SHORT REPORT

Survival and critical care use among people with dementia in a large English cohort

EMEL YORGANCİ1, KATHERINE E. SLEEMAN1, ELIZABETH L. SAMPSON2,3, ROBERT STEWART4,5, The EMBED-Care Programme†

1Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King’s College London, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, London SE5 9PJ, UK
2Division of Psychiatry, University College London, London W1T 7NF, UK
3Liaison Psychiatry, Royal London Hospital, East London NHS Foundation Trust, London E1 1FR, UK
4Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King’s College London, London SE5 8AB, UK
5South London and Maudsley NHS Foundation Trust, London SE5 8AB, UK

Address correspondence to: Emel Yorganci, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King’s College London, Bessemer Road, London SE5 9PJ, UK. Email: emel.yorganci@kcl.ac.uk
†Acknowledgements of Collaborative Authorship: The EMBED-Care programme co-applicants are Elizabeth L Sampson, Catherine J Evans, Katherine E Sleeman, Nuriye Kupeli, Kirsten J Moore, Nathan Davies, Clare Ellis-Smith, Jane Ward, Anna Gola, Bridget Candy, Rumana Z Omar, Jason D Warren, Janet E Anderson, Richard Harding, Robert Stewart and Simon Mead.

Abstract

Background: Admitting people with dementia to critical care units may not always lead to a clear survival benefit. Critical care admissions of people with dementia vary across countries. Little is known about the use and trends of critical care admissions of people with dementia in England.

Objective: To investigate critical care use and survival among people with dementia in a large London catchment area.


Results: Of 19,787 people diagnosed with dementia, 726 (3.7%) had ≥1 critical care admission at any time after receiving their dementia diagnosis. The overall 1-year survival of people with dementia, who had a CCA, was 47.5% \((n = 345)\). Dementia severity was not associated with 1-year survival following a critical care admission (mild dementia versus moderate–severe dementia odds of 1-year mortality \(OR: 0.90, 95\% CI [0.66–1.22]\)). Over the 12-year period from 2008 to 2019, overall critical care use decreased \( \beta = -0.05; 95\% CI = -0.01, -0.0003; P = 0.03 \), while critical care admissions occurring during the last year of life increased \( \beta = 0.11, 95\% CI = 0.01, 0.20, P = 0.03 \).

Conclusions: In this cohort, while critical care use among people with dementia declined overall, its use increased among those in their last year of life. Survival remains comparable to that observed in general older populations.

Keywords: critical care, dementia, survival, routine data, intensive care, older people

Key Points
• In a large cohort with a dementia diagnosis, while overall critical care use decreased over the years, a slight increase was observed among critical care admissions which took place in the last year of the decedents’ lives.
• One-year survival of people with dementia following a critical care admission was 48%, similar to that observed in general older populations.
Data linkages and clinically relevant routinely collected data are essential for informing service planning and evaluating the care quality of people with dementia.
24.1%) died in hospital, including 11.1% (n = 81) in the critical care unit; the remaining 551 (75.9%) were discharged after a median of 10 (IQR: 4–21) days of total hospitalisation. Compared to people who did not have a CCA, people who had ≥1 CCA were younger when diagnosed with dementia (median age of 79, IQR: 73–84 versus median age of 82, IQR: 77–87) and had a higher MMSE score (21 IQR: 17–24 versus 19 IQR: 15.0–23.0), indicating milder cognitive impairment at the time of their diagnosis (see Supplementary Data). The overall 1-year survival of people with dementia who had a CCA was 47.5% (n = 345). Dementia severity was not associated with 1-year survival following CCA (mild dementia versus moderate–severe dementia odds of 1-year mortality, OR: 0.90, 95% CI [0.66–1.22]) (Figure 1). Age-sex-standardised annual critical care use of people with dementia ranged between 0.5% (512 per 100,000 people with dementia) and 9.8% (9,797 per 100,000 people with dementia). Over the 12-year period from 2008 to 2019, there was a decrease in overall critical care use (β = −0.05; 95% CI = −0.01, −0.0003; P = 0.04), while 1-year survival remained steady (Figure 2). Age-sex-standardised annual critical care use during the last year of life ranged between 0.9 (905 per 100,000 people with dementia) and 3.9% (3,859 per 100,000 people with dementia). Between 2008 and 2019, there was an increase in CCAs in the last year of life (β = 0.11, 95% CI = 0.01, 0.20, P = 0.03).

Discussion

In a large cohort of people with dementia, 3.7% experienced a CCA, potentially reflecting the careful selection process for admission to critical care units. Previous estimates of annual CCA rates for people older than 80 range between 3.0 and 16.5% [15]. The 1-year survival following CCA of 47.5% is slightly lower than that reported among people with dementia in England admitted to hospital (58.5%) [16]. It is consistent with the 1-year survival following a CCA reported among older people generally (30–70%) [17] and among people with cancer (40–55%) [18]. However, our observed proportion of CCAs that ended in death on a critical care unit (11.1%) was lower than in general population reports (14–20%) [19].

In our study, CCAs among people with dementia decreased over the years observed, while CCAs in the last year of life increased. Evidence on temporal CCA trends is scarce. Previous US studies of CCA trends of older people (2001–08) [20] and of people with dementia (1998–2015) [21] found no change. By contrast, US data showed increases in CCAs (2000, 6.1%–2007, 9.5%) [4] and life-sustaining treatments such as mechanical ventilation among people with advanced dementia [3]. Our findings agree with reported increases in other aspects of potentially burdensome care (e.g. Emergency Department attendance in the last months of life) [22]. Reasons for up-trending CCAs in the last year of life among people with dementia may be complex. The increasing emphasis on timely diagnosis of dementia in England [23], social care funding implications of having a formal dementia diagnosis [24] and provision of general hospital liaison psychiatry services [25] may have changed the composition of our cohort over time, contributing to observed trends. Following, the 2015 Prime Minister’s Challenge on Dementia policy, which aimed that 66% of people with dementia in England should receive a diagnosis, an increase in this percentage was observed: from 47 to 59% between 2011 and 2015. Implementation of incentives by the National Dementia Commissioning for Quality and Innovation [26] also led to increased recognition of dementia in acute hospitals [27]. While recognition of dementia by clinical teams has increased, skills and knowledge to deliver care for those who may be approaching the end of life are often lacking. Quality indicators such as the percentage of people with dementia who had a CCA in the last month and year of life and the documentation of treatment and care preferences may drive improvements in the care quality for people with dementia until the end of their lives [28].

This study has limitations. Our sample were diagnosed with dementia in a single mental health trust and may not be representative [29]. Furthermore, we did not have sufficient information about reasons for the CCAs, treatments...
received and frailty measures (e.g. the Clinical Frailty Scale) [30], which inform clinical decisions [31, 32] and have an increasingly large influence on CCA decisions than dementia severity. Finally, decisions to admit to critical care units may depend on the critical care capacity. However, data on local/regional critical care bed occupancy or capacity were not available for further exploration [33]. Study strengths include the source data linkage, which enabled us to determine CCA use among people with dementia diagnosed over a long time period. While most available information on critical care use among people with dementia is limited to those which occurred in the last year of life or only to people who had advanced dementia [3, 34], we were able to identify any CCA after the dementia diagnosis date.

Financial and individual burdens associated with dementia care are high and will increase in future. Critical care use among people with dementia and relevant outcomes, such as their survival and the concordance of care with their preferences, should be monitored to minimise burden and to meet care needs appropriately. To make good judgements about the appropriateness of care and inform service provision at the population level, access to high-quality and clinically relevant routinely collected data is essential.

**Supplementary Data:** Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

**Acknowledgements:** The authors would like to thank Dr Daisy Kornblum and Hitesh Shetty, for their support in data extraction, and Drs Javiera Leniz and Joanna Davies for their guidance on age and sex standardisation. The authors would like to thank the EMBED-Care public and patient involvement (PPI) group for their contributions, who include Frank Arrojo, Helen Findlay, Roberta McKee-Jackson, Rita Meek, Christine Reddall and Jane Ward.

**Declarations of Conflicts of Interest:** R.S. declares research support received in the last 3 years from Janssen, GSK and Takeda.

**Declarations of Sources of Funding:** This project is funded by the Economic and Social Research Council (ESRC) and National Institute for Health and Care Research (NIHR) through the ESRC/NIHR Dementia Initiative 2018 (Grant Reference Number ES/S010327/1). R.S. is part-funded by (i) the National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre at the South London and Maudsley NHS Foundation Trust and King’s College London; (ii) 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; (iii) the DATAMIND HDR UK Mental Health Data Hub (MRC grant MR/W014386); (iv) the UK Prevention Research Partnership (Violence, Health and Society, MR-VO49879/1), an initiative funded by UK Research and Innovation Councils, the Department of Health and Social Care (England) and the UK devolved administrations and leading health research charities. K.E.S. is the Laing Galazka Chair in palliative care at King’s College London and is funded by an endowment from Cicely Saunders International and the Kirby Laing Foundation. This project was funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). ESRC is part of the UK Research and Innovation. The views expressed are those of the authors and not necessarily those of the ESRC, UKRI, NHS, the NIHR or the Department of Health and Social Care.

**Data Availability Statement:** The datasets used in this study are based on patient data, which are not publicly available. Although the data are pseudonymized, that is, personal details of the patient are removed, the data still contain information that could be used to identify a patient. Access to these data requires a formal application to the CRIS Patient Data Oversight Committee of the NIHR Biomedical Research Centre. On request and after suitable arrangements are put in place, the data and statistical analyses used in this study can be viewed within the secure system firewall. The corresponding author can provide more information about the process.

**References**

Survival and critical care use among people with dementia


Received 2 December 2022; editorial decision 27 June 2023
NOW
KNOW FASTER SO YOU CAN ACT QUICKER

Now, you can provide rapid molecular respiratory testing for COVID-19, influenza, RSV and strep A in any acute care setting, where and when it’s needed most.

NOW
IMPROVED WORKFLOW
with single patient swab for COVID-19 and influenza A & B