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PAIN OR NO PAIN? THAT IS THE QUESTION

**An evaluation of the observational pain
assessment instrument Abbey Pain Scale in
patients with cancer**

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Title

Pain or no pain? That is the question - an evaluation of the observational pain assessment instrument Abbey Pain Scale in patients with cancer.

Abstract

Background: The Abbey Pain Scale (APS) is an observational pain assessment instrument that was created for use among patients with dementia. It is sometimes used in Sweden to assess pain in patients with advanced cancer who are unable to vocalize their pain, but it has never been evaluated in this population.

Aim: To evaluate observational pain assessment for people with advanced cancer in a palliative care setting, focusing on the APS.

Methods: The APS was translated and adapted into a Swedish dementia context through interviews with health care professionals (n=11). The resulting APS-SE was then used in a qualitative content analysis exploring health care professionals' experience of using the instrument in patients with advanced cancer (n=12). The psychometrics of the APS-SE when used in patients with advanced cancer (n=72) were determined through test-retest and inter-rater reliability, internal consistency reliability, and responsiveness to opioids. Criterion validity was determined against the patients' self-reported pain (n=45).

Results: The APS-SE was comprehensible by users within dementia care, regardless of their educational and linguistic background. The qualitative analysis revealed that when used in patients with advanced cancer, the APS-SE fulfilled the need for an observational pain assessment instrument, but was not always on target and did not fully suit the clinical situation. The psychometric analysis showed slight criterion validity ($\kappa=0.08$) and unacceptable internal consistency reliability (Cronbach's $\alpha=0.01$). The test-retest reliability was good (ICC=0.82) and the inter-rater reliability moderate (ICC=0.64), but the latter had a confidence interval ranging from poor to good. Responsiveness to opioids was demonstrated ($p=0.01$).

Conclusions: This thesis underscores the need for a specialized observational pain assessment instrument explicitly tailored for patients with advanced cancer. The current lack of a recognized alternative emphasizes the importance of developing such an instrument to address the critical gap in observational pain assessment in the palliative oncology setting.

Keywords:

Abbey Pain Scale, APS-SE, cancer pain, observational pain assessment, advanced cancer, end-of-life care, palliative oncology.

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