Featured Article

Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data

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Abstract

Introduction: A fall in hospital deaths in dementia has been interpreted as indicating an improvement in end-of-life care. Whether other indicators of quality of end-of-life care, such as emergency department (ED) attendance, show a similar trend is unclear.

Methods: Retrospective cohort study using electronic medical records from a large mental health care provider, linked to national mortality and hospital use data (2008–2013).

Results: Of 4867 patients, 78.6% (3824) had at least one ED attendance during their last year of life (mean 2.13, standard deviation 2.34, range 0–54). ED attendance increased over the time period (incidence rate ratio 1.62, 95% confidence interval 1.46–1.80 for 2012–2013 compared with 2008–2009).

Discussion: ED attendance in the last year of life for people with dementia is common and is increasing. Policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death.

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Keywords: Dementia; End-of-life; Emergency department; Palliative; Policy

1. Introduction

Over the past decade there has been a strong policy focus in the UK and elsewhere on dying out of hospital as a marker of good quality end-of-life care [1,2]. A fall in hospital deaths and a reciprocal increase in home deaths during this time period have been considered to suggest success of these strategies [3]. However, the place of death only provides a snapshot of the care received by a patient at the end of their life, and does not tell us about the care received during their last weeks and months.

Emergency department (ED) visits for people who are approaching the end-of-life can be distressing for patients and families and challenging for staff, and are considered potentially preventable in a high proportion of cases [4]. At a population level, ED use toward the end-of-life has been used to indicate poor quality of care [5]. For people with dementia, ED visits and acute hospital care can lead to cognitive and physical deterioration with increased risk of hospital acquired infections, bedsores, and worsening of behavioral problems [6]. However, ED attendance among people with dementia remains common [7], and studies in the United States have shown that ED use rises sharply as death approaches [8]. Whole population mortality data analysis has shown that hospital deaths in dementia in England began falling in 2005/2006 [9]. Whether other indicators of poor

quality end-of-life care in dementia such as ED attendance show a similar trend is not known.

Routinely collected data, for example, mortality data, are increasingly used in end-of-life care research and offers the methodological advantage of negating the challenges of primary data collection in this potentially vulnerable population [10]. Furthermore, routine data analysis is usually more economical and timely than primary data collection, and can be carried out for large population-based samples [5]. However, research in this area is limited by a paucity of relevant clinical information in administrative data and incomplete recording of data [11]. Linking administrative with clinical data can overcome these limitations, while allowing examination of outcomes in naturalistic samples and settings [12]. The aim of this study was to use linked data from a large mental health database to examine the frequency, and identify predictors, of ED attendance among people with dementia in their last year of life.

2. Methods

2.1. Setting and data source

This retrospective observational study used data from the South London and Maudsley National Health Service (NHS) Foundation Trust (SLAM) Biomedical Research Centre Case Register and the Clinical Record Interactive Search (CRIS) data extraction tool. This data resource has been described previously [13–17]. It provides researcher access to full anonymized copies of electronic medical records from SLAM, one of Europe's largest mental health care providers covering a geographic catchment of 1.2 million residents in four boroughs of South London. SLAM delivers a comprehensive range of services, including dementia assessment and treatment. Data are currently archived on more than 300,000 cases with a range of mental disorders.

2.2. Population

The records of all patients with a diagnosis of dementia recorded in SLAM and who were aged 60 years or older at death were retrieved from the SLAM Biomedical Research Centre Case Register. Diagnosis of dementia was determined from structured fields in the source record (based on ICD-10 codes F00x-03x) and supplemented by a bespoke natural language processing algorithm using General Architecture for Text Engineering software [18]. This extracts information from unstructured text data within clinical records (including correspondence and case notes), returning text strings associated with diagnostic statements [13,19,20]. CRIS data have been linked with Office for National Statistics (ONS) death certification data, and this linkage was used to identify cohort members who had died, restricting the analysis to this group. CRIS is also linked to Hospital Episodes Statistics (HES), a record-based system covering all NHS Trusts in England, which was used to determine ED attendance during the last 12 months of life.

Because the HES-ED linkage is only available in CRIS from April 1, 2007, the cohort was restricted to those who died after April 1, 2008 so that 12 months of HES-ED data were available for all patients before death.

2.3. Covariates

CRIS was used to extract data on age, gender, ethnicity (White British, Other White, African Caribbean, other, not known) and recorded dementia subtype (Alzheimer's disease, vascular, unspecified, Lewy body, unknown). Socioeconomic status was estimated from the 2015 Index of Multiple Deprivation, a measure of relative deprivation for small areas termed Lower Super Output Areas (LSOAs) in England, with LSOAs ranked from 1 (most deprived) to 32,844 (least deprived). Index of Multiple Deprivation was derived from the LSOA associated with the patient's most recent address (at the time of death) and converted into quintiles for ease of interpretation. Dementia severity was estimated from the most recently recorded Mini–Mental State Examination (MMSE) score, drawn from a structured field in the source record and a further General Architecture for Text Engineering information extraction application [13,17]. The most recent Health of the Nation Outcome Scale (HoNOS) was also ascertained from the source record. HoNOS is a functional outcome measure used routinely in mental health care and comprising 12 subscales each rated 0 (no problem) to 4 (severe or very severe problem). We dichotomized the HoNOS scores (scores of 0 and 1 were grouped as no or minor problems, scores of 2, 3, and 4 represented mild to severe problems) to facilitate interpretation. Care home residence was determined from a data linkage to residential postcode. Linkage with ONS death certification data provided information on the place of death, which was categorized as private residence/own home, hospice, hospital, care home (including residential and nursing homes) and "other" (e.g., prisons, street). Place of death was categorized from free text provided by ONS by one author (K.E.S.) and independently checked by a second author (G.P.). Where there were discrepancies these were discussed and a category was agreed. The time interval (in months) between the last face-to-face contact by a SLAM staff member and death was determined using the date of death from ONS mortality data. The age at death was determined from the date of death in ONS mortality data and the date of birth in CRIS. Information on ED attendance, mode of arrival (ambulance or other), referral mode (via GP, emergency services, or self-referred), outcome of ED attendance (admission to hospital, discharge with GP follow-up, or discharge with no follow-up), and time of attendance was determined using the HES-ED linked data. Out of hours was defined as 8 PM to 8 AM on weekdays, or any time on Saturday, Sunday, and Bank Holidays.

The primary outcome was number of ED attendances in the last year of life, modeled as a continuous variable.