Original Study

Epidemiology of Pain in People With Dementia Living in Care Homes: Longitudinal Course, Prevalence, and Treatment Implications

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ABSTRACT

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Introduction: Knowledge regarding the longitudinal course, impact, or treatment implications of pain in people with dementia living in care homes is very limited.
Methods: We investigated the people with dementia living in 67 care homes in London and Buckinghamshire, United Kingdom. Pain, dementia severity, neuropsychiatric symptoms, depression, agitation, and quality-of-life were measured using appropriate instruments at baseline (N = 967) and after 9 months (n = 629).
Results: Baseline prevalence of pain was 35.3% (95% CI 32.3–38.3). Pain severity was significantly correlated with dementia severity, neuropsychiatric symptoms, depression, agitation, and quality of life at both time points. Regular treatment with analgesics significantly reduced pain severity. Pain was significantly associated with more antipsychotic prescriptions. Pain was significantly associated (OR 1.48; 95% CI 1.18–1.85) with all-cause mortality during follow-up.
Conclusions: Pain is an important determinant of neuropsychiatric symptoms, mortality, quality-of-life, and antipsychotic prescriptions. Improved identification, monitoring, and treatment of pain are urgent priorities to improve the health and quality-of-life for people with dementia.

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There are 850,000 people with dementia in the United Kingdom (UK), representing a major public health issue that costs the UK economy over £26 billion each year.[1] One-third of people with dementia reside in long-term care facilities.[2] These individuals have highly complex treatment and care needs resulting from moderate to severe dementia, associated mental health symptoms, medical comorbidity, and communication difficulties.[3] Pain is common in people with dementia living in care homes and is a major contributor to the challenge of care. Pain is often associated with medical comorbidities, particularly musculoskeletal conditions and long-term neuropathic conditions such as diabetes.[4,5] Despite widely available treatment options, pain is often unrecognized or untreated because of difficulties in identifying and assessing pain in this patient group. Impairment in verbal communication, and insight into their condition is inherent in the later stages of dementia, thus, hindering timely diagnosis and effective pain management.[6]

Despite the importance of pain as a key driver of health and well-being in people with dementia in care homes, there is a concerning lack of consensus regarding its prevalence and epidemiology in these settings. Within the evidence base, studies principally evaluating the prevalence, nature, and mental health correlates of pain in people with dementia living in care homes are few in number and usually based on modest samples,[5,7] often including people without dementia, with disparate prevalence estimates for pain ranging from 19.8% to 73.0%.[8,9] Three large longitudinal studies have been published, involving 3926, 5761, and 372 care home residents across European care homes and reporting a prevalence of pain of 48.4%, 50%, and up to 67.6% respectively.[7–9] However, none of these studies employed validated observational pain assessment instruments designed specifically for measuring pain in people with dementia and communication difficulties and, thus, detailed interpretation of the outcomes cannot be made.[8,9]

Initial evidence suggests that pain may be associated with behavioral symptoms[10] including agitation, aggression, and depression,[11,12] and the risk of polypharmacy in people with dementia. These issues are major drivers of quality of life (QoL), which suggests a potential association, but no study has examined the specific impact of pain and its intensity on QoL. More robust studies are needed to establish the true correlations between pain and these important health-related outcomes. To date, no study has used standardized measures of neuropsychiatric symptoms to examine association with pain.

There is a clear need for robust evaluation of the epidemiology, associations, and impacts of pain in people with dementia to build on the current evidence base and inform the development of optimal pathways for assessment, monitoring, and treatment. Despite the importance of pain as a clinical issue in dementia, the guidance available for physicians is limited. A recent review of available guidelines has identified only 3 clinical guidelines for managing pain in dementia, of which none are tailored for the unique environment presented by a care home.[6] Such lack of robust clinical guidelines adds to the difficulties in optimally managing pain and related mental health symptoms in this population, and highlights the need to fully understand the issues around pain management in this setting. Hence, this research aimed to conduct the first comprehensive large longitudinal study examining the nature, prevalence, and impact of pain exclusively in people with dementia living in care homes using a validated pain measure, and to assess the longitudinal course of pain and its associations with mental health symptoms, and QoL in people with dementia.

Methods

Study Design

This longitudinal study used data from the Well-Being and Health for People with Dementia National Institute for Health Research (NIHR) program and has been ethically approved (National Research Ethics Service Committee South Central-Oxford C Reference: 13/SC/0281).

Setting

Sixty-seven care homes were recruited across sites in South London, North London, and Buckinghamshire, UK. Suitable care homes were initially searched using local care home directories. Care homes were included, if at least 60% of their residents had dementia and they demonstrated minimum acceptable standard of care according to the Care Quality Commission. Care homes that received local authority special support, had insufficient staffing resource, were undergoing systematic service improvement programs or another research, or anticipated major internal changes within the next 12 months were excluded. Consent for care home involvement was obtained from the management of the homes.

Participants

All residents in the participating care homes meeting diagnostic criteria for dementia, and having a score of one or greater on the Clinical Dementia Rating Scale[13] were invited to participate. If residents lacked capacity, informed consent was obtained with the involvement of a nominated or personal consultee, who represented the residents' interests, and wishes in accordance with the Mental Capacity Act, 2005. Cluster sizes (the number of recruited participants per care home) varied from 12 to 25 participants.

Outcome Measures

Pain was assessed using the Abbey pain scale (APS).[14] APS is a brief observational pain assessment instrument, designed specifically for measuring pain in people with dementia, who cannot verbalize. APS includes 6 nonverbal indicators of pain, vocalization, facial expression, change in body language, behavioral change, physiological change, and physical changes, which are rated absent (0), mild (1), moderate (2), or severe (3). Total APS score ranges from zero to 18, and pain is considered to be present when the total APS score is 3 and above. Total scores between 3 and 7 indicate mild pain, moderate pain is defined as scores between 8 and 13, and severe pain is defined as a score of 14 and above. APS also categorizes the type of pain as acute, acute on chronic, or chronic.[14] The Functional Assessment Staging Tool (FAST),[15] a validated functional assessment scale in people with dementia, was employed to assess the severity of dementia. Agitation, depression, and mental health symptoms in dementia of the participants were evaluated using the Cohen-Mansfield Agitation Inventory (CMAI),[16] Cornell Scale for Depression in Dementia (CSDD),[17] and Neuropsychiatric Inventory-Nursing Home version (NPI-NH),[18] respectively. QoL of the participants were systematically assessed by the caregiver version of assessment of QoL for people with dementia (DEMQoL-Proxy),[19] and by the QoL in Late-Stage Dementia (QUALID) scale.[20] Higher DEMQoL-Proxy scores indicate better QoL, while lower QUALID scores reflect better QoL. Trained research assistants completed the assessments at baseline, and after 9 months.

Statistical Analyses

Participants' characteristics, their clinical profile, and APS scores were initially analyzed by descriptive statistics. Differences between subgroups were analyzed by appropriate tests of statistical significance. Correlations between APS scores and FAST, CSDD, CMAI, DEMQoL-Proxy, and QUALID scores were assessed using Spearman rank-order correlation with Bonferroni corrections at baseline and at the follow-up. Associations between the changes in pain severity and