

## RESEARCH PAPER

# A population-based retrospective cohort study of end-of-life emergency department visits by people with dementia: multilevel modelling of individual- and service-level factors using linked data

LESLEY E. WILLIAMSON<sup>1</sup>, JAVIERA LENIZ<sup>2</sup>, EMEKA CHUKWUSA<sup>1</sup>, CATHERINE J. EVANS<sup>1,3</sup>,  
KATHERINE E. SLEEMAN<sup>1</sup>

<sup>1</sup>King's College London, Cicely Saunders Institute, London SE5 9PJ, UK

<sup>2</sup>Departamento de Salud Pública, Escuela de Medicina, Pontificia Universidad Católica de, Santiago, Chile

<sup>3</sup>Sussex Community NHS Foundation Trust, Brighton General Hospital, Brighton BN2 3EW, UK

Address correspondence to: Lesley E. Williamson, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, Bessemer Road, Brixton, London SE5 9PJ, UK. Email: [Lesley.Williamson@kcl.ac.uk](mailto:Lesley.Williamson@kcl.ac.uk); Tel: 020 7848 5544

## Abstract

**Background:** emergency department (ED) visits have inherent risks for people with dementia yet increase towards the end-of-life. Although some individual-level determinants of ED visits have been identified, little is known about service-level determinants.

**Objective:** to examine individual- and service-level factors associated with ED visits by people with dementia in the last year of life.

**Methods:** retrospective cohort study using hospital administrative and mortality data at the individual-level, linked to health and social care service data at the area-level across England. The primary outcome was number of ED visits in the last year of life. Subjects were decedents with dementia recorded on the death certificate, with at least one hospital contact in the last 3 years of life.

**Results:** of 74,486 decedents (60.5% women; mean age 87.1 years (standard deviation: 7.1)), 82.6% had at least one ED visit in their last year of life. Factors associated with more ED visits included: South Asian ethnicity (incidence rate ratio (IRR) 1.07, 95% confidence interval (CI) 1.02–1.13), chronic respiratory disease as the underlying cause of death (IRR 1.17, 95% CI 1.14–1.20) and urban residence (IRR 1.06, 95% CI 1.04–1.08). Higher socioeconomic position (IRR 0.92, 95% CI 0.90–0.94) and areas with higher numbers of nursing home beds (IRR 0.85, 95% CI 0.78–0.93)—but not residential home beds—were associated with fewer ED visits at the end-of-life.

**Conclusions:** the value of nursing home care in supporting people dying with dementia to stay in their preferred place of care must be recognised, and investment in nursing home bed capacity prioritised.

**Keywords:** dementia, end-of-life, emergency department, emergency care, community care, care homes, older people

## Key Points

- Being resident in a local authority with more nursing home beds (but not residential home beds) was associated with fewer emergency department (ED) visits.
- There was a negative dose–response association between emergency department (ED) visits and increasing socioeconomic position.
- Being of South Asian ethnicity was associated with more emergency department (ED) visits in the last year of life.
- Access to clinical continuity may help to reduce reliance on emergency department (ED) visits for people with dementia who are nearing the end-of-life.

## Introduction

Emergency department (ED) visits are common among people with dementia who are nearing the end-of-life [1]. The number of ED visits is observed to increase with proximity to death, with a quarter made within the last month of life [2]. These visits can be distressing [3], and risk secondary complications in hospital [4].

A recent systematic review of international literature identified moderate-to-high strength evidence that having lower socioeconomic position, being from ethnic minority backgrounds and living in more rural settings were associated with higher ED visits among people nearing the end-of-life (defined as likely to be in the last year of life [5]), whereas care home residence and palliative care input were associated with lower ED visits [6]. The review concluded that community services may have a role in mediating end-of-life ED visits. Improving community care to reduce hospitalisation is a policy priority [7, 8], but understanding how to achieve this is limited.

Although community service use is associated with ED visits towards the end-of-life [9], this has only been examined at the individual level. Area-level service factors, such as workforce and service capacity, are likely to influence end-of-life service use [10]. Given the ‘postcode lottery’ of access to health and social care in England, a population-based examination of potentially modifiable service factors could inform policy to improve end-of-life care for people with dementia. We therefore aimed to examine individual- and service-level factors associated with ED visits by people with dementia in the last year of life.

## Methods

### Study design and settings

This retrospective cohort study used routinely collected data to examine factors associated with ED attendance in last year of life. Socio-ecological models of end-of-life care [10, 11] and previous population-based studies of end-of-life service use [2, 9, 12] informed the reporting of results as sociodemographic, clinical and service factors, with the latter comprising workforce and capacity.

We used the REporting of studies Conducted using Observational Routinely-collected Data (RECORD) extension of STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines [13].

### Data sources

We used routinely collected administrative data from national Hospital Episode Statistics (HES) from National Health Service (NHS) Digital, linked with Civil Registrations of Deaths from the Office of National Statistics (ONS). The HES database comprises data reporting patient contacts with care delivered by all NHS hospitals in England. We used two HES datasets: ED attendance (HES Accident & Emergency) and inpatient care (HES Admitted Patient

Care). Mortality data from Civil Registrations of Deaths were available as a ‘secondary care cut’, which linked to the HES datasets. This cut limited mortality data to date, place and cause of death (including underlying cause of death and any mention), and decedent gender [14].

Data on service-level factors were from publicly available health and social care service datasets (Supplementary data S1). We derived primary care and adult social care workforce data from NHS Digital [15] and Skills for Care [16], respectively. We derived bed numbers in care homes, with and without nursing care, from the Care Quality Commission (CQC) [17]. We obtained the number of General Practitioner (GP) surgeries from NHS Digital [15] and type 1 EDs (consultant-led department providing 24-h emergency care [18]) from NHS Digital in response to a Freedom of Information request posted online [19]. We obtained numbers of urgent care centres, minor injury units and walk-in centres from the CQC [17] and categorised them as ‘urgent treatment centres’ for simplicity.

### Data access, cleaning and linkage

Individual-level data were linked using encrypted patient identifiers, with the quality of each match ranked from one (highest quality match) to eight (lowest quality match). Similar to other studies [12], we removed data with match ranks three to eight, as these data are partially matched or matched using less reliable measures [14]. We also removed cases with addresses outside England. We removed cases where the only hospital contact was an outpatient appointment, as these cases comprised mortality data only.

We used Upper Tier Local Authorities as the geographical unit of analysis, retrieved from the ONS Geoportals [20]. Local authorities are areas of local government responsible for protecting and improving health and wellbeing of the local population [21]. When datasets did not include local authority details, data were linked to local authorities by postcode, using the ONS Postcode Directory file, November 2019 version [22]. The ONS Postcode Directory comprises all UK postcodes linked to local authorities, electoral wards, Clinical Commissioning Groups and Lower Layer Super Output Areas (LSOAs).

### Ethical approval and other permissions

There was a single flow of linked pseudonymised record-level data from NHS Digital to King’s College London, under Data Sharing Agreement DARS-NIC-365602-V5H3Z. As we used previously collected, non-identifiable information from decedents, the study did not require ethical approval.

### Study sample

The cohort comprised adults (aged  $\geq 18$  years) who: (i) died between 01 April 2018 and 31 March 2019; (ii) had a diagnosis of dementia recorded on the death certificate, as either the underlying cause of death or any mention as a cause of death, using filters based on ICD-10 codes F00\*-03\*

and G30\* as used elsewhere [23]; and (iii) had at least one HES record between 01 April 2016 and 31 March 2019. We included contacts over 3 years to increase the sample size.

### Primary outcome

The primary outcome was the count of ED visits in the last year of life. We defined ED visits as any unplanned visit to any type 1 ED.

### Explanatory variables

The ED and inpatient datasets provided gender (male, female), and 19 ethnicities from which we recoded as White, Black, South Asian, Mixed, Other and unknown/not stated ethnicities (Supplementary data S2). We derived age at death by calculating the difference between recorded dates of birth and death from ED and mortality data and centred by median age. We omitted civil status as an explanatory variable, as this was available in the inpatient dataset only. We derived settlement of usual residence (urban/rural) from aggregating results from the 2011 Rural–Urban Classification, which is an ONS measure used to distinguish urban and rural areas based on settlements of more or less than 10,000 resident population [24]. We derived socioeconomic position from the Index of Multiple Deprivation, which uses LSOA geography of usual residence to compare neighbourhood deprivation in England [25]. We derived region of usual residence from the Local Authority District to Region (April 2019) dataset, from the ONS Geoportal [26].

Dementia subtype was based on dementia ICD-10 codes in the mortality data, recorded as either the underlying cause of death or a cause of death mention. As most dementias are recorded as unspecified on death certificates [27], we triangulated the ‘unspecified dementia’ ICD-10 code (F03) with all dementia ICD-10 codes in inpatient data. Underlying causes of death in mortality data were grouped according to previous studies [28]: dementia, chronic lower respiratory disease (ICD-10 J40–47), cancer (ICD-10 C00–97, D00–48), cardiovascular disease (ICD-10 I00–52, I70–99), cerebrovascular disease (ICD-10 I60–69), chronic neurological disease (ICD-10 G12, G20, G35) and ‘other’ (remaining ICD-10 codes).

Service workforce included full-time equivalent (FTE) numbers of GPs, and Adult Social Care workers providing direct care. Service capacity included number of nursing home beds (residential facility with partial or full nursing care) and residential home beds (residential facility without nursing care), urgent treatment centres and type 1 EDs in local authority areas. In each local authority, we expressed service workforce and capacity data as totals per 10,000 at-risk population. We used the number of adults  $\geq 65$  years in each local authority as the denominator to denote the at-risk population [29], as this population is more likely to have dementia and to use primary [30] and social care services [31] than younger populations. The estimated counts per

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10,000 of at-risk population were grouped into quintiles, ranging from 1 (lowest) to 5 (highest).

We also measured FTE numbers of primary care nurses and Adult Social Care regulated professionals (nurses, occupational therapists and social workers), Adult Social Care expenditure and proximity of EDs, urgent treatment centres and GP surgeries, in line with existing models [10]. However, we excluded these from the final model due to issues of collinearity and poor model fit.

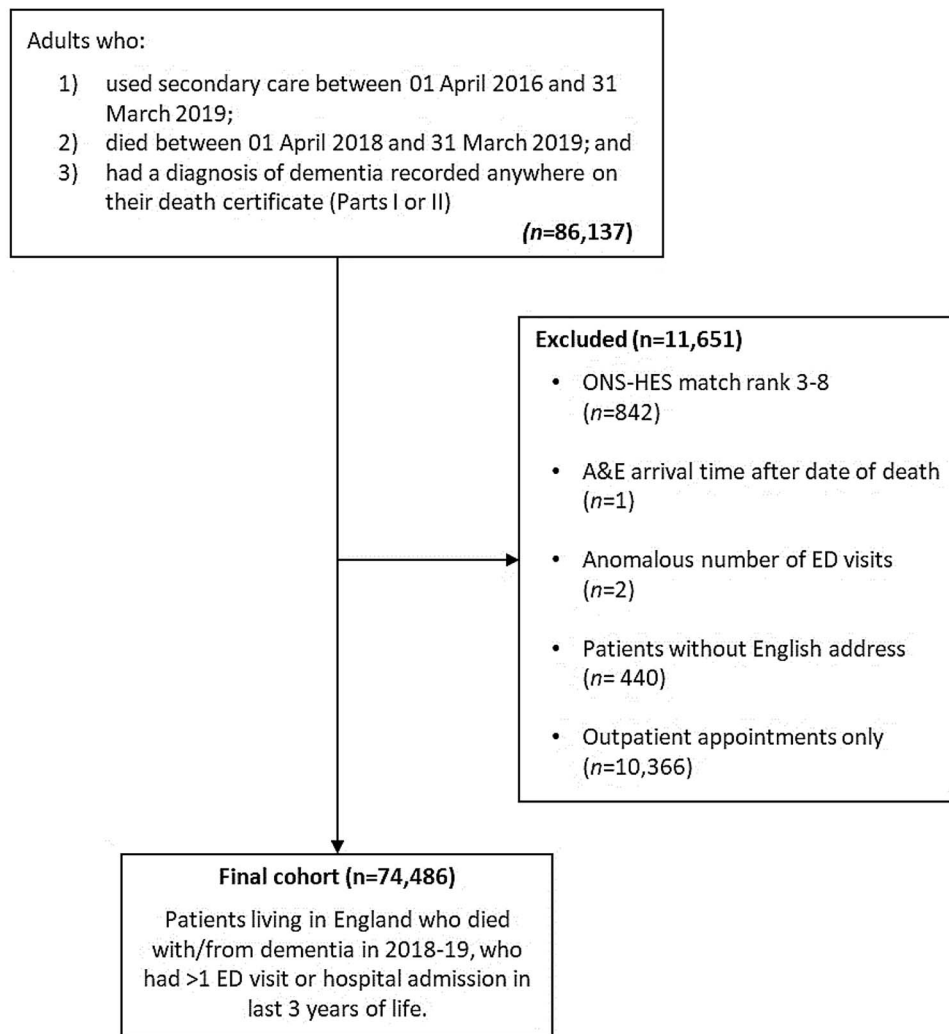
### Statistical analyses

We used frequencies and percentages to describe the cohort and ED visits. As the primary outcome (number of ED visits) was overdispersed, we used a negative binomial regression model with a random intercept at the local authority level to account for correlation within local authorities. Explanatory variables were selected based on improved model fit ( $P < 0.01$ ) and a priori hypotheses. Missing GP FTE data ( $< 1\%$ ) were imputed using local authority median number of FTEs. The strength of association was described using Incidence Rate Ratios (IRRs) and 95% confidence intervals (95% CIs) at the  $P < 0.05$  significance level. As the sample excluded decedents who had no contact with secondary care in the preceding 3 years, we completed a sensitivity analysis with a subset cohort of patients with at least one ED visit in the last year of life using zero-truncated negative binomial regression, with robust cluster variance. Analyses were performed using Stata, version 17 (StataCorp, College Station, TX, USA).

## Results

There were 86,137 patients who had at least one hospital contact between 01 April 2016 and 31 March 2019 and who died with or from dementia between 01 April 2018 and 31 March 2019. After removing cases based on eligibility criteria, including two cases with anomalous numbers of ED visits in the last year of life (349 and 269 visits), the final cohort comprised 74,486 patients (Figure 1). Most decedents in the final cohort (Table 1) were women ( $n = 45,072$ , 60.5%) and of white ethnicity ( $n = 65,180$ , 87.5%). The mean age at death was 86.9 (SD: 7.1). The most common specified dementia subtype was Alzheimer’s disease ( $n = 25,701$ , 34.5%). Compared with national averages, the cohort was less deprived [32] with similar rural–urban distribution [33]. Table 2 displays summary statistics of service factors, by local authority.

In the last year of life, 82.6% ( $n = 61,491$ ) of the final cohort visited the ED 154,508 times, with 53.2% ( $n = 39,596$ ) attending at least twice (Supplementary data S3). For 58.1% ( $n = 89,776$ ) of all visits in the last year of life, the ED outcome was hospital admission. For 0.5% ( $n = 840$ ), the ED outcome was death in the department. The proportion of visits that were in the month before death was 23.9% ( $n = 36,849$ ), and for 66.7% ( $n = 24,569$ ) of these, the ED outcome was hospital admission. Most



**Figure 1.** Flow chart of study population selection

patients attended by ambulance (89.6%) with just over half attending out-of-hours (defined as 8 pm–8 am weekdays and anytime weekends and Bank Holidays [2]; 54.2%). Common classifiable primary diagnoses included respiratory conditions (excluding asthma; 11.6%) and urological conditions, including cystitis (11.3%).

#### Factors associated with ED visits in the last year of life

In the unadjusted analysis (Supplementary data S4), all covariates were statistically significantly associated with the primary outcome, except mixed ethnicity and the third quintile of nursing home beds. In the adjusted multilevel model (Table 3, model 1; Figure 2), factors that were statistically significantly associated with fewer end-of-life ED visits included: older age (IRR 0.99, 95% CI 0.99–0.99,  $P < 0.01$ ), female gender (IRR 0.84, 95% CI 0.82–0.85,  $P < 0.01$ ), unknown ethnicity (IRR 0.86, 95% CI 0.84–0.88,  $P < 0.01$ ) and living in the South West (IRR 0.80, 95% CI 0.72–0.89,  $P < 0.01$ ). Factors that were statistically

significantly associated with higher end-of-life ED visits included: South Asian ethnicity (IRR 1.07, 95% CI 1.02–1.13,  $P < 0.01$ ), diagnosis of vascular dementia (IRR 1.14, 95% CI 1.13–1.16,  $P < 0.01$ ) or unspecified dementia (IRR 1.12, 95% CI 1.10–1.14,  $P < 0.01$ ), underlying cause of death as chronic respiratory (IRR 1.33, 95% CI 1.28–1.38,  $P < 0.01$ ), cardiovascular (IRR 1.17, 95% CI 1.14–1.20,  $P < 0.01$ ), or cerebrovascular disease (IRR 1.14, 95% CI 1.11–1.18,  $P < 0.01$ ), other underlying causes of death (IRR 1.22, 95% CI 1.19–1.25,  $P < 0.01$ ), being a resident in an urban settlement (IRR 1.06, 95% CI 1.04–1.08,  $P < 0.01$ ) and selected regions. There was a negative dose–response association between ED visits and increasing socioeconomic position (IRR 0.92, 95% CI 0.90–0.94,  $P < 0.01$ ). Being a resident in a local authority with more nursing home beds was statistically significantly associated with fewer ED visits (IRR 0.87, 95% CI 0.80–0.95,  $P < 0.01$ ). Results for number of GP FTE and type 1 EDs were less clear.

Sensitivity analysis with the subset cohort of patients who had at least one ED visit in the last year of life showed similar results (Table 3, model 2), except that some variables became

**Table 1.** Population characteristics

|                                 |                              | Total cohort (column %)<br>(n = 74,486) | At least one unplanned<br>type 1 ED visit in the last<br>year of life (column %)<br>(n = 61,491) |
|---------------------------------|------------------------------|---|--|
| <b>SOCIODEMOGRAPHIC FACTORS</b> |                              |   |  |
| Age at death, mean (SD)         |                              | 87.1 (7.1)                              | 86.9 (7.1)   |
| Gender                          | Men                          | 29,414 (39.5)                           | 25,255 (41.1)  |
|                                 | Women                        | 45,072 (60.5)                           | 36,236 (58.9)  |
| Ethnicity                       | White                        | 65,180 (87.5)                           | 53,768 (87.4)  |
|                                 | Black                        | 920 (1.2)                               | 836 (1.4)  |
|                                 | South Asian                  | 1,167 (1.6)                             | 1,078 (1.8)  |
|                                 | Mixed                        | 106 (0.1)                               | 94 (0.2)   |
|                                 | Other ethnicity              | 637 (0.9)                               | 554 (0.9)  |
|                                 | Unknown/not stated           | 6,476 (8.7)                             | 5,161 (8.4)  |
| Settlement                      | Rural                        | 13,585 (18.2)                           | 10,726 (17.4)  |
|                                 | Urban                        | 60,901 (81.8)                           | 50,765 (82.6)  |
| Socioeconomic position          | 1 (most deprived)            | 14,332 (19.2)                           | 12,225 (19.9)  |
|                                 | 2                            | 14,660 (19.7)                           | 12,283 (19.9)  |
|                                 | 3                            | 15,578 (20.9)                           | 12,781 (20.8)  |
|                                 | 4                            | 15,456 (20.8)                           | 12,592 (20.5)  |
|                                 | 5 (least deprived)           | 14,460 (19.4)                           | 11,610 (18.9)  |
| Region                          | South East (most populous)   | 12,694 (17.0)                           | 10,094 (16.4)  |
|                                 | London                       | 7,504 (10.1)                            | 6,704 (10.9)   |
|                                 | North West                   | 10,300 (13.8)                           | 8,746 (14.2)   |
|                                 | East of England              | 9,053 (12.2)                            | 7,572 (12.3)   |
|                                 | West Midlands                | 8,467 (11.4)                            | 7,206 (11.7)   |
|                                 | South West                   | 7,765 (10.4)                            | 5,709 (9.3)  |
|                                 | Yorkshire and Humberside     | 7,806 (10.5)                            | 6,506 (10.6)   |
|                                 | East Midlands                | 7,075 (9.5)                             | 5,983 (9.7)  |
|                                 | North East (least populous)  | 3,822 (5.1)                             | 2,971 (4.8)  |
| <b>CLINICAL FACTORS</b>         |                              |   |  |
| Dementia subtype                | Alzheimer's disease          | 25,701 (34.5)                           | 20,633 (33.6)  |
|                                 | Vascular dementia            | 19,298 (25.9)                           | 16,114 (26.2)  |
|                                 | Dementia in other diseases   | 1,071 (1.4)                             | 890 (1.5)  |
|                                 | Unspecified dementia         | 28,416 (38.2)                           | 23,854 (38.8)  |
| Underlying cause of death       | Dementia                     | 51,816 (69.6)                           | 41,723 (67.9)  |
|                                 | Chronic respiratory disease  | 1,759 (2.4)                             | 1,555 (2.5)  |
|                                 | Cancer                       | 4,623 (6.2)                             | 3,827 (6.2)  |
|                                 | Cardiovascular disease       | 5,243 (7.0)                             | 4,554 (7.4)  |
|                                 | Cerebrovascular disease      | 3,343 (4.5)                             | 2,988 (4.9)  |
|                                 | Chronic neurological disease | 2,022 (2.7)                             | 1,656 (2.7)  |
|                                 | Other                        | 5,680 (7.7)                             | 5,188 (8.4)  |

**Table 2.** Service characteristics

| <b>SERVICE FACTORS</b>   | <b>Per local authority</b>  | <b>Per 10,000 ≥ 65 year adult Local Authority population</b> |
|--|-----------------------------|--|
| <b>Service workforce; median (lower quartile-upper quartile)</b>       |                             |  |
| GP, FTE  | 332.2 (159.3–504.5)         | 30.6 (26.7–36.0)   |
| Adult Social Care direct care workers, FTE                             | 6,600 (3,100–11,000)        | 626.8 (576.6–764.1)  |
| <b>Service capacity, median (lower quartile-upper quartile; range)</b> |                             |  |
| Nursing home beds  | 2,213 (982–3,725; 0–7,664)  | 217 (186–261; 0–404)   |
| Residential home beds  | 2,116 (1003–4,692; 0–8,506) | 239 (195–272; 0–478)   |
| Type 1 EDs   | 2 (1–2; 0–5)                | —  |
| Urgent Treatment Centres   | 3 (2–7; 0–20)               | —  |



**Table 3.** Negative binomial regressions of factors associated with ED visits in the last year of life by people with dementia

|   |   | Model 1: Multilevel<br>analysis with full<br>cohort (n = 74,486) | Model 2: Sensitivity<br>analysis with reduced<br>cohort (with at least<br>one ED visit in last<br>year of life; n = 61,491) |
|---|---|--|---|
| Incident Rate Ratio (IRR; 95% CI)                 |   |  |   |
| <b>FIXED PART: INDIVIDUAL LEVEL</b>               |   |  |   |
| Intercept   |   | <b>1.70 (1.47–1.97)</b>  | <b>1.59 (1.40–1.81)</b>   |
| Age (centred)                                     |   | <b>0.99 (0.99–0.99)</b>  | <b>0.99 (0.99–0.99)</b>   |
| Gender (ref: men)                                 | Women   | <b>0.84 (0.82–0.85)</b>  | <b>0.83 (0.81–0.84)</b>   |
| Ethnicity (ref: white)                            | Black   | 1.01 (0.96–1.07)   | 0.98 (0.91–1.05)  |
|   | South Asian   | <b>1.07 (1.02–1.13)</b>  | 1.04 (0.97–1.11)  |
|   | Mixed   | 0.93 (0.78–1.09)   | <b>0.79 (0.66–0.96)</b>   |
|   | Other   | 0.97 (0.91–1.04)   | 0.93 (0.85–1.01)  |
|   | Unknown   | <b>0.86 (0.84–0.88)</b>  | <b>0.81 (0.78–0.85)</b>   |
|   | Vascular dementia                                     | <b>1.14 (1.13–1.16)</b>  | <b>1.19 (1.16–1.22)</b>   |
| Subtype (ref: Alzheimer's disease)                | Dementia in other diseases                            | 1.04 (0.99–1.10)   | 1.06 (0.97–1.16)  |
|   | Unspecified dementia                                  | <b>1.12 (1.10–1.14)</b>  | <b>1.15 (1.12–1.18)</b>   |
|   | Chronic respiratory disease                           | <b>1.33 (1.28–1.38)</b>  | <b>1.36 (1.28–1.43)</b>   |
| Underlying cause of death (ref: dementia)         | Cancer  | <b>0.98 (0.96–1.01)</b>  | <b>0.95 (0.92–0.99)</b>   |
|   | Cardiovascular disease                                | <b>1.17 (1.14–1.20)</b>  | <b>1.13 (1.08–1.17)</b>   |
|   | Cerebrovascular disease                               | <b>1.14 (1.11–1.18)</b>  | <b>1.04 (1.00–1.08)</b>   |
|   | Chronic neurological disease                          | 0.97 (0.93–1.01)   | 0.99 (0.93–1.05)  |
|   | Other   | <b>1.22 (1.19–1.25)</b>  | <b>1.14 (1.10–1.17)</b>   |
|   | Urban   | <b>1.06 (1.04–1.08)</b>  | <b>1.09 (1.05–1.13)</b>   |
| Settlement (ref: rural)                           | Quintile 2  | <b>0.96 (0.94–0.98)</b>  | <b>0.94 (0.91–0.97)</b>   |
|   | Quintile 3  | <b>0.95 (0.93–0.97)</b>  | <b>0.92 (0.89–0.95)</b>   |
|   | Quintile 4  | <b>0.93 (0.91–0.95)</b>  | <b>0.89 (0.87–0.92)</b>   |
|   | Quintile 5 (least deprived)                           | <b>0.92 (0.90–0.94)</b>  | <b>0.89 (0.85–0.93)</b>   |
| Socioeconomic position (ref: 1, more deprived)    | London  | <b>1.34 (1.21–1.49)</b>  | <b>1.36 (1.24–1.48)</b>   |
|   | North West  | <b>1.13 (1.02–1.24)</b>  | <b>1.10 (1.02–1.19)</b>   |
|   | East of England                                       | 1.03 (0.91–1.16)   | 1.03 (0.94–1.13)  |
|   | West Midlands   | <b>1.12 (1.00–1.25)</b>  | <b>1.17 (1.07–1.27)</b>   |
|   | South West  | <b>0.80 (0.72–0.89)</b>  | <b>0.84 (0.77–0.92)</b>   |
|   | Yorkshire and the Humber                              | <b>1.13 (1.02–1.26)</b>  | <b>1.14 (1.04–1.25)</b>   |
|   | East Midlands   | 1.07 (0.95–1.22)   | <b>1.14 (1.05–1.24)</b>   |
|   | North East  | 0.97 (0.86–1.08)   | <b>1.17 (1.01–1.35)</b>   |
| <b>FIXED PART: AREA LEVEL</b>                     |   |  |   |
| GP FTE (ref: 1, lowest quintile)                  | Quintile 2  | <b>1.08 (1.00–1.17)</b>  | 1.02 (0.96–1.08)  |
|   | Quintile 3  | <b>1.12 (1.03–1.23)</b>  | 1.04 (0.97–1.12)  |
|   | Quintile 4  | 0.97 (0.89–1.07)   | 0.95 (0.88–1.02)  |
|   | Quintile 5 (highest)                                  | 1.08 (0.95–1.23)   | 1.00 (0.91–1.10)  |
|   | ASC Direct care worker FTE (ref: 1, lowest quintile)  | Quintile 2   | 0.99 (0.92–1.07)  |
| Quintile 3  |   | 1.05 (0.96–1.14)   | 1.03 (0.96–1.11)  |
| Quintile 4  |   | 1.10 (1.00–1.21)   | 1.04 (0.95–1.13)  |
| Quintile 5 (highest)                              |   | 1.05 (0.94–1.17)   | 1.05 (0.96–1.14)  |
| No. of nursing home beds (ref 1: lowest quintile) |   | Quintile 2   | 0.99 (0.91–1.07)  |
|   | Quintile 3  | 0.93 (0.85–1.01)   | <b>0.94 (0.88–1.00)</b>   |
|   | Quintile 4  | <b>0.90 (0.83–0.99)</b>  | <b>0.91 (0.85–0.99)</b>   |
|   | Quintile 5 (highest)                                  | <b>0.87 (0.80–0.95)</b>  | <b>0.88 (0.82–0.95)</b>   |
|   | No. of residential home beds (ref 1: lowest quintile) | Quintile 2   | 1.05 (0.95–1.16)  |
| Quintile 3  |   | 1.04 (0.94–1.15)   | 0.98 (0.91–1.06)  |
| Quintile 4  |   | 0.97 (0.88–1.07)   | 1.00 (0.93–1.08)  |
| Quintile 5 (highest)                              |   | 1.02 (0.90–1.14)   | 1.00 (0.91–1.09)  |
| No. of EDs (ref 1: lowest quintile)               |   | Quintile 2   | <b>1.12 (1.02–1.23)</b>   |
|   | Quintile 3  | <b>1.11 (1.02–1.22)</b>  | <b>1.04 (0.97–1.12)</b>   |
|   | Quintile 4  | <b>1.10 (1.01–1.20)</b>  | <b>1.06 (0.98–1.15)</b>   |
|   | Quintile 5 (highest)                                  | 1.03 (0.95–1.13)   | 1.07 (0.98–1.16)  |
|   | No. of UTCs (ref 1: lowest quintile)                  | Quintile 2   | 1.04 (0.95–1.13)  |
| Quintile 3  |   | 1.06 (0.98–1.15)   | <b>1.07 (1.00–1.14)</b>   |
| Quintile 4  |   | 1.07 (0.98–1.15)   | 1.06 (0.99–1.13)  |
| Quintile 5 (highest)                              |   | 1.08 (0.99–1.17)   | <b>1.09 (1.01–1.18)</b>   |

(Continued)

Table 3. Continued

|                                    | Model 1: Multilevel analysis with full cohort ( $n = 74,486$ ) | Model 2: Sensitivity analysis with reduced cohort (with at least one ED visit in last year of life; $n = 61,491$ ) |
|------------------------------------|--|--|
| <b>RANDOM PART</b>                 |  |  |
| Local authority intercept variance | 0.00   | —  |
| <u>Marginal statistics</u>         |  |  |
| Marginal variance                  | 2.14   | —  |
| Patient                            | 3.63   | —  |
| Local authority                    | 0.09   | —  |
| Patient VPC                        | 3.54   | —  |
| Local authority VPC                | 0.02   | —  |
| <u>Fit statistics</u>              |  |  |
| Deviance                           | 277065.93  | 209669.91  |

GP = general practitioner; FTE = full-time equivalent; ASC = adult social care; EDs = type 1 emergency department; UTCs = urgent treatment centres; VPC = variance partition coefficients. Bold values = statistically significant ( $P < 0.05$ ).

statistically non-significant although the direction of effect remained the same.

## Discussion

In this large population-based study, we identified individual- and service-level factors associated with ED visits at the end-of-life. At the individual-level, we found that fewer ED visits were associated with higher socioeconomic position, whereas more ED visits were associated with living in urban areas, being of South Asian ethnicity and having chronic respiratory, cardiovascular and cerebrovascular diseases as underlying causes of death. Of all the service-level factors we measured, only nursing home beds were associated with fewer ED visits.

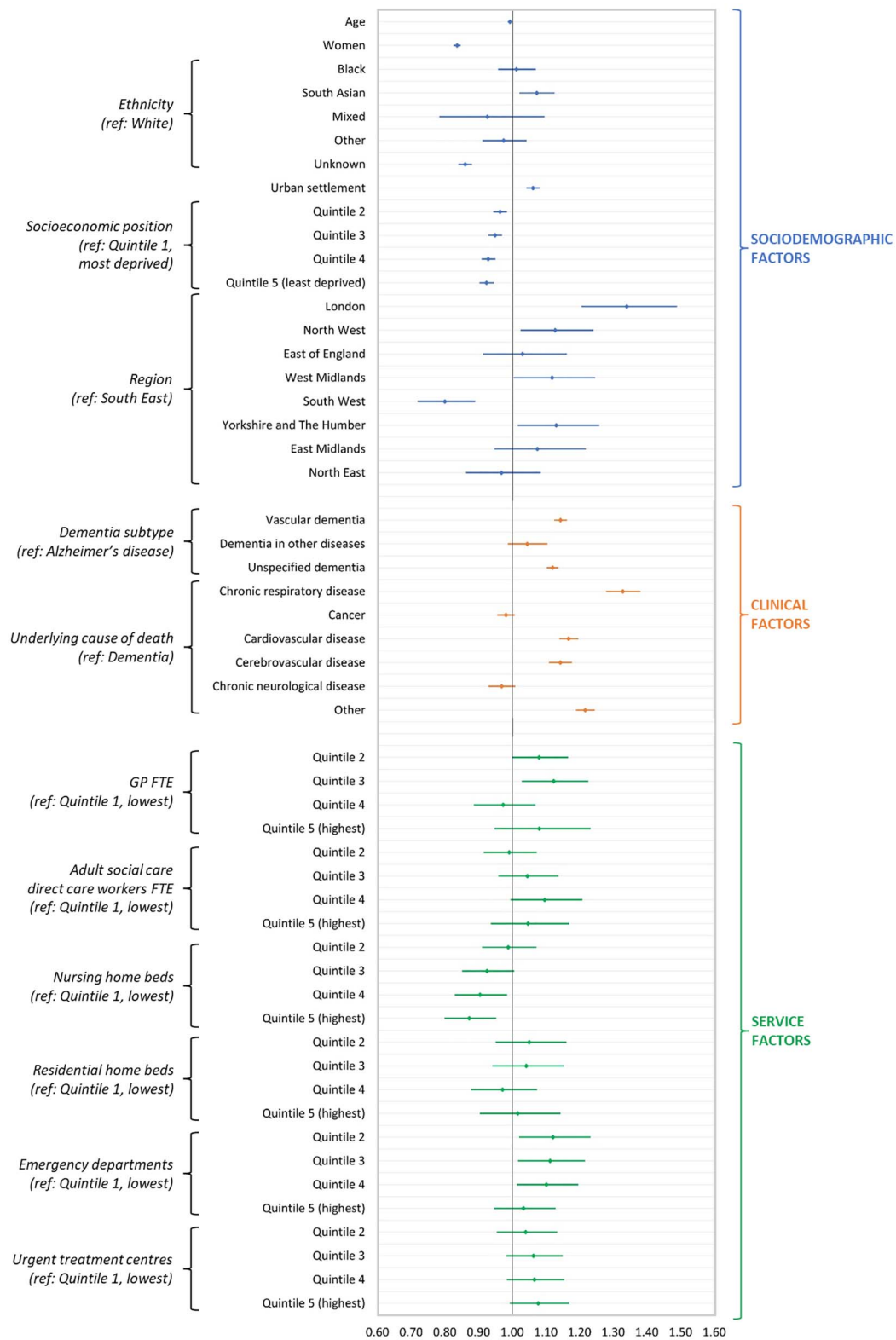
We found a significant association between higher numbers of nursing home beds and fewer end-of-life ED visits. We found no significant association with numbers of residential home beds. Associations between care home residence and reduced end-of-life ED attendance have been identified in the literature [6], but not variation by care home type. The potentially 'protective' effect of nursing homes has important policy implications and underlines the importance of timely clinical input in community care [34]. However, community care workforce capacity to support clinical continuity is tentative, with staff turnover in social care highest among registered nurses [35]. Therefore, it is essential that community care is supported with appropriate local workforce planning, including primary care, ensuring clinical continuity for people with dementia, irrespective of setting.

We found that living in urban rather than rural areas was associated with more end-of-life ED visits. This contradicts findings of international literature [6], but is similar to English studies examining hospitalisation of people with dementia [36]. The difference may therefore be explained by contextual variation between countries. We also observed a stepwise reduction in visits with higher socioeconomic position. These findings are not new in end-of-life literature

[37], but they are concerning. People affected by dementia in England are disproportionately disadvantaged, self-funding 60% of social care costs, which are projected to increase [38, 39]. Attempts to 'level-up' quality-of-life across the country must extend to quality of end-of-life, with focus on people with dementia, who are disproportionately impacted.

We found that South Asian ethnicity was associated with more ED visits in the last year of life. This is consistent with evidence that minority ethnicity was associated with increased ED visits [6]. Our findings have important clinical implications, as South Asian people are more likely to receive substandard end-of-life care [40] and are less likely to access dementia care [41]. The number of people with dementia from minority ethnic communities is expected to double in the next 40 years, with disproportionate increase in South Asian communities [42]. Therefore, there is urgent need for resources to support end-of-life care discussions with people from South Asian communities, and provision of accessible, culturally sensitive end-of-life dementia care.

In this study, urinary tract infections and respiratory conditions were common ED diagnoses. These conditions can often be treated with community support, minimising the need for burdensome transitions [43]. To improve end-of-life care for people with dementia, we echo recommendations for continuity of primary care [44], and for clinicians to optimise community-based management of chronic respiratory conditions and prioritise vaccination for individuals with dementia [45, 46]. Respiratory infections such as pneumonia should also prompt clinicians to initiate advance care planning discussions [47]. Addressing palliative care needs in people with dementia is associated with fewer end-of-life hospitalisations [44]. However, inequitable access to palliative care is well-recognised for people with dementia [48], with issues of service integration, training, and recognising dementia as a terminal illness [48]. As palliative care is not routinely monitored in England, we could not include it in our analyses. This is a missed opportunity in need of urgent redress.



**Figure 2.** Sociodemographic, clinical and service factors associated with number of ED visits in the last year of life for people with dementia (IRR and 95% CI of estimates for each explanatory variable from the adjusted model)

**Strengths and limitations**

This study is novel in its use of nationwide routinely collected data and record linkage with several databases to

examine individual- and service-level factors associated with end-of-life ED visits by people with dementia. However, there are limitations. Using mortality data may bias case



identification due to incomplete death certification [23] and underreporting of dementia compared with hospital records [49]. Despite attempts to tighten specificity of dementia subtype, ‘unspecified dementia’ remained most prevalent. This is consistent with data from other countries [50], suggesting broader issues around subtype diagnosis and documentation. Due to data limitations, we were unable to include care home admission or residence, comorbidities, or civil status, despite high-strength evidence of their influence on ED attendance [6]. We were also unable to include voluntary service, specialist community palliative care, or primary care data. Future studies should incorporate these data, where available, to better understand the influence of wider community services.

Our sample comprised people with hospital contact within 3 years of death. As prior hospital use is associated with end-of-life ED visits [6], it is possible that people visiting the ED in the last year of life are over-represented in this study. However, we are reassured that the proportion of the final cohort attending the ED in the last year of life is similar to other studies [2] (82.6 vs. 78.6% respectively), and we observed similar results in the sensitivity analysis.

## Conclusions

Individual- and service-level factors are associated with end-of-life ED visits by people with dementia. These data address an important gap in the evidence base and may aid clinicians to identify those most likely to attend the ED towards the end-of-life. Our findings underscore the value of services that are tailored to the needs of individuals from different minoritised ethnic groups, and identify policy priorities for investment in nursing home bed capacity and enhanced community models of care to better support people dying with dementia.

**Declaration of Conflicts of Interest:** None.

**Declaration of Sources of Funding:** This paper represents independent research funded by the Alzheimer’s Society (AS-CP-18-002), Cicely Saunders International (TCCR), The Atlantic Philanthropies (24611), the National Institute for Health Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King’s College London (BRC-1215-20,018) and Royal Marsden Partners.

Dr Emeka Chukwusa is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King’s College Hospital NHS Foundation Trust.

Professor Catherine J. Evans is supported by Health Education England and the National Institute of Health Research (HEE/NIHR Senior Clinical Lectureship, ICA-SCL-2015-01-001).

Professor Katherine E. Sleeman is funded by an NIHR Clinician Scientist Fellowship (CS-2015-15-005) and is the Laing Galazka Chair in Palliative Care at King’s College

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London, funded by an endowment from Cicely Saunders International and the Kirby Laing Foundation.

Dr Javiera Leniz is funded by an Royal Marsden Partners Pan London Research Fellowship Award.

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

**Data Availability Statement:** The data supporting the findings of this study are available within the article and in supplementary files in Age and Ageing online. This includes links to resources for all service-level data used.

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**Received 12 August 2022; editorial decision 22 November 2022**