ASSESSING PAIN IN PEOPLE WITH DEMENTIA 1: THE CHALLENGES

AUTHOR Stephen D.M. Smith, BSc, MN, RGN, RMN, is coordinator, dementia/palliative care project, West Lothian healthcare division, NHS Lothian.


This article is the first of a two-part unit on dementia and pain assessment. It examines literature that describes the problem of pain for people with dementia and the challenges nurses face in undertaking pain assessments.

BACKGROUND
Dementia demographics
To understand how much people with dementia experience pain, there is a need to first understand the numbers of people with the condition and the evidence that describes the extent of the problem.

The number of people in the UK with dementia rises annually. It is estimated that 700,000 people have the condition and this is expected to rise to 840,000 by 2010 (Alzheimer’s Society, 2006). Dementia as a syndrome predominantly affects older people and the number of older people is rising in proportion to the rest of the population.

Looking at these statistics, it can be argued that dementia care will have an increasing impact on many families and a variety of service providers.

Pain and people with dementia
With an understanding of these background figures, there is a need to consider the extent and nature of the problem of pain for people with dementia. How many have problems with pain and what types of pain do people experience? Work has been done in a range of dementia care settings where the prevalence of pain has been researched.

In the acute hospital setting, it has been reported that people with dementia received less analgesia following surgery for a hip fracture than older people without cognitive

LEARNING OBJECTIVES
1. Describe the extent and nature of pain experienced by people with dementia
2. Identify the challenges involved in assessing pain for people with dementia

impairment. People with dementia received only a third of the opioid medication received by cognitively intact patients. This research concluded that the majority of people with dementia in the study were in severe pain post-operatively (Morrison and Sui, 2000). The study did not specifically state or investigate the direct experience of pain for people with dementia but drew conclusions from comparisons of analgesia both requested and given. These results are striking and raise further questions.

In a similar way, the use of analgesics in nursing home settings has been researched and findings indicate that people with cognitive impairment are prescribed and administered fewer analgesics than those without impairment (Horgas and Tsai, 1998). It is important to consider the broader issues of pain in older people, as the demographic figures show that people with dementia are mainly in older age groups.

Incidence of pain in older people
A number of authors have highlighted the proportion of older people affected by pain. Herr (2002) identified that 25–80% of older people living in the community experience pain as a problem. Pain has also been described as a common problem for 40–80% of older people living in long-term care facilities (Thomas et al, 2001; American Geriatrics Society, 1998). This means that care provided for people with dementia will require the assessment and management of pain for a quarter of people at home and just under half of those in long-term care settings. These significant figures bring home the need for effective pain management.

Experience of pain
More direct attempts to research the experience of pain for people with dementia have been carried out in long-term care settings. Weiner et al (1999) studied the prevalence of pain and found it to be as high as 83% in these settings. Ferrell (1990) identified that 24% of nursing home residents were in constant pain and only 29% reported no problems with pain.

Moreover, there is a growing body of literature that highlights undetected and untreated pain in people who have dementia which also, importantly, recognises pain assessment as a significant challenge (Kovach et al, 2002; Lefebvre-Chapiro, 2001; Krulewitch et al, 2000; Morrison and Sui, 2000; Weiner et al, 1999).

This evidence highlights a real need for nurses and carers to be looking out for pain as a potential problem within any care setting. If there is any evidence of distress or changes in behaviour, the possibility of pain should be in our minds.

CHALLENGES IN ASSESSING PAIN
Many authors identify the difficulties of assessing pain in people with dementia as a result of diminishing verbal skills as disease progresses (Frampton, 2003; Cohen-Mansfield et al, 2002; Ferrell et al, 1995).

Pain has been described as an essentially personal, private experience; the preferred way to complete an assessment is therefore to encourage the person to describe their pain. Understanding the description, experience and what meaning is attached to the pain are key requirements.

Communication
For people with dementia whose verbal skills are diminishing, this form of report is challenging or may not be possible at all. Ferrell et al (1992) considered the broader challenges of communication for people
with dementia, over and above diminishing verbal skills, which affect ability to participate in a pain assessment.

Cognitive impairment

Specific cognitive impairments in memory may hinder a person’s ability to consider what a pain has been like during the course of a day, when it started, whether it is related to something and what its cause might be. A memory deficit can reduce the information available to the assessor.

Inability to concentrate and maintain attention can also affect participation in a pain assessment.

Loss of language (aphasia) and disturbances in visual spatial skills can further limit the ability to provide detailed information. These losses indicate that simple measures to assess pain should be used, such as abstract measures, for example visual analogue scales. However, assigning a value to describe the intensity of pain may be beyond the capability of some clients.

Visualagnosias, where people with dementia can no longer recognise everyday items, can also affect assessment. A client shown a body map and asked where their pain is may not understand – the picture could be misinterpreted or not recognised at all.

In considering all these issues it would seem that a person with dementia can never participate in pain assessment; this, however, is certainly not the case.

The problems identified above affect people at different times during their dementia and to a lesser or greater degree. When thinking about these issues, the worry is we assume that no participation in pain assessment is possible.

Individual capabilities

Professional carers can take this stance and bypass simple questioning in preference to reporting behavioural observations that may indicate the presence of pain. This second-hand observation may be unnecessary if the client can answer questions. The important issue is to understand the person’s individual and current communication abilities and make the most of these.

OTHER POTENTIAL BARRIERS

Cook et al (1999) identified further elements that are barriers in the assessment of pain. These are reported to be: the reporting habits of older people; the acceptance of these reports by care staff; and the inappropriateness of existing pain assessment measures. Older people report less pain than younger people (Sengstaken and King, 1993; Ferrell et al, 1990).

Miller et al (2000) highlighted that nurses lack the knowledge and skills to assess pain in people with dementia. In addition, beliefs can be present, such as that group of people are unable to report pain and, more fundamentally, that they actually do not experience pain or the sensation is altered as a result of physiological changes caused by their form of dementia.

Care providers’ skills

Another important issue is to consider how much training carers receive about communication with clients. Communication skills in dementia care are vital and form the basis of any pain assessment. Basic features of this communication include, for example, the deliberate use of closed questions and the avoidance of multiple questions. These issues are made more complex by the fact that a large proportion of those providing direct care are unpaid carers or paid staff with limited training. It is the direct care providers who will be in the position of identifying pain. Informing and supporting these carers needs to be a priority if we are to provide effective pain care.

Closs (1996) identified from a survey of 208 nurses that older people in hospital are less likely to complain of pain. The author said that this is because they feel they need permission to complain.

Brockopp et al (1996) surveyed 124 older people about pain and pain assessment. They felt that complaining about pain had implications, namely time in hospital to investigate the cause. They also thought older people were not taken seriously when they complained of pain. Although this survey was small, the findings appear logical. A further scenario is older people may seek to play down pain, in the belief that it comes with old age (Lefebvre-Chapiro, 2001).

CONCLUSION

It is important to use the client’s individual abilities in the assessment of pain and to remember that, as dementia deteriorates, self-reporting of pain is less possible. For multiple reasons older people, in general, report less pain. Communication skills, knowledge about pain and pain assessment, and the attitude of carers are key issues in effective assessment.

Part 2 of this unit, which examines practical steps for effective pain assessment, will be published in next week’s issue.