Assessing pain in people with dementia

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Mrs Watson is 85 years old, lives in a nursing home and has moderately severe dementia. She has occasional falls and no longer walks. Her talk is often confused and she is resistive to nursing staff during her morning shower. Occasionally she is found crying. Could she be in pain?

Pain in the elderly can be difficult to recognise for a variety of reasons – the most salient being dementia. Dementia may limit a person's ability to communicate any pain they experience. A greater duty of care therefore may rest with the physician in assessing and managing pain in people who cannot adequately manage the pain themselves. This becomes increasingly challenging as the dementia advances. Communication becomes more limited and changing cognitive function can impact on the person's understanding of their pain experience. These barriers make pain assessment more difficult (but not impossible) and highlight the importance of good pain assessment in this vulnerable group.

Where to start?

Dementia may impact on the perception and experience of pain, partly due to compromised affective and cognitive processing.[1,2] However, the consequences of this are still unclear. Certainly there is no evidence to show that people with advanced dementia are unable to experience pain. Therefore, the assumption should be that any condition indicative of pain in people without dementia is also painful in those with dementia.[3] The predominate pain-related condition for older people is musculoskeletal pain,[4] although pain related to internal organs and neurological conditions are also common.[5] Any pain conditions (such as osteoarthritis) should be flagged and previous injuries (such as fractures) should be suspicious as potential sources of recurring pain.

Self-report is the 'gold standard' for pain assessment and may still be meaningful for people with dementia. Word scales have the best chance of being endorsed by people with cognitive impairment, with one study showing that in a sample of nursing home residents with moderate dementia, 83% could still complete at least one self-report scale.[6] Despite anecdotal concerns about the accuracy of self-report in people with dementia, considerable evidence demonstrates the reliability and validity of this approach provided the answer is consistent with the context of the assessment scale. If self-report is not possible, proxy ratings from carers or family or the use of a behavioural observation scale become necessary. If using proxy ratings be mindful that medical staff generally underestimate pain whereas family tend to overestimate it.[7]

Key points

- **Dementia can be a significant barrier in pain assessment.**
- **Self-report scales may still be appropriate for people with dementia.**
- **If self-report is not possible, proxy scales and behavioural observation scales may be necessary.**
- **Mobilisation is critical for an effective pain assessment in people with dementia.**

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Hence for a more systematic assessment of pain in people with dementia, it is strongly advised to use self-report (if possible), in conjunction with behavioural observational scales.[8] See Box 1 for some examples of self-report pain assessment scales that can be used in people with dementia.

Behavioural observation scales

Most observational scales assess the presence of pain by evaluating the three main behavioural indicators of pain – facial expression, vocalisation and body language. There are many well-validated scales that have been developed for people with dementia, for example, the ABBEY, Non Community Patient's Pain Assessment Instrument (NOPPAIN) and Pain Assessment in Advanced Dementia (PAINAD) scales, have all been shown to be effective in detecting the presence of pain, as well as the severity (see Box 2).[9,10,11] There are a number of benefits in using these scales – it is a systematic approach to pain assessment, the scales quantify what you see, and when used over a period of time they allow for an unbiased evaluation of any pain treatment or a better understanding of how a painful condition may be progressing.[12] Although many behaviour scales may not explicitly state this in their instructions, moving the person's body while using these scales is essential.

1. Examples of self-report scales

a. Verbal Descriptor Scale

Please indicate the words that best describe the current level of pain:

___ The most intense pain imaginable
___ Extreme pain
___ Severe pain
___ Moderate pain
___ Mild pain
___ Slight pain
___ No pain

b. Visual Analogue Scale

No pain — Worst pain imaginable

Mobilisation

Pain from tissue damage or inflammation (nociceptive pain) is often exacerbated by movement; therefore, getting the person to move may trigger any underlying pain conditions. The method of mobilisation that you use is not so important, as long as you observe a comprehensive range of body articulation. If thwe person can weight-bear, have them stand and observe them walking.

2. Examples of behavioural observation scales

a. ABBEY Pain Assessment scale[9]

Q1. Vocalisation e.g. whimpering, groaning, crying	Absent 0	Mild 1	Moderate 2	Severe 3
Q2. Facial expression e.g. looking tense, frowning, grimacing, looking frightened	Absent 0	Mild 1	Moderate 2	Severe 3
Q3. Change in body language e.g. fidgeting, rocking, guarding part of the body, withdrawn	Absent 0	Mild 1	Moderate 2	Severe 3
Q4. Behavioural change e.g. increased confusion, refusing to eat, alteration in usual patterns	Absent 0	Mild 1	Moderate 2	Severe 3
Q5. Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor	Absent 0	Mild 1	Moderate 2	Severe 3
Q6. Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injuries	Absent 0	Mild 1	Moderate 2	Severe 3

Total score = ☐

0–2	3–7	8–13	14+
No pain	Mild	Moderate	Severe

b. Pain Assessment In Advanced Dementia (PAINAD) scale[10]

Item	0	1	2	Score
Breathing independent of vocalisation	Normal	Occasional laboured breathing, short period of hyperventilation	Noisy laboured breathing, long periods of hyperventilation, Cheyne–Stokes respirations	
Negative vocalisation	None	Occasional moan or groan, low-level speech with a negative or disapproving quality	Repeated troubled calling out, loud moaning or groaning, crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body language	Relaxed	Tenses, distressed pacing, fidgeting	Rigid, fists clenched, knee pulled up, pulling or pushing away, striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			Total	

Total scores range from 0 to 10 with a higher score indicating more severe pain (0 = no pain to 10 = severe pain).

If the person is unable to walk, then passive assisted movement is necessary. Manually test upper and lower limbs through a full range of available movement, with emphasis on shoulder, wrist, knee and ankle joints. Manipulation of the fingers can often also provoke pain. Finally test the person's back and neck with gentle rotation.

During mobilisation, pay particular attention to how the person reacts. Do they complain or moan? Does their facial expression change to a grimace or do they shut their eyes tight? Do they resist or stiffen up when you try to move a certain joint? Are they afraid, agitated or anxious? These are all indicators of pain and suggest further investigation is warranted.

Abnormal pain responses

Complaints of tingling, numbness, shooting or burning pain may be indicative of pain due to a malfunction of the nervous system (neuropathic pain). If a neuropathic condition is suspected, a clinical examination with appropriate sensory testing of abnormal pain responses may be possible in certain cases.

Both allodynia (when a normally non-painful stimulus is perceived as painful) and hyperalgesia (an increased sensitivity to a painful stimulus) are associated with neuropathic pain. Brush tests and pin-prick tests may be appropriate in identifying allodynia and hyperalgesia, respectively. However, the ability of such sensory testing to assist with differential diagnosis in people with advanced dementia has yet to be reported and validity, reliability, sensitivity and specificity require further study in this population.

Behavioural and psychological symptoms of dementia

Research suggests that pain may trigger behavioural and psychological symptoms of dementia (BPSD). Social disruption, repetitive behaviours, resistance, aggression and agitation are BPSD that all increase with pain, with only wandering being shown to decrease in people with pain.[13] A large open study in 2011 has shown that use of analgesics were as effective as antipsychotics at reducing BPSD (particularly agitation) in nursing home residents.[14]

Analgesic interventions

The final step in pain assessment is to consider prescribing a suitable analgesic for a short period of time (a few weeks). For people with suspected neuropathic pain, anticonvulsants or antidepressants should also be considered. Ask the carer or family to pay close attention to how the patient behaves during this time, and compare this with how the patient was before the intervention. If the patient is in care, ask the nursing staff to start a behaviour chart for use before, during and after treatment. If behaviours improve, then you have stronger evidence of underlying pain. But keep in mind that pain relief may not be the foremost consideration. Has function improved? Is the patient more active, more mobile? Evidence shows that inactivity is often the strategy most used to reduce pain.[4] Has mood improved? Does the patient seem less agitated or less depressed? These may be entirely appropriate benchmarks as to whether analgesics are effective and needed.

Conclusion

When a person has dementia, a greater duty of care for pain assessment and management may rest with the physician. Pain has a dramatic impact on the course of dementia, and may quicken cognitive deterioration and precipitate functional decline.[15] Disruptive BPSD may also be triggered by unrelieved pain. Standardised assessments using self-report scales and observational behaviour scales can be used in conjunction for patients with dementia. The use of mobilisation is critical for effective pain assessment.

Could Mrs Watson be in pain? Although her talk may be confused, she may still respond to a simple word-based self-report scale. Her resistance to showering may be due to underlying pain that is exacerbated with movement. A mobilisation routine used with a behavioural observation scale may elucidate any pain. Crying may be directly or indirectly related to pain, so a short analgesic intervention may improve her function and mood state. **PMT**

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