

Pain Measures for Persons with Advanced Dementia

Pain in Dementia

Pain is more common in older persons than in younger cohorts, and compromises the quality of life of those who experience it. As the perception of pain is subjective and varies between individuals, self-report is often considered the gold standard for pain assessment.¹ Though a person's mental capacity of self-monitoring and reflecting their inner state appropriately may deteriorate as dementia progresses, feedback via self-report should not be disregarded completely and still sought in mild to moderate stages of dementia.² It is therefore advisable to adapt the form of the self-report assessment to the abilities of persons with mild to moderate dementia, and to concurrently use an observational tool.²

However, as dementia progresses to more advanced stages with more severe cognitive and language deficits, individuals are unable to clearly communicate their experience of pain, which can then go undetected and under- or untreated.³ Pain can worsen delirium and contribute to changed behaviours as well (for example, a person can become more depressed or aggressive) when it is under- or untreated.^{4,5} Hence, the use of observational pain measures may be more appropriate for the moderately severe to advanced stages of dementia.

Existing Observational Pain Measures

A reliable and valid observational pain assessment to detect pain and measure its intensity, especially in moderately severe to advanced stages of dementia, is essential to providing adequate treatment. It is widely agreed that observational pain tools should look at three behavioural domains that reflect an individual's state of pain, and that include their facial expressions, verbal expressions and body movements.⁶ Over the years, several observational assessments measuring the 3 domains have been developed to measure pain in dementia. The following are some examples that are more frequently used:

- Abbey Pain Scale⁷;
- Non-Communicative Patient's Pain Assessment Instrument⁸ (NOPPAIN);
- Pain Assessment Checklist for Seniors with Limited Ability to Communicate⁹ (PACSLAC);
- Pain Assessment in Dementing Elderly¹⁰ (PADE);
- Checklist of Nonverbal Pain Indicators¹¹ (CNPI); and
- Pain Assessment in Advanced Dementia⁶ (PAINAD).



The University of Iowa has listed down a number of existing non-verbal pain behaviour tools as of 2019, with varying psychometric properties and clinical utility. The institution provides each tool and a summary of it in PDF documents for users to download.¹²

Many systematic reviews have been conducted to evaluate and compare the reliability, validity and clinical utility of existing observational pain measures for dementia but with differing results and conclusions.^{1,3,13-15} Some reviews concluded that certain tools have adequate psychometric properties and demonstrated good test sensitivity to differentiate between painful and non-painful states, like the abovementioned list of tools^{3,13,15}. Others have indicated that no one pain measure appears to be more reliable and valid than the others. None of them seems to be the most appropriate to use, as there were variations in how the psychometric properties, feasibility, and clinical utility were assessed, and as they were conducted on small samples.¹



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