older people with dementia do not have the ability to report pain or, are less inclined to report it, McClean (2003) proposes that older people with mild-to-

Table 1: Rates for patients with Alzheimer’s disease (AD) compared to non-AD (Pickering et al., 2006)

<table>
<thead>
<tr>
<th>Condition</th>
<th>AD (%)</th>
<th>Non-AD (%)</th>
</tr>
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<tbody>
<tr>
<td>Arthritis/arthritis/osteoarthritis</td>
<td>70</td>
<td>65</td>
</tr>
<tr>
<td>Postsurgical states and fractures</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Neuropathic pain</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>25</td>
<td>20</td>
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moderate cognitive impairment have the ability to report pain as accurately as their younger counterparts, using unilateral pain-rating scales [e.g. using measures such as Visual Analogue Scales (VAS), Verbal Rating Scales (VRS), Numeric Rating Scales (NRS) and Facial Pain Scales (FPS)]. Thus, a pain-rating scale should be used until people are no longer considered to be able to respond to the scale for themselves.

Although self-report is considered the ‘gold standard’ when assessing pain in older people, the communication challenges that dementia presents compromise this process, particularly in the advanced stages of the disease. Lack of verbal communication ability has therefore been identified as a major contributing factor to inadequate assessment and treatment of pain in older adults with dementia (Horgas & Tsai, 1998; Fisher et al., 2006). As dementia progresses and people experience a reduced ability to recall and/or verbalise a self-report of pain, a broader approach to pain assessment becomes necessary. Assessing pain using behavioural indicators can assist healthcare professionals at this stage. There are a number of non-verbal behavioural indicator pain-assessment scales available (Herr et al., 2006a; Zwakhalen et al., 2006) that place the observations of carers/healthcare professionals of the older person into a framework that consists of physiological changes (e.g. colour, vital signs, sleep pattern, guarding, sweating, loss of appetite), body language changes (e.g. agitation, aggression, weeping reaction to touch, increased or decreased movement) and behavioural changes (e.g. facial expression, withdrawal, assuming a foetal position).

Despite the variety of scales existing, the psychometric properties of the tools have been evaluated to be moderate at best (Zwakhalen et al., 2006). It has been argued that behavioural pain tools are reliable and valid if they are appropriately applied, staff interpret the behaviour to be pain, and subsequently administer analgesia with a positive effect (Simons & Malabar, 1995). However, Chapman and Marshall (1993) refute this as they consider that behavioural pain scales rely heavily upon the experience of the user. Kovach et al. (1999) propose that much of the discomfort experienced by patients with late stage dementia is as a consequence of non-physical sources. As behavioural pain scales do not necessarily indicate the nature, both physical and affective (emotional), or the location of the pain being experienced, these dimensions of the patient’s discomfort need skilled clinical consideration.

While debate concerning the most appropriate tool continues (see two recently published systematic and state-of-the-science reviews of pain-assessment tools for use in older adults with dementia e.g. Herr et al., 2006a; Zwakhalen et al., 2006), the American Geriatrics Society (AGS) Panel on Persistent Pain in Older Persons (2002) have outlined six areas that should be incorporated into behavioural pain-assessment charts. They are as follows:

- Facial expression
- Negative vocalisation
- Body language
- Changes in activity patterns
- Changes in interpersonal interactions
- Mental status changes.

Currently, only the Assessment of Discomfort in Dementia Protocol (ADD) (Kovach et al., 1999) and The Abbey Pain Scale (Abbey et al., 2004) incorporate all six areas.

Barriers to inadequate assessment and/or treatment

The conscientious use of a pain-assessment tool across all settings, where older people with dementia are cared for, is a major challenge to improving pain management practices. Alcock et al. (2002) found that 75% of the nursing homes in their study did not use a standardised pain-assessment tool. Although a multitude of pain-assessment tools for use in older adults have been published in recent years (for systematic/state-of-the-science reviews on pain-assessment tools, see Herr et al., 2006a; Zwakhalen et al., 2006), clinical judgement is still required to know which tool is most appropriate to use in a given context. It is important that behavioural pain scales ‘fit’ within the clinical setting in which they are being used. The acute setting does not easily lend itself to labour-intensive pain-assessment scales, whereas people in long-term care long settings may receive enhanced pain relief if multidimensional pain scales are used. Nevertheless, in all settings, people with dementia may receive better pain relief if their pain is assessed in conjunction with family members and carers who may be able to provide some understanding of their history and preferences. Further testing is therefore necessary before any one pain-assessment tool, if one exists, can be recommended for broad adoption in clinical practice (Herr et al., 2006a).

Additionally, deficient health professional knowledge regarding pain in dementia has been identified as a barrier to pain assessment and management. Knowledge deficits have been observed for the areas of: behavioural symptoms of pain; pharmacologic pain management and side effects; addiction, dependence and tolerance; and use of non-pharmacologic strategies (Jones et al., 2004). Zwakhalen et al. (2007) found that nursing staff had knowledge deficits with regard to pain assessment despite being satisfied about the way pain was assessed on their wards. It may be interesting to note that social norms and negative attitudes towards pain assessment frequently prevail and can have an inhibitory
effect on pain management. This suggests that pain-assessment practices are shaped by the social context in which healthcare professionals work (Lauzon Clabo, 2008). Research has also shown that education specific to the specialised areas of pain and dementia is not routinely provided to nursing staff, with one study finding that only 44% of nursing homes provided education for qualified staff, with even fewer (34%) that provided education for care assistants (Allcock et al., 2002). Attitudes that support enhanced pain management approaches and teams who embark upon regular discussions regarding pain, can create a new ‘type of group think’ (Wilde & Mitchell, 2002) that can provide positive outcomes for patients (Brown & McCormack, 2011).

Education programmes need to explore the way in which healthcare professionals respond to pain once they have ascertained its existence. In a prospective cohort study of patients recovering from hip fracture, Morrison and Siu (2000) found that patients with advanced dementia received only one-third the amount of opioid analgesia as patients without dementia. Similarly, Scherder and Bouma (1997) found that only 33% of patients with dementia (in this case, Alzheimer’s disease) received appropriate analgesic medication compared with 64% of control (cognitively intact) patients. These findings were supported by AGS (2002) who reported that people undergoing hip fracture repair were 2:1 less likely to receive opioid analgesia for each five-point decrease in their mini-mental state examination (MMSE) score.

Older people with dementia in community settings appear to fare no better than those in acute environments. Shega et al. (2006) found that 54% reported pain ‘on an average day’. For over half of these people, caregivers did not report analgesic use. Almost half of these people were assessed as having potentially insufficient analgesia, and this was found to be associated with increased age, MMSE < 10, and impairment in daily functioning (Shega et al., 2006).

It could be argued that the finding that people with dementia receive less analgesia is simply because they are assessed as requiring less analgesia than patients who are cognitively intact. However, this explanation is not supported by the findings of Scherder and Bouma (1997), who demonstrated that patients with dementia received less analgesia than their cognitively intact peers despite the two patient groups having been assessed by a physician as having a similar need for pain medication. Therefore, not only are patients with dementia prescribed less analgesia, they are also at risk of not receiving analgesia even when it is prescribed (Horgas & Tsai, 1998). Morrison and Siu’s study (2000) revealed that 83% of patients with dementia did not have a standing order for postoperative analgesia, despite the high likelihood of communication impairment, which has been identified as a major barrier to pain detection, especially in severe dementia. Subsequent studies have found that actual administration of prescribed analgesia does not eventuate in up to 83% of patients (Cunningham, 2006).

Consequences of inadequate assessment and/or treatment

Pain that is inadequately assessed and either untreated or undertreated can contribute to emotional, functional and behavioural impairment in the older person with dementia. Left untreated, pain in this population also has the potential to further exacerbate the existing cognitive impairment (Duggleby & Lander, 1994; Cunningham, 2006).

The full spectrum of consequences of unrelieved pain in persons with dementia can be seen in Table 2. Consequences include depression and anxiety (Parmelee et al., 1991; AGS Panel on Persistent Pain in Older Persons, 2002), sleep disturbance (Cole & Richards, 2007; Wolkove et al., 2007), decreased socialisation (AGS Panel on Persistent Pain in Older Persons, 2002), impaired ambulation (AGS Panel on Persistent Pain in Older Persons, 2002) and increased healthcare utilisation (AGS Panel on Persistent Pain in Older Persons, 2002).

Untreated pain can also result in agitated behaviour. A study that examined the factors that predict the development of aggression in community-dwelling patients aged 60 + years with dementia (n = 215) found that those participants with high pain, or increases in pain, had increased risk of developing aggression (Kunik et al., 2010). Often, concerns regarding treatment-related harm because of the age-related changes in pharmacokinetic and pharmacodynamic processes (Barber & Gibson, 2009) can contribute to the undertreatment of pain in older adults with dementia. Paradoxically, this pain-related agitation often leads to inappropriate treatment with neuroleptics or sedatives rather than analgesia (Geda & Rummans, 1999), which can have the effect of masking symptoms related to pain (Kovach et al., 1999), thus further hindering pain treatment.

Table 2 Consequences of unrelieved pain in persons with dementia
(From Shega et al., 2007)

<table>
<thead>
<tr>
<th>Physical</th>
<th>Psychosocial</th>
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<tbody>
<tr>
<td>Gait impairment</td>
<td>Decrease in daily activities</td>
</tr>
<tr>
<td>Decreased appetite</td>
<td>Impaired cognition</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>Verbal aggression</td>
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<tr>
<td>Agitation</td>
<td>Depression</td>
</tr>
<tr>
<td>Physical combativeness</td>
<td>Social isolation</td>
</tr>
<tr>
<td>Wandering</td>
<td>Learned helplessness</td>
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In terms of types of treatments, both pharmacological and non-pharmacological interventions have been investigated, albeit in relatively few intervention studies, and with most having small sample sizes. Clinical guidelines approved by the American Society for Pain Management Nursing suggest that simple analgesics (acetaminophen) should be used as a first treatment step in non-verbal patients with advanced dementia (Herr et al., 2006b). Further research into acetaminophen treatment for people with moderate-to-severe dementia found that social interaction of residents improved with the analgesic treatment condition (Chibnall et al., 2005; Elliott & Horgas, 2009). However, acetaminophen is only a first-line drug, and other analgesic options and their potential adverse effects (Hallingbye line drug, and other analgesic options and their potential adverse effects (Hallingbye et al., 2011) should be considered depending upon the physiological and pain-assessed needs of the individual person.

While analgesic drugs remain the most commonly used treatment modality (Barber & Gibson, 2009), a combination of both pharmacological and non-pharmacological interventions has been recommended for the management of chronic pain, and recent expert recommendations advocate for the increased use of non-pharmacological pain management strategies in the older person (AGS Panel on Persistent Pain in Older Persons, 2002).

In response to this recommendation, the clinical efficacy of non-pharmacological approaches is beginning to be explored. The use of reflexology in nursing home residents with mild-to-moderate dementia was investigated in an experimental, repeated-measures, crossover design study (n = 21) by Hodgson and Andersen (2008). A reduction in observed pain and physiological stress (as measured by salivary a-amylase) occurred for the reflexology treatment condition, providing some support for reflexology treatment. Meland (2009) reported case studies of the effects of Reiki on pain and anxiety in older adults diagnosed with dementia. Of the three participants who experienced pain, two participants experienced a decrease in average pain. The effect of music on pain was also investigated in a quasi-experimental study of home-dwelling persons with dementia (Park, 2010). Pain levels after listening to preferred music were reported to be significantly lower than before listening to music (t = 2.21, df = 28; P < 0.05), suggesting that music intervention may be beneficial as an adjunct in pain management. However, larger, more rigorous studies are needed to more fully elucidate the effect of these treatments on pain. In addition, research investigating the combined effect of pharmacological and non-pharmacological treatments for pain in the older adult with dementia is required.

Systematic evaluation of interventions is as important as good assessment and treatment of pain in older people with dementia, especially when verbal impairment is present. Improved treatment of pain in people with dementia has been associated with positive outcomes, such as improvements in behaviour and activities of daily life (Buffum et al., 2007), improvements in cognition and depressive symptoms (de Siqueira et al., 2010) and increased social interaction (Chibnall et al., 2005). Several studies have also found that those with recognised and treated pain have better cognitive function (Cohen-Mansfield & Lipson, 2002; Black et al., 2006). These parameters need to be considered when evaluating the effectiveness of any given pain treatment (Scherder et al., 2009).

Conclusion

This paper has provided a very brief overview of the current literature in relation to pain in older adults with dementia. It has indicated that there is a high prevalence of both pain and dementia in older adults in both residential, community and acute care settings. Challenges of pain assessment in the verbally impaired older adult, finding the right pain-assessment tool, considering the most appropriate action to take and deficiencies in healthcare professional knowledge and expertise in the areas of dementia and pain have all been outlined. It is clear that there are many contributing factors to the underassessment and undertreatment of pain and healthcare professionals require practical strategies to alter the context and culture in which they work. There is also a requirement for further research in relation to pain-assessment tools, and changing assessment and intervention practices to at least take account of what research already exists to enhance care for older people with pain and dementia. The implications of these findings for clinical practice are discussed in the next paper in this Practice Development section.

References


