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

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## 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.<sup>1</sup> While many admissions

## Key messages

### What was already known?

- Palliative patients wish to avoid hospital presentations.
- Most people attend emergency department in their final year of life.

### What are the new findings?

- Most presentations by palliative patients attend in working hours, by ambulance and result in admission.
- The majority involve investigations and treatment.

### What is their significance?

#### Clinical

- Advance care planning and communication are priorities.

#### Research

- Understanding patient/carer experiences is vital.

will play an important role in prolonging life and improving symptoms, most people wish to spend their final days at home,<sup>2</sup> 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.<sup>3</sup>

Palliative care services are well placed to support advance care planning, including establishing ceilings of treatment.<sup>4</sup> The complex nature of palliative care means that such services frequently collate information from multiple services, providing constant support in a changing situation.<sup>5</sup>

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

## Short report

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.<sup>6</sup>

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 V.15.<sup>7</sup> 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

**Table 1** Mode of presentation and leaving department by age

Mode of arrival at department						
Age range (years)	Palliative care population			General population		
	Number presenting via ambulance (%)	Self-presentation (%)	Total	Number presenting via ambulance (%)	Self-presentation (%)	Total
18–40	14 (73.7)	5 (26.7)	19	18 938 (19.4)	78 536 (80.6)	97 474
40–49	39 (81.2)	9 (18.8)	48	8943 (24.2)	28 043 (75.8)	36 986
50–59	122 (76.7)	37 (23.3)	159	8686 (25.7)	25 126 (74.3)	33 812
60–69	203 (80.1)	48 (19.9)	251	9119 (32.5)	18 935 (67.5)	28 054
70–79	407 (86.4)	64 (13.6)	471	14 434 (48.4)	15 365 (51.6)	29 799
80–89	313 (88.7)	40 (11.3)	353	17 349 (67.2)	8461 (32.8)	25 810
90+	85 (90.4)	9 (9.6)	94	6988 (83.7)	1356 (16.3)	8344
<b>Total</b>	<b>1183 (84.4)</b>	<b>212 (15.6)</b>	1395	<b>85 544 (32.1)</b>	<b>181 348 (67.9)</b>	266 892
Mode of leaving department						
Age range (years)	Palliative population			General population		
	Admitted (%)	Discharged/other (%)	Total	Admitted (%)	Discharged/other (%)	Total
18–40	14 (73.7)	5 (26.3)	19	12 845 (13.2)	84 629 (86.8)	97 474
40–49	37 (77.1)	11 (22.9)	48	6458 (17.5)	30 528 (82.5)	36 986
50–59	112 (70.4)	47 (29.6)	159	6763 (20.0)	27 049 (80.0)	33 812
60–69	197 (78.5)	54 (21.5)	251	7834 (27.9)	20 220 (72.1)	28 054
70–79	364 (77.3)	107 (22.7)	471	11 867 (39.8)	17 932 (60.2)	29 799
80–89	256 (72.5)	97 (27.5)	353	13 520 (52.4)	12 290 (47.6)	25 810
90+	68 (72.3)	26 (27.7)	94	5255 (63.0)	3089 (37.0)	8344
<b>Total</b>	<b>1048 (75.1)</b>	<b>347 (24.9)</b>	1395	<b>65 496 (24.5)</b>	<b>201 396 (75.5)</b>	266 892

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.<sup>8</sup>

### 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.<sup>8</sup> 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.<sup>1</sup>

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.<sup>9</sup> 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<sup>10</sup> 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,<sup>11</sup> with crisis support out of hours. Our data suggest that an ideal form of crisis response needs to be 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.<sup>4 12</sup>

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.<sup>13</sup>

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<sup>3</sup> and patient/family observations in existing studies regarding the difficulty in navigating local services.<sup>14</sup>

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.

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care service. SM led the project, manages the CUREd database and provided clinical insight from emergency medicine.

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**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.

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