Emergency department presentations in palliative care patients: a retrospective cohort study

Paul Taylor, Tony Stone, Rebecca Simpson, Sam Kyeremateng, Suzanne Mason

ABSTRACT
Objectives To map the patient journey for individuals known to palliative care presenting to the emergency department (ED).
Methods A linked dataset from the CUREd database and palliative care services in a region in the North of England was used. The study describes day and time of presentations, events occurring in the ED, mode of leaving the department and length of hospital admissions for presentations occurring within 90 days of a contact with palliative care. Findings were compared with the wider population in the CUREd database.
Results A significant proportion of individuals known to palliative care (29.4%) presented to the ED. Presentations typically occurred in working hours. Most presented by ambulance (84.4%) and were admitted to hospital (75.1%); these observations persisted across age groups. Most presentations involved investigations (88.5%) and/or treatment (84.1%).
Conclusions Palliative patients exhibit significant use of the ED; some have the potential to benefit from attendances, but there is a minority for whom ED is unlikely to have improved their care. Advance care planning and communication between services are important for empowering those who stand to benefit from ED, while ensuring appropriate care is planned for those who prefer to avoid presenting.

BACKGROUND
Emergency department (ED) use in the final year of life represents a significant challenge. A 2018 report by Marie Curie demonstrated that, in England, cancer patients in the final year of life experience an average of 3.49 emergency admissions, compared with 3.01 for non-cancer patients. While many admissions will play an important role in prolonging life and improving symptoms, most people wish to spend their final days at home, illustrating a discrepancy between expressed preference and reality. National guidance provides recommendations to support palliative patients attending ED, but there remains scope to reduce avoidable attendance.

Palliative care services are well placed to support advance care planning, including establishing ceilings of treatment. The complex nature of palliative care means that such services frequently collate information from multiple services, providing constant support in a changing situation.

Reducing inappropriate use of the ED, while still enabling appropriate use by those who need it, requires an understanding of population demographics and patterns of use. This study used linked...
data on care transitions provided to a palliative population across emergency services, emergency inpatient services and palliative community services in a single city over a 2-year period.

**Aims**
The aim of this study was to describe ED use by palliative patients in a 2-year period in a city in the North of England.

**METHODS**
The study used the CUREd database, which is a research dataset of episodes linking the urgent and emergency care system. It contains over 23 million patient episodes of care between 2011 and 2017. CUREd is a unique resource, which enables the investigation of patient journeys across time, services and providers.

The study dataset comprised CUREd data relating to ED attendances and hospital admissions, which was linked with data on community palliative care contacts, covering the period April 2014–March 2017. A de-identified dataset was used for analysis. The study cohort was all adults known to the palliative care service from January 2015 to December 2016, defined as having received at least 1 contact with palliative care within the preceding 90 days.

Analyses used Stata V15. Pre-hoc outcomes were defined from existing literature and refined with a Patient and Public Involvement (PPI) group and included demographics, mode of presentation/discharge, events in ED and length of hospital stay.

**RESULTS**
The complete dataset included 2983 cases known to the palliative care service. Of the cases, 1480 (49.6%) were male (mean age: 73.8 years) and 1503 (50.4%) female (mean age: 73.6 years).

**Presentations, arrival and discharge**
ED presentations were included if they occurred within 90 days of a palliative care contact, and 1395 presentations were recorded. Most occurred within normal working hours and early evening but appear shifted later in the day when compared with the wider population (online supplemental graphs 1 and 2).

Most (2105, 70.6%) individuals in the cohort had no ED presentations. The attendances occurred in 878 individuals (29.4%), with 584 (19.6%) having a single attendance and 294 (9.9%) presenting on two or more occasions. The majority (748, 53.6%) of ED presentations occurred within 7 days of a palliative contact.

**Table 1** outlines the modes of arrival and discharge from the department, presented according to age. Most presentations (1183, 84.8%) occurred via ambulance, with 212 (15.2%) via self-presentation. In contrast, these figures for the wider population are 32.1% and 67.9%, respectively. The majority of patients were admitted (1048, 75.1%) or discharged (318, 22.8%); a small number transferred to a different area or died.
in the department (29, 2.1%). This contrasts with the overall population, where 23.7% are admitted.

**Events in department**

Investigations were undertaken in 88.5% of cases, with blood tests being the most common (74.9% of cases), followed by X-rays (58% of cases). Others involved ECGs (41.9%), arterial blood gas (22.5%), microbiology tests (20.5%) and other imaging (12.6%).

Treatments were administered in 84.1% of presentations, with 51.5% being invasive (intravenous interventions, oxygen and invasive procedures). The full list of treatments in each category is outlined in online supplemental table 1.

Overall, there were only 74 ED presentations (5.3%) involving neither investigation nor treatment. This is smaller than that of the general population, where over 20% have neither treatment nor investigation.

**Subsequent hospital stays**

From the 1048 cases admitted to hospital, admission data were available for 1038 cases. These admissions resulted in a median length of stay of 6 days (mean: 10.6 days).

**DISCUSSION**

The palliative population make significant use of the ED, with 29.4% presenting at least once within 3 months of a palliative care contact, over half of these within a week and mainly via emergency transport. A minority has no investigations or treatments in ED; arguably, their presentations could have been avoided. For those that are admitted, these patients have a median length of stay of 6 days; for many, this is a period where time at home would ordinarily be a high priority. Average length of stay figures are comparable with English data from Marie Curie exploring service use in the final year of life.

While ED use in this population is high compared with the wider population, recent reports in the West Midlands show that the majority (around 80%) of individuals in their final 2 years of life present at least once to the ED. It should be noted, however, that this study cohort is likely to comprise a much shorter time period. Data limitations regarding date of discharge from palliative care and date of death mean that precise time known to palliative care is not recorded here; nevertheless, a 2016 UK study highlighted that median time between referral to palliative care and death was 34 days.

We have defined the study population pragmatically. Given national variation in palliative care caseload management and discharge processes, this generates a definition of being ‘known’ to a service that can be contextualised in other areas. Data limitations affected our ability to explore some findings, specifically NHS 111 telephone service, emergency ambulance service data and death registry data. Our study reflects a single area, which includes both an independent and an NHS palliative care in-patient unit; as service design for palliative care services varies, this will affect the transferability of the findings.

Models for responsive palliative care community services should recognise that most emergency presentations occur during the day. Community teams use varied models for delivery, with crisis support out of hours. Our data suggest that an ideal form of crisis response needs to able to respond at any time.

The high number of presentations in this population means that palliative services should pre-empt emergency admissions, through advance care planning and guidance for management of crises. Such advice is in keeping with national strategy, ambitions and guidelines.

Rapid access to medical information is vital to ensure that decisions are made with the best available data and ensures that an ED presentation has the best opportunity to improve an individual’s care; the importance of such systems is recognised but not consistently implemented.

Education for ambulance service and ED professionals, and ensuring links with local palliative care services, are recommended to improve the care of those patients who do present. This is in keeping with Royal College of Emergency Medicine’s guidance and patient/family observations in existing studies regarding the difficulty in navigating local services.

For further research, our key recommendation is to work within legal and ethical frameworks to make continued use of linked data for developing interventions, service evaluation and research. Such approaches should be supplemented by research into the experience of the patient and their loved ones, to understand the human impact of emergency presentations in palliative patients.

**Conclusion**

This study has outlined modes of attendance and events during and following ED presentation in patients who are known to a palliative care service. While clinically relevant definitions of ‘palliative’ may vary, this is a population which can be readily identified and targeted with interventions to ensure appropriate use of EDs. The results outline a number of key findings, which will help to target use of such interventions and guide further research.

**Acknowledgements** The authors thank Dr James Davies, consultant in Palliative Medicine, for reviewing the manuscript and providing additional insights on the interface between emergency medicine and hospital palliative care.

**Contributors** All authors revised and contributed to the manuscript and met to develop the project, discuss and support research progress. PT developed the question, analysed data and wrote the manuscript. TS linked data, generated a study database and provided governance support. RS analysed data, generated images and provided statistical guidance. SK provided clinical insight and support from clinical palliative care.
care service. SM led the project, manages the CUREd database and provided clinical insight from emergency medicine.

**Funding** This study was funded by a grant from the Sheffield Healthcare Challenges Collaboration, a local partnership between Universities and healthcare organisations. (grant no. X/012793-13).

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** The CUREd database has approval from the Leeds East National Health Service Research Ethics Committee (18/YH/0234) and the NHS Health Research Authority’s Confidentiality Advisory Group (18/CAG/0126) to receive, link and provide data for research purposes. This study was granted approval by the CUREd Data Release Committee for access to a de-personalised dataset.

**Provenance and peer review** Not commissioned; internally peer reviewed.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

**ORCID iD**
Paul Taylor http://orcid.org/0000-0001-9140-4972

**REFERENCES**

1. Curie M. In and out of hospital: understanding disparities in emergency admissions in the final year of life, 2018. Available: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergency-admissions-report-2018.pdf

2. Sudbury-Riley L, Hunter-Jones P, Al-Abdin A. Introducing the trajectory Touchpoint technique: a systematic methodology for capturing the service experiences of palliative care patients and their families. *BMC Palliat Care* 2020;19:1–13.

3. Royal College of Emergency Medicine. Best practice guideline end of life care for adults in the emergency. *End Life Care Adults Emerg Dep* 2015;1–15.

4. NICE. Chapter 15 Advance care planning [Internet]. Guideline 94. Emergency and acute medical care in over 16s: service, delivery and organisation. NICE, 2018. Available: https://www.nice.org.uk/guidance/ng94/evidence/15advance-care-planning-pdf-172397464602

5. Pask S, Pinto C, Bristowe K, et al. A framework for complexity in palliative care: a qualitative study with patients, family carers and professionals. *Palliat Med* 2018;32:1078–90.

6. University of Sheffield. CUREd Research Database: How to access data or collaborate, 2021. Available: https://www.sheffield.ac.uk/schar/research/centres/cure/projects/cured-how-access-data [Accessed 11 Aug 2021].

7. Statacorp. *Stata statistical software: release 15*. College Station, TX: Statacorp LP, 2017.

8. O’Keeffe C, Mason S, Jacques R, et al. Characterising non-urgent users of the emergency department (ED): a retrospective analysis of routine ED data. *PLoS One* 2018;13:1–14.

9. The strategy unit: Midlands and Lancashire commissioning support. Health service use in the last two years of life, 2020. Available: https://www.strategyunitwm.nhs.uk/publications/health-service-use-last-two-years-life

10. Bennett MI, Ziegler L, Allsop M, et al. What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK City. *BMJ Open* 2016;6:1–6.

11. Payne S, Eastham R, Hughes S, et al. Enhancing integrated palliative care: what models are appropriate? A cross-case analysis. *BMC Palliat Care* 2017;16:1–10.

12. Department of Health. End of life care strategy. DEP heal London, 2008. Available: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/ dh_086345.pdf?source=Cru/sebreavementcare.org.uk/BPPpapers/EolCMikeRichards.pdf

13. Leniz J, Weil A, Higginson IJ, et al. Electronic palliative care coordination systems (EPaCCS): a systematic review. *BMJ Support Palliat Care* 2020;10:1–11.

14. Cooper E, Hutchinson A, Sheikh Z, et al. Palliative care in the emergency department: a systematic literature qualitative review and thematic synthesis. *Palliat Med* 2018;32:1443–54.