

Title: The palliative care symptoms of people with dementia on admission to a mental health ward.

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A recent systematic review suggests that between 2%-8% in of people with dementia die during their admission to a mental health ward¹. Furthermore, estimates suggest that between 16.4%-46% of people with dementia will die within a year of discharge^{2,3}. The high levels of distress and behavioural disturbance that typically trigger such an admission may overshadow a person's palliative care needs and will make the assessment of these needs more complex. As part of a single-site service improvement project, we sought to describe the palliative care needs of people with dementia on admission to a mental health ward and to examine the relationship between palliative care needs and neuropsychiatric symptoms.

The site is a 14-bed mixed-sex inpatient dementia ward in the North of England. Data was collected for a 12-month period between the 31st January 2022 to 31st January 2023. We examined routinely collected data on patient characteristics and outcomes. Neuropsychiatric symptoms were assessed using the Neuropsychiatric Inventory-Questionnaire (NPI-Q⁴) which is routinely collected at admission and discharge. The NPI-Q⁴ was performed as an interview a member of the nursing team. The symptoms were registered as present or not, and, if present, the severity of the symptom ranged from 1 to 3, giving an item score ranging from 0 to 3 and a sum score of the scale ranging from 0 to 30. The Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem⁵) was newly introduced to the ward as part of an approved service improvement project to improve recognition of palliative symptoms. The IPOS-Dem is designed to detect and assess palliative symptoms in people with dementia The IPOS-DEM asks for symptoms across three domains: (1) physical symptoms, (2) emotional, social and existential (ESE) concerns, and (3) family concerns.

Over the 12-month period 30 people were admitted to the ward. The average length of admission was 109 days (range 34-225). The majority of patients were male (60%) and the mean age was 75.6 years. Alzheimer's disease formed the main diagnosis (43%), followed by mixed (26.7%); six people did not have a diagnosis at admission and five of these were subsequently diagnosed with dementia. At admission the number of average comorbidities per person was 1.4, (SD 0.9). Most people were admitted to the ward from an acute hospital (66.7%), of these 12 (60%) were previously living at home and eight (40%) in residential care. Other routes to admission included residential care (20%) and from home (13.3%). Only one patient had an advanced care plan in place at admission.

Two data sets were incomplete for the NPI so total number of patients assessed was 28. In terms of distress, the average NPI-Q total score on admission was 22 (SD 14), the most common symptoms were anxiety (89.3%), irritability/lability (85.7%) and agitation/aggression (85.7%).

All patients had some symptoms that were recorded on the IPOS-Dem. Figure 1 shows details of symptom prevalence and severity. ESE concerns were the most prevalent and severe with a mean item score of 1.6 (SD 1.3) compared to physical symptoms with a mean score of 0.4 (SD 0.9) and family concerns with a mean score of 2.9 (SD 1.2).

A Pearson correlation coefficient was computed to assess the relationship between NPI-Q and IPOS-DEM scores. Results indicated a non-significant small positive relationship, $r(26) = .117$, $p = .552$. Meaning that those people with the highest NPI scores also had the highest IPOS-Dem scores.

The assessment of palliative care needs in people with dementia is challenging⁶⁷, particularly in the population of people with dementia admitted to mental health wards who have some of the most complex care needs. However, if these palliative needs are undetected and undertreated, they are likely to add to a person's distress. Our findings indicate the range of concerns experienced at the point of admission and highlight the importance of undertaking a thorough assessment of palliative care needs. The diagnostic overshadowing of behavioural and psychological symptoms⁷⁸ particularly in the context of a mental health wards is a concern. We propose that the IPOS-Dem can provide a feasible and acceptable way to support the assessment and management of palliative care symptom and concerns in mental health wards.

Figure legends

Figure 1: Prevalence and severity of physical symptoms, ESE concerns and family concerns

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Conflicts of Interest: The authors have no conflicts of interest to declare.