PAIN MEASURES FOR PERSONS WITH ADVANCED DEMENTIA

TOOLS FOR DEMENTIA PRACTICE & RESEARCH

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 use an observational tool concurrently.[2]

However, as the condition of persons living with dementia progresses to more advanced stages, during which these persons experience more severe cognitive and language deficits, they become unable to clearly communicate their experience of pain and to use self-report measures. Under such conditions, pain can go undetected and be under-treated or untreated.[3] It is important that pain treatment is not missed for many reasons: the presence of pain compromises the person's well-being, worsens delirium, and contributes to behavioural changes (for example, a person can become more depressed or aggressive) when pain is under-treated or untreated[4,5]. Pain measures help carers measure the pain, describe it, and treat it. During the moderately severe to advanced stages of dementia, observational pain measures make it possible to do so, and they are more appropriate than self-report measures for this purpose.

Existing Observational Pain Measures

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

- Abbey Pain Scale[7];
- Non-Communicative Patient's Pain Assessment Instrument[8] (NOPPAIN);
- Pain Assessment Checklist for Seniors with Limited Ability to Communicate[9] (PACSLAC);
- Pain Assessment in Dementing Elderly[10] (PADE);

- Checklist of Nonverbal Pain Indicators[11] (CNPI); and
- Pain Assessment in Advanced Dementia[6] (PAINAD).

The University of Iowa has compiled a list 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 format for users to download [here](.)[12]

An Evaluation of Observational Pain Measures

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 are variations in how the psychometric properties, feasibility, and clinical utility were assessed, and as they were conducted on small samples.[1]

References

1. Lichtner, V., Dowding, D., Esterhuizen, P., Closs, S. J., Long, A. F., Corbett, A., & Briggs, M. (2014). Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. *BMC Geriatrics*, *14* (138), 1-19. http://www.biomedcentral.com/1471-2318/14/138

2. Achterberg, W., Lautenbacher, S., Husebo, B., Erdal, A., & Herr, K. (2020). Pain in dementia. Pain in dementia. *Pain Reports, 5*(1), e803. doi: 10.1097/PR9.0000000000000803

3. Zwakhalen, S. M., Hamers, J. P., Abu-Saad, H. H., & Berger, M. P. F. (2006). Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools. *BMC Geriatrics, 6*(3), 1–15. doi: 10.1186/1471-2318-6-3.

4. Marzinski, L. R. (1991). The tragedy of dementia: Clinically assessing pain in the confused non-verbal elderly. *Journal of Gerontological Nursing, 17*(6), 25-28.

5. Sentagen, E. A., & King, S. A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society, 41*(5), 541-544.

6. Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *Journal of the American Medical Directors Association, 4*(1), 9-15. doi: 10.1097/01.JAM.0000043422.31640.F7.

7. Abbey, J., Piller, N., Bellis, A. D., Esterman, A., Parker, D., Giles, L., & Lowcay, B. (2004). The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing, 10*(1), 6-13*.* doi: 10.12968/ijpn.2004.10.1.12013.

8. Snow, A. L., Weber, J. B., O'Malley, K. J., Cody, M., Beck, C., Bruera, E., Ashton, C., & Kunik, M. E. (2004). *NOPPAIN: A Nursing Assistant-Administered Pain Assessment Instrument for Use in Dementia. Dementia and Geriatric Cognitive Disorders, 17*(3), 240-246. doi:10.1159/000076446.

9. Fuchs-Lacelle, S. & Hadjistavropoulos, T. (2004). Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing, 5*(1), 37-49. doi: 10.1016/j.pmn.2003.10.001.

10. Villanueva, M. R., Smith, T. L., Erickson, J. S., Lee, A. C., & Singer, C. M. (2003). Pain assessment for the dementing elderly (PADE): Reliability and validity of a new measure. *Journal of the American Medical Directors Association, 4*(1), 1-8. doi: 10.1097/01.jam.0000043419.51772.a3.

11. Feldt, K. S. (2000). The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing, 1*(1), 13-21. doi: 10.1053/jpmn.2000.5831

12. The University of Iowa. (n.d.). *List of nonverbal pain behavior tools 2019.* https://geriatricpain.org/pain-behavior-tool-critique

13. Ammaturo, D. A., Hadjistavropoulos, T., & Williams, J. (2017). Pain in dementia: Use of observational pain assessment tools by people who are not health professionals. *Pain Medicine, 18*(10), 1895-1907. https://doi.org/10.1093/pm/pnw265

14. Carezzato, N. L., Valera, G. G., Vale, F. A. C., & Hortense, P. (2014). Instruments for assessing pain in persons with severe dementia. *Dementia Neuropsychologia, 8*(2), 99-106. doi: 10.1590/S1980-57642014DN82000003

15. Lints-Martindale, A. C., Hadjistavropoulos, T., Lix, L. M., & Thorpe, L. (2012). A comparative investigation of observational pain assessment tools for older adults with dementia. *The Clinical Journal of Pain, 28*(3), 226–237. doi:10.1097/ajp.0b013e3182290d90