

Recognition and management of pain in dementia

Due to the increased prevalence of dementia with increasing age, people presenting with cognitive impairment and dementia, either as a main problem or as part of general comorbidity, will be more common. Pain is also more prevalent in older people as they suffer from chronic conditions. This is no different in people with dementia. Here, we discuss the differences that may lie in the detection and management of that pain and in some specific issues around management.

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The dementia spectrum encompasses mainly Alzheimer's disease, Alzheimer's disease with cerebrovascular disease, vascular dementia, Lewy body dementia, Parkinson's disease dementia and frontotemporal dementia. This article will not differentiate dementia-specific, pain-related issues since there is scant evidence that differences exist. In practice, the clinical considerations will range from mild through to the most severe cases of dementia, where end-of-life care, including pain management, is important. These patients will be encountered at home, in hospital and perhaps in the most significant numbers in institutional care.

Aetiology

The causes of pain in people with dementia are not different from those in people without the condition (Table 1).

Prevalence

Prevalence estimates of pain in patients with dementia vary. This is due to the different disease staging methods, patient location and the nature of the survey. The ability to communicate is a key consideration as is whether the pain has been assessed at rest or on movement. A community survey in the US revealed that 32% of dementia

patients self-reported pain at the time of the survey, with 65% rating their pain as mild, 27% as moderate and 8% as severe. Simultaneous caregiver ratings reported current pain in 52% of patients, with 52% of those rated as mild, 30% as moderate and 18% severe.

In this study, 21% of those surveyed had Mini Mental State Examination (MMSE) scores <10, which would usually be

Table 1: Chronic pain conditions in patients with Alzheimer's disease and those without dementia¹

	No dementia	AD
MMSE	23±5	6±7
Arthritis/arthrosis/osteoporosis	65%	70%
Neuropathic pain	16%	15%
Cancer	27%	4%
Post surgery/fractures	6%	5%
Miscellaneous	20%	25%

considered severe dementia.² In a more severe sample (MMSE 6), pain was reported by 44% of patients.³ A more recent study using observational scales in nursing home residents with moderate/severe dementia reported a prevalence of 47%.⁴

Manifestation

The manifestation of pain in people with dementia will depend on a number of factors. There may be very little difference in the perception of acute pain in patients with AD¹ although the severity of the dementia can influence how much the pain is reported by the patient. Thus, the perception of chronic pain in these patients may be reduced. While it is suggested that many people at very advanced stages of dementia can communicate their pain,³ it is a concern that

quite a few may not. Therefore, it becomes essential to realise how pain may manifest and how best to recognise and assess it.

The first consideration is to maintain a high index of suspicion that pain exists. In the initial and subsequent assessments of patients with dementia, it is important to obtain a full history, including details of past medical history and consumption of medication, including over-the-counter medication. In this way, the presence of conditions that may cause pain is identified and should be noted. It has been suggested generally that “pain” should be the fifth vital sign (after pulse, temperature, blood pressure and respiration) and that this should be practised particularly in people with dementia. The problem then with dementia patients is that pain can manifest in different

ways, usually with a change noted in the patient’s condition and often in the presence of neuropsychiatric symptoms.⁵

Thus, in common with people without dementia, pain can affect mood, sleep, appetite, basic (eg. dressing and feeding) and instrumental (eg. driving and management of finances) activities of daily living, and the ability to socialise. Behavioural pain indicators are listed in Table 2.

Assessment

It is therefore important to have a structured approach to the assessment of pain in people with dementia. It is useful to have a cognitive assessment in order to select the best way to approach the patient. The principles of pain assessment in older people have been outlined in a multidisciplinary report (Royal College of Physicians, British Geriatrics Society and British Pain Society).⁶ These are shown in Table 3. As recommended for capacity, it is most useful to assume that the patient can communicate something about pain. This is the common starting point for all patients whether demented or not and there is a hierarchy of assessment (Table 4).⁷

As stated above, an index of suspicion, informed by the history and existing medication, is required. The degree of ability to understand and communicate usually dictates how the approach then proceeds. If the patient can communicate, proceed to assess the severity of pain and its location, take a full

Table 2: Behavioural pain indicators⁵

- Facial expressions:
 - frown, sad, frightened, grimacing
- Body movements:
 - rigid, tense body posture, guarding, fidgeting, pacing, rocking, restricted movement
- Autonomic changes:
 - pallor, sweating, tachypnoea, altered breathing patterns, tachycardia, hypertension
- Verbalisations:
 - sighing, moaning, groaning, grunting, chanting, calling out, noisy breathing, asking for help
- Changes in interpersonal interactions:
 - aggressive, combative resistive, less interactive, inappropriate, disruptive, withdrawn, verbally abusive
- Changes in activity patterns
 - refusing food, appetite change, increase in sleep, cessation of routines, wandering
- Changes in mental status:
 - crying, increased confusion, irritability, distress

history, examine the patient, and treat the cause. As is the case for some patients with chronic pain, the underlying cause may not be readily apparent and further investigations may be needed. Nevertheless, it is important to institute treatment.

The difficulty clearly lies in the individual with severe dementia. Attention should focus on pain-causing conditions, such as arthritis and back pain, and recent clinical changes that could be causing the pain, such as a fall or infection.

If the situation remains unclear, the focus should then centre on observation of behaviours. The key here

is a change in behaviour. The patient's pre-existing status is important as is an awareness of how the patient usually behaves. Common behaviours are listed in Table 2. Clearly some behaviours are associated with pain, such as moaning, facial grimacing and rubbing/holding a part of the body. Others, such as agitation, aggression and behaviours that are more obvious, often prompt discussion of pain, whereas pain may not be an immediate consideration when the patient becomes withdrawn or develops anorexia. Observation at rest and during movement, such as transfers or walking, is important.

There are a number of scales

described in the literature for the non-verbal assessment of pain, which are the subject of extensive reviews.^{8,9,10} These are mainly observational. Each scale should be validated and reproducible, which is not the case for many. Clinicians and nurses should consider which scale is most applicable. For most situations in clinical practice, a simple scale such as the Abbey Pain Scale¹¹ is useful—this is recommended by the British guideline⁶ and is quick and simple to complete. It does not differentiate between distress and pain and is recommended for use during movement, such as transfers and nursing care. Many feel that the usefulness of the Abbey Pain Scale lies in its ability to get a general indication that pain exists.

Many scales are subjective. A recent study reported on the nurse-administered assessment Mobilisation-Observation-Behaviour-Intensity-Dementia Pain Scale (MOBID), which is based upon observations of defined pain behaviour indicators during standardised, active-guided movements for patients with severe cognitive impairment.¹² This is an excellent concept. The scale had good internal consistency and inter-rater reliability, but it needs further validation. A major difficulty can be in distinguishing pain from agitation, which the Mahoney Pain Scale attempts to do.¹³ This appears to be acceptable to nursing staff, is said to take five minutes and involves mapping pain on a diagram. This is a worthy design and will require further study for validation.

Table 3: Key components of an assessment of pain⁶

- *Direct enquiry about the presence of pain*
 - including the use of alternative words to describe pain
- *Observation for signs of pain*
 - especially in older people with cognitive/communication impairment
- *Description of pain to include:*
 - sensory dimension
 - the nature of the pain (eg. sharp, dull, burning etc)
 - pain location and radiation (by patients pointing to the pain on themselves or by using a pain map)
 - intensity, using a standardised pain assessment scale
 - affective dimension
 - emotional response to pain (eg. fear, anxiety, depression)
 - impact: disabling effects of pain at the levels of:
 - functional activities (eg. activities of daily living)
 - participation (eg. work, social activities, relationships)
- *Measurement of pain*
 - using standardised scales in a format that is accessible to the individual
- *Cause of pain*
 - examination and investigation to establish the cause of pain

The assessment of pain in older people: national guidelines. Concise guidance to good practice series, No 8. Royal College of Physicians, British Geriatrics Society and British Pain Society, 2007

Table 4: Hierarchy of pain assessment techniques⁷

- Patient self-report
- Searches for possible causes of pain/discomfort
- Observation of patient behaviours
- Surrogate reporting (eg, caregiver, nursing) of pain
- Analgesic trial

An attempt should be made to assess pain severity. In mild to moderate dementia, a verbal rating scale or numerical rating scale is recommended. Whilst for more severe degrees of dementia, a coloured visual analogue scale seems best (British Guideline).⁶ Scales used should use large writing and be applied in good light. Vertical rather than horizontal scales are preferred.

Patients will be residing at home or in institutional care and may also be seen in the acute setting. The views of caregivers and nurses are therefore useful. It is important that nurses and other healthcare professionals are educated about pain, and that caregivers are educated about its importance. This is because surrogate reporting forms an important part of the hierarchy of assessment. This relates mainly to changes in the patient's condition or behavioural patterns.

It may still be unclear whether the patient is in pain and its exact cause and severity. In this case, the decision ought to be to proceed with a trial of analgesia. The analgesic chosen will depend on assessment of pain severity. Although the patient may be manifesting neuropsychiatric symptoms and

there may be pressure to initiate psychotropic medication, using an analgesic trial to validate the presence of pain before starting the psychotropic medication has several advantages: response will be seen more quickly with analgesia, adverse reactions to analgesics are usually less serious than those to psychotropic medication, and pain will not be obscured by the sedative properties of psychotropic agents.⁷ Still, it remains a concern that pain manifesting as neuropsychiatric symptoms is initially managed using a psychotropic approach. These medications are associated with increased sedation, accelerated cognitive decline and increased mortality.

Management

The key to successful pain management is prompt recognition, assessment, intervention, monitoring and documentation. Management involves both non-pharmacological and pharmacological approaches. Since people with dementia are usually older, there are concerns about adverse events. Comorbidity, in particular renal function, and concurrent

medication need to be considered. Regular analgesia is important and the route of drug delivery is also a consideration. The approach to analgesia is based on the WHO analgesic ladder (Table 5).¹⁴ Adjunctive medication approaches may be necessary.

Where communication is not considered a problem, it may be straightforward to evaluate pain severity. However the principles of pain management in communicative and non-communicative patients with dementia are similar. Non-pharmacological approaches, such as physiotherapy, cold or heat therapy, massage, supportive verbal communication and music therapy, are worth consideration.¹⁵

For continuous pain, long-acting or sustained-release formulations are necessary, and medications should be given regularly. Regular paracetamol is the recommended starting point for treating mild pain. Caution is needed in patients with hepatic impairment. Non-steroidal anti-inflammatory drugs (NSAIDs) are used with great caution in older people with dementia, and many geriatricians try to avoid extended use to reduce gastric, cardiovascular and renal adverse events. The main indication for NSAIDs would be bone pain. For this reason, opioids tend to be used more frequently, in particular for moderate to severe pain. This may be in the form of compound analgesia, such as codeine and paracetamol combinations initially. The use of charts that refer to the doses of opioids as morphine equivalents

are useful. It may be necessary to use scheduled doses of short-acting medications, titrated as necessary and then converted to long-acting formulations. A major consideration is renal function. It has been reported that, for all opioids with the exception of buprenorphine^{16,17} the half-life of the drug and metabolites is increased in older people and those with renal impairment. This implies that lower doses, increased dosing intervals and monitoring of renal function are necessary. There is some evidence that hydromorphone and fentanyl have safer profiles in patients with renal dysfunction so can be used with caution.¹⁸ The adverse events of confusion and sedation are the main considerations in people with dementia. Opioid-induced bowel dysfunction, often manifesting as constipation or dyspepsia, can induce further neuropsychiatric symptoms, and so must be addressed.

For neuropathic pain, pregabalin or gabapentin could be considered; lower starting doses are needed and renal function is important. Both can cause drowsiness and sedation in older people with dementia.

Tricyclic antidepressants, such as amitriptyline, nortriptyline and desimipramine, have been used. The major problem with these drugs in dementia, even at low doses, is their anticholinergic side-effects, which can worsen cognitive impairment. Topical analgesia, such as the lidocaine patch, can be useful due to the lack of systemic effects.

One issue that can be a problem in people with dementia is the issue of drug delivery. Some patients may not be able to swallow or may refuse or spit out medication. Liquid formulations may be required although this often does not help in chronic pain as these are not generally long acting. Transdermal drug delivery is useful and can often be the most effective method of ensuring that the patient is getting analgesic medication delivery at a sustained level.

Summary

Pain is common in people with dementia and may not be recognised. A particular challenge is in patients with dysphasia or severe dementia. Often a change in the patient's

clinical condition, in particular in relation to neuropsychiatric symptoms, is the indication. A high index of suspicion that pain might be present is necessary, informed by previous history and existing analgesia. This will ensure that pain is less likely to be overlooked. There are practical scales that can be used for assessment where communication is difficult.

Management options are the same as for non-demented people and a main consideration is renal function. The other main issue with dementia lies in possible central adverse events due to the analgesia used, although any adverse event in this population can exacerbate the situation. Drug delivery issues are also a major factor as compliance needs to be ensured.

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Table 5: WHO pain relief ladder

STEP 3	Strong opioid eg. morphine, hydromorphone, oxycodone, buprenorphine, fentanyl, methadone
STEP 2	Weak opioid eg. codeine, dihydrocodeine, tramadol
STEP 1	Non-opioid eg. aspirin, ibuprofen, diclofenac, cox-2 inhibitors, paracetamol

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