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Exploring healthcare assistants’ role and experience in pain assessment and management for people with advanced dementia towards the end of life: a qualitative study

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Abstract

Background: Pain assessment and management are critical aspects of care for individuals with dementia nearing the end of life. However, challenges arise when patient self-report is compromised or unavailable. Observational pain assessments are recommended in such cases, but healthcare professionals often face difficulties in their application without additional patient information. Little research has focused on the role, perspectives, and experiences of healthcare assistants in pain assessment and management in dementia care, highlighting the need for exploration in this area.
Methods: This qualitative study utilized key informant interviews with healthcare assistants caring for individuals with advanced dementia nearing the end of life, across hospice, nursing home, and acute care settings. Thematic analysis was employed to interpret interview data collected .
Results: Fourteen participants, predominantly female with an average of 15.4 years of caring experience, contributed to the study. Three key themes emerged: recognizing pain, reporting pain, and the need for upskilling. Participants demonstrated the ability to identify obvious and subtle indicators of pain, drawing on their extensive knowledge of patient norms. Effective pain reporting was influenced by professional relationships and perceived value in their role, impacting the thoroughness and accuracy of pain reports. Participants expressed a desire for additional training, particularly in the use and reporting of basic pain assessment tools.
Conclusions: Healthcare assistants play a crucial frontline role in patient care, often being the first to detect changes suggestive of pain and communicate with professional staff. However, addressing stigma associated with their role and providing opportunities for upskilling are essential to enhance the quality of pain assessment and management in dementia care.
Keywords: Dementia, Palliative care, Pain assessment, Pain management, Healthcare assistants

Background

Pain is a common issue among individuals with dementia, often stemming from advanced age and various comorbidities. However, recognizing and assessing pain in this population poses significant challenges due to extensive cognitive decline, which can limit or eliminate patient self-reporting and increase the risk of inadequate pain assessment and treatment. In cases where patient communication is limited or impaired, healthcare professionals rely on observing behavioral and nonverbal cues, such as grimacing, guarding, frowning, moaning, agitation, and aggression, as potential indicators of pain in nonverbal individuals with cognitive impairment. (Bunn et al., 2014)

To facilitate standardized pain assessment, professionals use structured tools to assign estimated pain severity scores to each observed behavioral indicator and then aggregate these scores to derive an overall pain estimate for the patient. However, challenges arise in using these tools due to the overlap of behavioral indicators with signs of other non-pain related conditions like hunger, distress, and boredom. Therefore, it's recommended to interpret assessment scores in conjunction with additional patient information and collateral knowledge. (Klapwijk et al., 2014)

As the workload of nurses and physicians increases, leading to reduced direct patient contact, healthcare assistants (HCAs) play a crucial role in providing direct care. HCAs, also known as nurse auxiliaries, healthcare support workers, or personal/clinical support workers, work under the supervision of Registered Nurses (RNs) in healthcare and social care settings. Their responsibilities include personal care, hygiene maintenance, assisting with eating and toileting, providing social and psychological support, and basic housekeeping tasks. Due to their extensive time spent with patients, HCAs often develop detailed knowledge of patients' preferences, routines, and behavior patterns, making them adept at recognizing changes in patients' physical and cognitive status. (Hendriks et al., 2015)

While previous research has explored the impact of HCAs on patient care in various contexts, including older adults, palliative care, and dementia, there is a lack of studies focusing on HCAs' perspectives and experiences in pain assessment and management for nonverbal patients with advanced dementia nearing the end of life. This study aims to fill this gap by investigating HCAs' insights into pain assessment and management in this challenging and crucial clinical area across hospice, acute care, and nursing home settings. It is part of a broader research program addressing pain assessment and management in this complex patient group, with several related articles already published. (Jordan & Lloyd-Williams, 2010)

Study Population and Sample

Criterion purposive sampling with maximum variation in age, educational attainment, and care experience was employed to recruit healthcare assistants (HCAs) caring for individuals with advanced dementia nearing the end of life or who had recently passed away. Participants were selected from hospice, secondary care, and nursing home settings), to capture diverse perspectives due to the range of end-of-life care contexts for people with dementia. Index contacts, including consultant physicians from acute care (geriatric medicine n = 2; palliative medicine n = 2, psychiatry n = 1), Medical Directors of hospices (n = 4), and nursing home managers (n = 5), facilitated recruitment by disseminating study information, including a cover letter, participant information sheet, and contact consent form, via email or in hard copy to eligible HCAs. Additional settings recommended by these index contacts were explored, and study information was provided following the same protocol.

Study Design, Data Collection, and Analysis

Semi-structured key informant interviews were conducted to explore participants' experiences and perspectives on pain assessment and management in advanced dementia. This approach allowed participants flexibility in describing their experiences and perspectives within the overarching topic, facilitating the identification and exploration of convergent and divergent themes. The interview schedule consisted of 10 questions developed through literature review on pain assessment and management in dementia, as well as studies involving HCAs in palliative care, dementia, and other patient populations. Questions were refined based on feedback from the Project Management Group (PMG) to ensure the study's focus was adequately addressed.

Data collection occurred with interviews conducted at participants' workplaces in private rooms away from other staff, patients, and families. Before the interviews, participants received a verbal summary of the project's aims, interview procedures, data analysis methods, and data handling protocols. Written informed consent was obtained from all participants, who were informed that the interviews would be digitally recorded. No incentives were offered for participation. Ethical approval was obtained from the Office for Research Ethics Committees

Verbatim transcripts of the interviews were created and cross-checked against the recordings by two PMG members for accuracy. Thematic analysis, following Braun and Clarke's approach, was used to analyze the qualitative data. Units of data were coded by content and grouped into themes, which were then reviewed against the raw data and labeled to reflect their content. The analysis process was documented, and findings were discussed and confirmed by the PMG in regular meetings.

Results

Fourteen healthcare assistants (HCAs) took part in the study, with an average age of 44.9 years (range: 20 to 62 years), and the majority were female (n = 13). Most participants had experience caring for people with dementia in various settings throughout their careers. On average, participants had 15.4 years of caregiving experience (range: 1 to 27 years).

The key themes derived from the data, supported by quotes from participants, are presented in Table 1 and elaborated on below.

Participant Characteristics (n/%)

- **Gender**
    - Male: 1 (7%)
    - Female: 13 (93%)
- **Care Setting (Specialty)**
    - Nursing Home: 9 (64%)
    - Acute Care (Hospital): 2 (14%)
    - Hospice: 3 (31%)
- **Length of Clinical Experience**
    - Average: 15.4 years
    - Range: 1 year to 27 years

Recognizing Pain

Most participants acknowledged pain as a significant concern for people with dementia, particularly for those unable to communicate their pain. While formal pain assessments were not mandatory, HCAs often conducted informal, relationship-centered pain assessments based on their daily interactions with residents. They used their knowledge of residents to identify changes in behavior, nonverbal cues, and deviations from normal activities as potential signs of pain or distress. However, some participants faced challenges in recognizing pain in certain residents.

Knowing the Resident

Frequent interactions with residents allowed HCAs to develop comprehensive knowledge about their preferences, behaviors, and physical condition. They noticed changes that could indicate pain or other health issues, such as altered appetite or toileting patterns. This familiarity with residents enabled them to identify potential causes of pain, like contractures or bruises, during care activities.

Observing and Interpreting Behavioral and Nonverbal Indicators of Pain

Although HCAs were not trained in formal pain assessment tools, they observed residents for behavioral and nonverbal cues associated with pain. This included facial expressions, movements, and changes in behavior. HCAs relied on their holistic understanding of residents to distinguish pain-related indicators from other states. Some HCAs mentioned difficulties in recognizing pain in newly admitted residents, prompting them to seek additional information from various sources.

Reporting Pain

All HCAs reported pain concerns to nursing staff, but the quality of reporting varied. HCAs with positive work relationships felt encouraged to report detailed observations and monitor patients' responses to pain relief. In contrast, those with negative relationships reported perfunctory reporting or relied solely on nurses' assessments.

Positive and Negative Work Identities and Relationships

Positive work-related identities and relationships led to thorough pain reporting and collaborative care. HCAs felt valued and supported in discussing patient concerns. Conversely, negative relationships resulted in vague reporting and communication breakdowns.

Upskilling

Most HCAs believed in the need for ongoing training to improve pain assessment and management skills. They expressed interest in learning standardized assessment tools like the Abbey Pain Scale and monitoring treatment responses. However, they criticized the current e-learning platforms for being unengaging and ineffective in addressing their learning needs.

Conclusion

The study highlighted HCAs' critical role in pain assessment for people with advanced dementia. Positive work environments and ongoing training are essential for enhancing their abilities and improving patient care outcomes.

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