“I don’t need a piece of paper with scores to tell me that somebody’s in pain and I need to do something about it”. Nurses’ and healthcare assistants’ perspectives on and use of pain assessment tools with people dying with advanced dementia

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Background: The use of pain assessment tools with patients with advanced dementia is widely recommended in healthcare policy but their impact on clinical outcomes for dying patients is unclear. Healthcare assistants have a significant role in caring for the dying but their contribution to pain recognition is unexplored.


Methods: Semi-structured, face-to-face interviews were conducted with 24 nurses and 14 healthcare assistants. Thematic analysis of verbatim transcripts was used to identify emergent themes. Three researchers confirmed final themes.

Results: The Abbey Pain Scale formed part of the pain assessment protocol for nurses across care settings but most reported challenges in using it with dying patients. Scores based on brief observation were perceived as a poor substitute for knowledge of the patient, observation over time and collateral history from healthcare assistants and family. Most nurses reported pain tools resulted in no measurable clinical outcomes for patients nearing death. Healthcare assistants described methods of recognising and reporting pain and their role in observing for treatment response and side effects. Nurses and healthcare assistants described mixed experiences discussing pain with physicians.

Conclusion: Nursing staff described challenges with integrating pain assessment tools in practice and preferred patient knowledge, observation and collateral history from family and healthcare assistants to assess pain. The contribution of healthcare assistants in recognising and reporting pain and in assessing treatment response is described. These findings have important implications for health policy, nurse education and healthcare provision.

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