

How many end-of-life care patients access unscheduled care via 999?

Andeep Chohan (Corresponding Author), Project Manager, Welsh Ambulance Services University NHS Trust; **Edward O'Brian**, Clinical Lead Palliative Care, Welsh Ambulance Services University NHS Trust; **Sarah Rees**, Senior Research Officer, Swansea University Medical School; **Ieuan Scanlon**, Senior Data Scientist, Swansea University Medical School; **Nikki Pease**, Macmillan Consultant in Palliative Medicine, Velindre NHS Trust, Cardiff, Wales. **Email:** andeep.chohan@wales.nhs.uk

Abstract

Background: In Wales, the number of patients who are in their last year of life who access unscheduled care via emergency ambulance services is undocumented. **Aims:** This study aimed to identify and analyse the number of adult end-of-life care patients in Wales accessing unscheduled care via ambulance services and subsequently transferred to hospital.

Method: Secure Anonymised Information Linkage (SAIL) datasets were cross-matched to a subset of Office for National Statistics' Annual District Deaths Extract, where people had been assessed as 'likely having a palliative condition pre death' by two independent palliative medicine doctors. **Findings:** On average, 89% of patients in Wales likely to have a palliative condition accessed unscheduled care via the ambulance service in their last year of life, most likely in their final 7 days. **Conclusion:** Ambulance services play a crucial role in supporting community end-of-life care.

Key words

- Ambulance
- Paramedic
- Unscheduled care
- End of life
- Palliative
- Last year of life

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Within Scotland and England, healthcare use and therefore costs in the last 12 months of life increase with proximity to death (Conti et al, 2019; Mason et al, 2020).

Much of this increased access is via unscheduled care, which is defined as any unplanned, urgent, and emergency care provided by healthcare services (Beegan and Jones, 2022).

Within Wales, the number of patients accessing unscheduled care who are in their last year of life is not documented.

Aims

This project sought to identify and analyse the number of adult end-of-life care (EoLC) patients accessing unscheduled care via the Welsh Ambulance Services University NHS Trust (WAST).

As part of this project, the team wanted to capture data on outcomes of WAST unscheduled care interactions in terms of the number of EoLC patients who attended the emergency department (ED) and were either admitted to an inpatient hospital ward or discharged. In addition, the average number of inpatient bed-days of EoLC patients who were admitted to an inpatient ward was calculated.

Method

Using the Secure Anonymised Information Linkage (SAIL) Databank, a Wales-wide research resource funded by Health and Care Research Wales (SAIL Databank, 2025), the WAST Macmillan Project Team was able to analyse a variety of anonymised data sets to determine the number of adult EoLC patients accessing unscheduled care via WAST. The SAIL analytical team extracted and provided the data through outputs it created (*Table 1*).

Data were analysed for four sequential years, from 1 January 2016 to 31 December 2019, to establish a baseline before the Covid-19 pandemic, acknowledging that the pandemic is likely to have affected yearly average unscheduled care data.

The Office for National Statistics (ONS) (2020) Annual District Death Extract (*Appendix 1*, online) was used to identify all adult deaths registered in Wales in the 5 years between 1 January 2016 and 31 December 2020; 2020 adult deaths were included to allow inclusion of all activity in the last year of life in 2019. From these data, researchers planned to:

Table 1. Data outputs

Output 1: Death record and cohort demographics	Extraction of a list of all registered deaths from the Annual District Death Extract dataset where the date of death was in the period 2016–2020. SAIL chose this period as it allowed them to analyse activity over 2016–2019 for people in the last 12 months of life. Death records were linked to the Welsh Demographic Service Dataset to determine the sex, age at death and Welsh Index of Multiple Deprivation (2019) quintile at death, excluding any deaths occurring under the age of 18 years. The underlying known cause of death was then matched against Annual District Death Extract dataset clinical codes to deem whether the patient was likely to be palliative before death
Output 2: Cohort access to unscheduled care via Welsh Ambulance Services University NHS Trust	Welsh Ambulance Services University NHS Trust (WAST) patient care records, ambulance patient care records to 999 computer-aided dispatch system, ambulance computer-aided dispatch system incident, and ambulance computer aided dispatch system vehicles tables were linked together. Transport was removed (based on the transport to hospital identification code) to ensure only incidents relating to 999 emergency ambulance requests were included. Incidents outside the 2016–2019 period were also excluded. SAIL linked this table to the cohort of patients using the anonymous linking field Annual District Death Extract death date and WAST incident date. Any incidents remaining were those linked to the cohort and occurred in the 12 months leading up to death
Output 3: cohort pathway	Emergency department (ED) attendances were identified by linking patient cohort to the ED dataset table using the anonymous linking field and ambulance incident date, where the ED attendance date is within one day of the ambulance incident date and the ED dataset arrival mode is through an ambulance. Inpatient admissions were identified by linking the patient cohort and the inpatient admission table using the anonymous linking field, ED attendance end date and inpatient admission start date, where the admission start date is within one day of the ED attendance end date and the inpatient admission is an 'emergency'.

- Identify a cohort of patients with an underlying cause of death that would come under the definition of an 'expected death' (based on expert opinion from two palliative medicine doctors who had independently categorised the ONS adult cause of death list. Where there was disagreement between the doctors, discussion took place until agreement was achieved
- Describe the demographics of this cohort e.g. sex/age/Welsh Index of Multiple Deprivation quintile
- Quantify ambulance service use during the last year of life
- Ascertain hospital inpatient admissions in their last year of life, whether there were repeated admissions in the immediate history before death, and whether death occurred within 48 hours of hospital admission
- Identify the proportion who were on a GP palliative care register (using existing Read v2 codes (NHS England, 2016) (*Appendix 2*, online).

Inclusion criteria

The SAIL datasets used (available from SAIL as core or core restricted data sources) are shown in *Table 2*.

Exclusion criteria

SAIL is only permitted to provide anonymised data from GP practices that have agreed to share their data. At the time of the review (September 2022), 83% of GP practices in Wales (covering 85% of population), were registered with SAIL. This means that 85% of the population of Wales will be represented in figures sourced from the GP dataset.

All patients aged <18 years were excluded. Incidents categorised as transport to hospital (e.g. planned health professional admission requests or inter-facility hospital transfers), which are likely to be an arranged transfer to hospital, were excluded to ensure only incidents relating to 999 unscheduled care were included in the dataset provided by SAIL. The rationale for this exclusion is that patients meeting the transport to hospital criteria have already been clinically assessed and their initial treatment/outcome determined.

Table 2. SAIL datasets

Welsh Demographic Service Dataset: for age/sex/deprivation quintile, and to identify which individuals were registered with a SAIL GP at time of death
Welsh Ambulance Services University NHS Trust dataset: to flag ambulance service use in the year before death
Annual District Death Extract (Office for National Statistics, 2020): to extract records for all deaths in between 1 January 2016 and 31 December 2020 (2020 adult deaths included to allow inclusion of all activity in the last year of life in 2019); and to create a subgroup based on cause of death
Patient episodes dataset for Wales: inpatient admissions in the year before death
Emergency department dataset: attendances at emergency departments
Welsh longitudinal general practice dataset: to flag individuals on a GP practice palliative care register (limited to GP practices registered and providing data to SAIL at some point in the last 12 months of life)
A subset of annual district deaths extract dataset: for likely palliative codes identified independently by a palliative medicine consultant and palliative medicine registrar

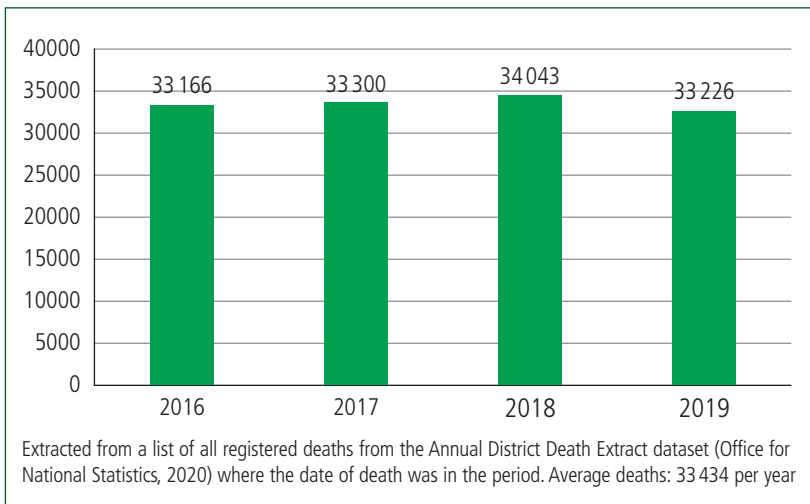


Figure 1. Total deaths in Wales per year (all causes of death, all ages)

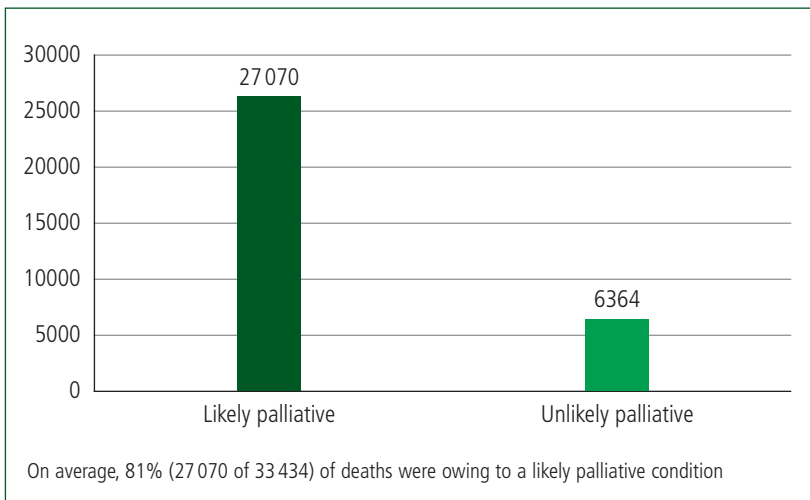


Figure 2. Average number of deaths in Wales per year likely/unlikely to be palliative

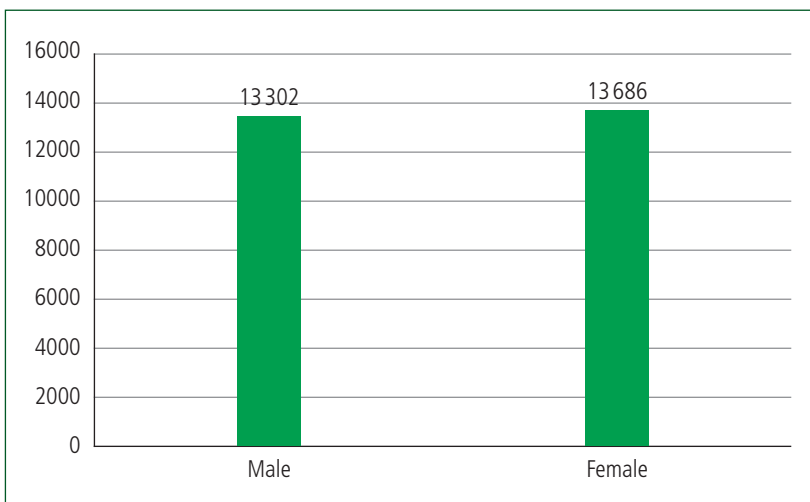


Figure 3. Average number of adult deaths in Wales likely palliative per year by sex

Caveats

SAIL provides data outputs in the form of descriptive summary tables in spreadsheet format. Data restrictions mean that SAIL cannot release any data where counts are <5 or where there is any risk of patient identifiable information being potentially disclosed.

It was impossible for SAIL to provide an accurate representation of patients' complete pathway from WAST incident to ED/admission to hospital, as there is no event identifier within the SAIL databank that can be used to follow an individual through this. However, within SAIL, each dataset can be linked using the anonymous linkage field (Swansea University Medical School, 2023), which is an identification code unique to an individual and linkable across datasets. Therefore, SAIL reviewed the ED admission mode (WAST admission) recorded in the SAIL ED dataset and compared the incident date with the WAST attendance and admission dates within the patient episodes dataset for Wales (inpatient admissions).

Results

SAIL output 1. Death record and cohort demographics

The following results represent the average numbers over the 4-year study period.

With the exception of *Figure 1*, results relate only to incidents or patients aged >18 years and in their last year of life owing to a likely palliative condition.

Figures 2–6 include only deaths with anonymous linking field and valid death registration in relation to a likely palliative condition based on the WAST Macmillan Project Team's review of all underlying cause of death codes.

The adult deaths in relation to a likely palliative condition during the four-year study period (2016–2019) were linked to their GP records using patient's anonymous linking field. Those with a palliative care Read v2 code (NHS England, 2016) recorded in their last 12 months of life were identified by cross-matching to the Quality and Outcomes Framework (NHS England, 2021) and the Gold Standards Framework (GSF) (2019).

Figure 7 shows the average number of adult deaths per year likely in relation to a palliative condition and whether a palliative event was recorded/not recorded by GPs (GP practices registered with SAIL at time of patient death).

SAIL output 2. Cohort access to unscheduled care via WAST

Output 2 excludes all incidents/patients identified as transport to hospital (e.g. planned health

professional admission requests or inter-facility hospital transfers) and those aged <18 years.

Figures 8–13 relate to all WAST incidents that occurred in the last 12 months of life that are likely palliative identified via the ONS (2020) underlying cause of death codes, using the list independently identified by two palliative medicine doctors.

The WAST incident data may include patients that accessed 999 more than once in their last year of life whereas the WAST patients are counted only once in the WAST data, which represents the total number of patients who contacted 999 in their last year of life.

Figures 8–10 include adult patients who accessed unscheduled care via WAST in their last year of life in 2019 but whose death was registered in 2020 in order to capture all related incidents for 2019.

SAIL output 3: cohort pathway – WAST attendance, emergency department admission and attendance, and admission to ward

The cohort identified in output 2 (those who accessed unscheduled care via WAST in the last 12 months of life) were then linked to the SAIL ED dataset and patient episodes dataset for Wales using anonymous linking field and incident date.

This determined the number of patients who were likely palliative admitted to ED via WAST and whether the patient was discharged from ED or admitted to an inpatient ward (Figure 11).

Over the 4-year study period, 41 patients died within an ED. It is not possible to present the number of patients who died within an ED in Figure 12 as the number is <5 (SAIL data restrictions). Figures 12, 13 and 14 include only WAST incidents that resulted in a hospital admission and WAST patients admitted to hospital only (e.g. incidents/ patients with ED attendance and admission to ward).

The incident data may include patients who accessed 999 more than once in their last year of life, whereas the patients are counted only once in the WAST data, which represent the total number of patients who contacted 999 in their last year of life.

Figures 11–14 include adult patients who accessed unscheduled care via WAST in their last year of life in 2019 but whose death was registered in 2020; so all related incidents for 2019 are captured.

In comparison to Figure 13, Figure 14 shows the average length of hospital stay over a 12-month period for WAST patients who are likely to have a palliative condition.

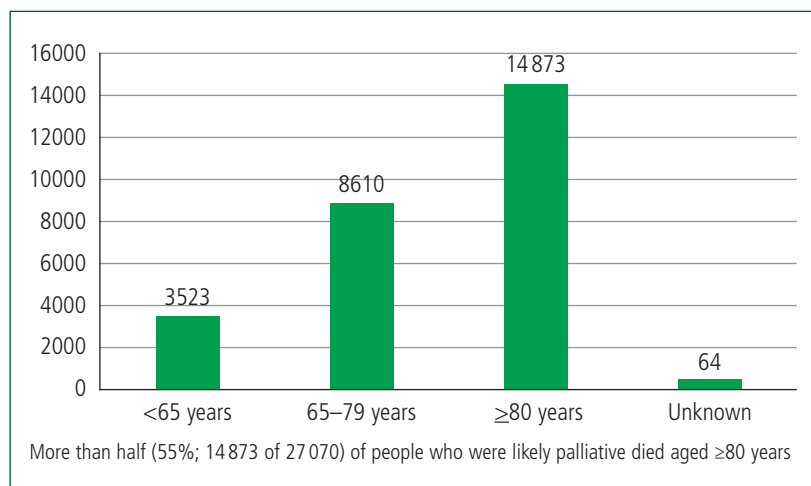


Figure 4. Average number of adult deaths in Wales likely palliative per year by age

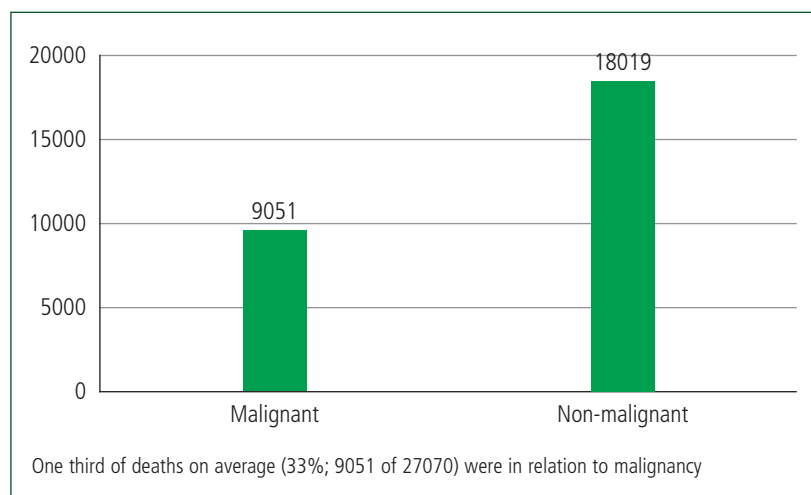


Figure 5. Average number of adult deaths in Wales likely palliative per year underlying cause of death by malignancy/ non-malignancy

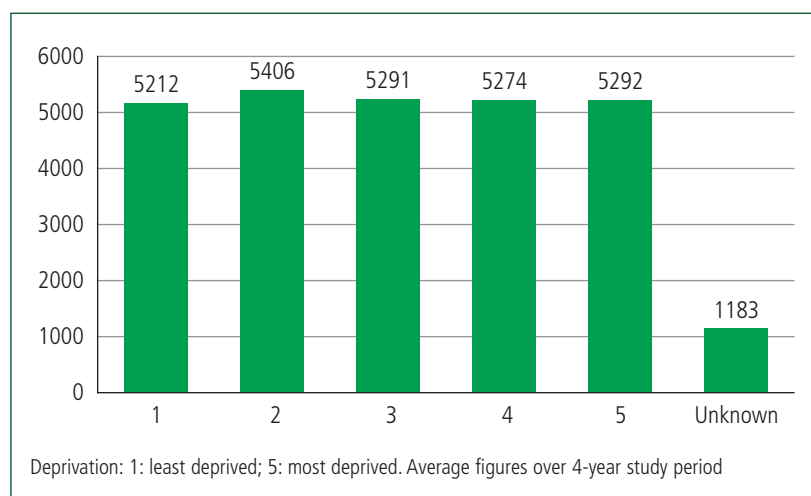


Figure 6. Average number of adult deaths in Wales likely palliative per year by deprivation

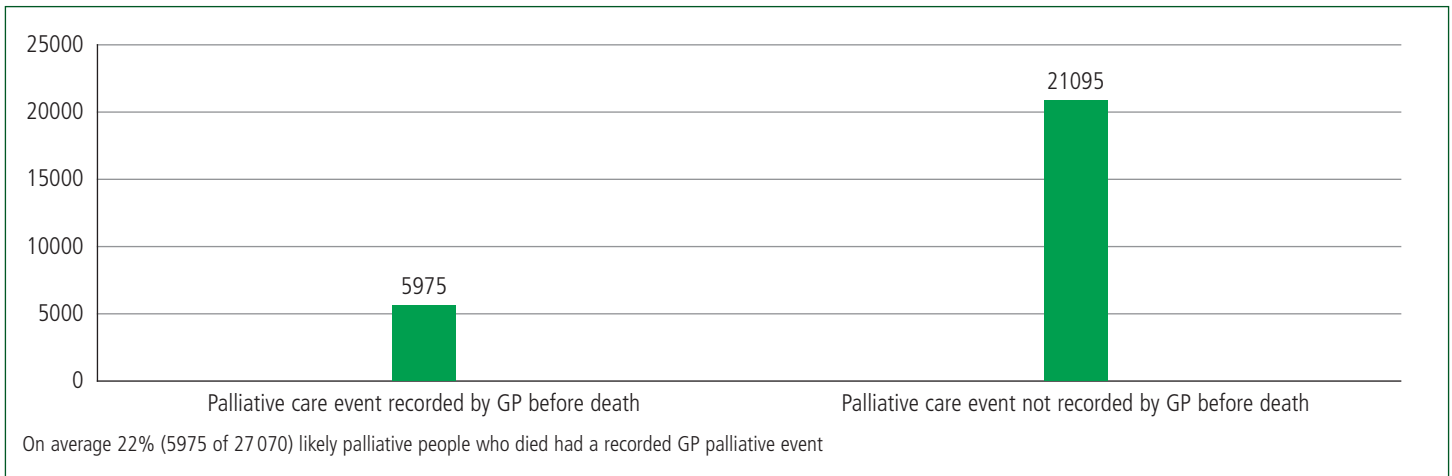


Figure 7. Average number of deaths per year in likely palliative patients by palliative care event recorded/not recorded by GP before death

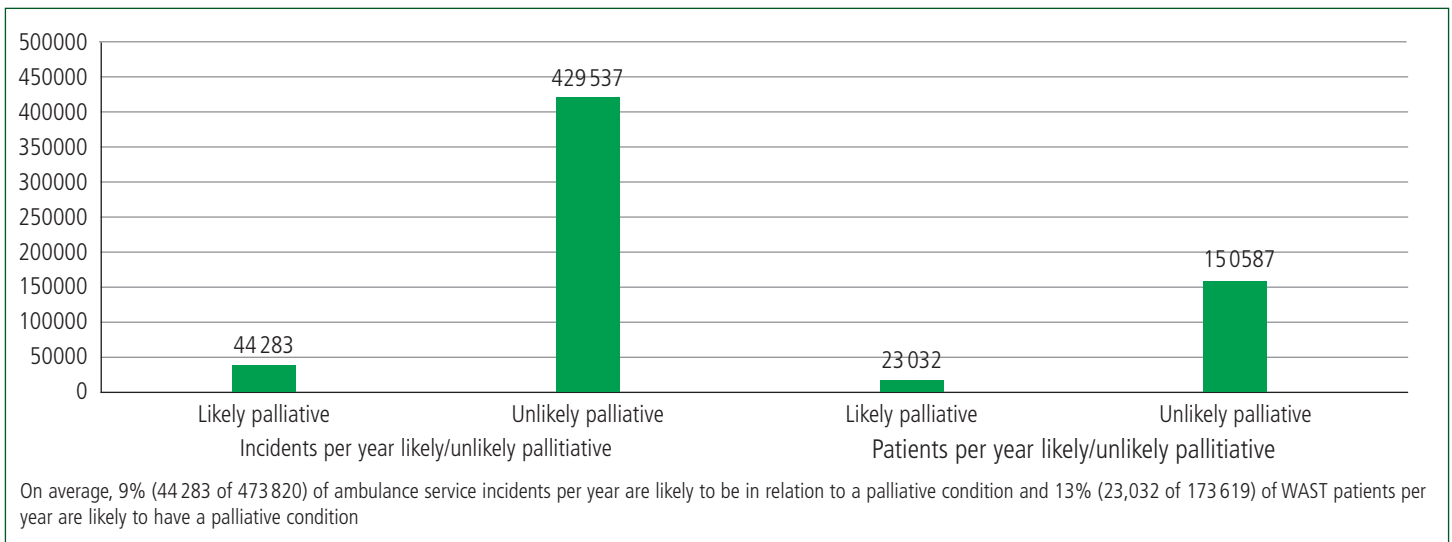


Figure 8. Average number of Welsh Ambulance Services NHS University Trust incidents/patients per year by likely/unlikely palliative status

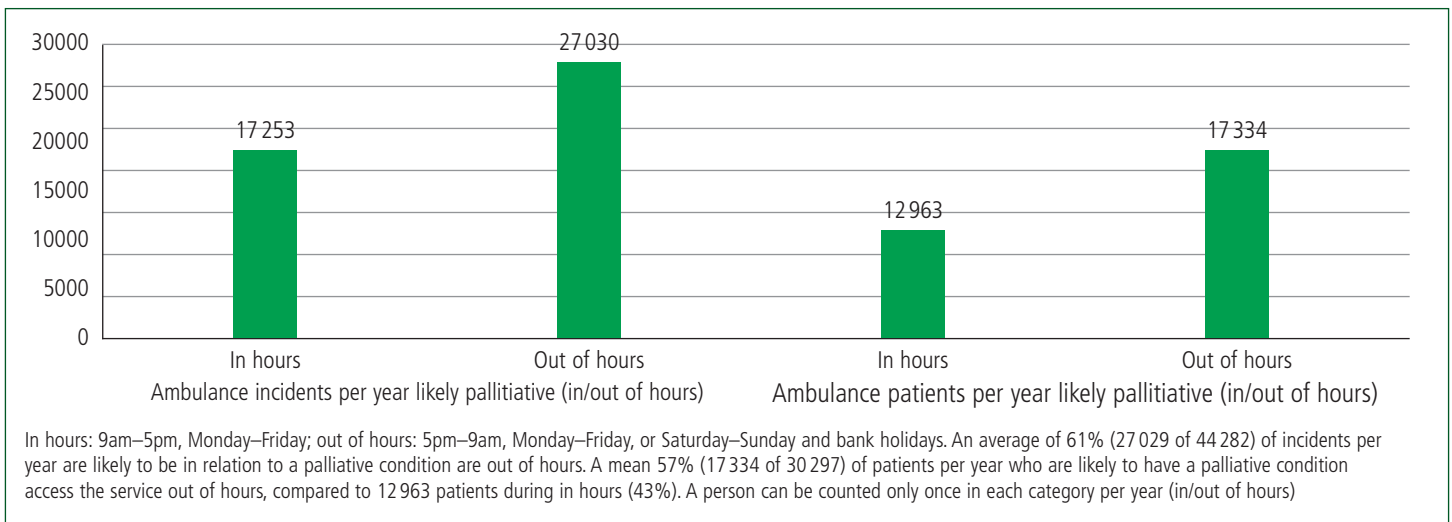


Figure 9. Average number of Welsh Ambulance Services NHS University Trust incidents/patients per year who are likely palliative contacting the service in and out of hours

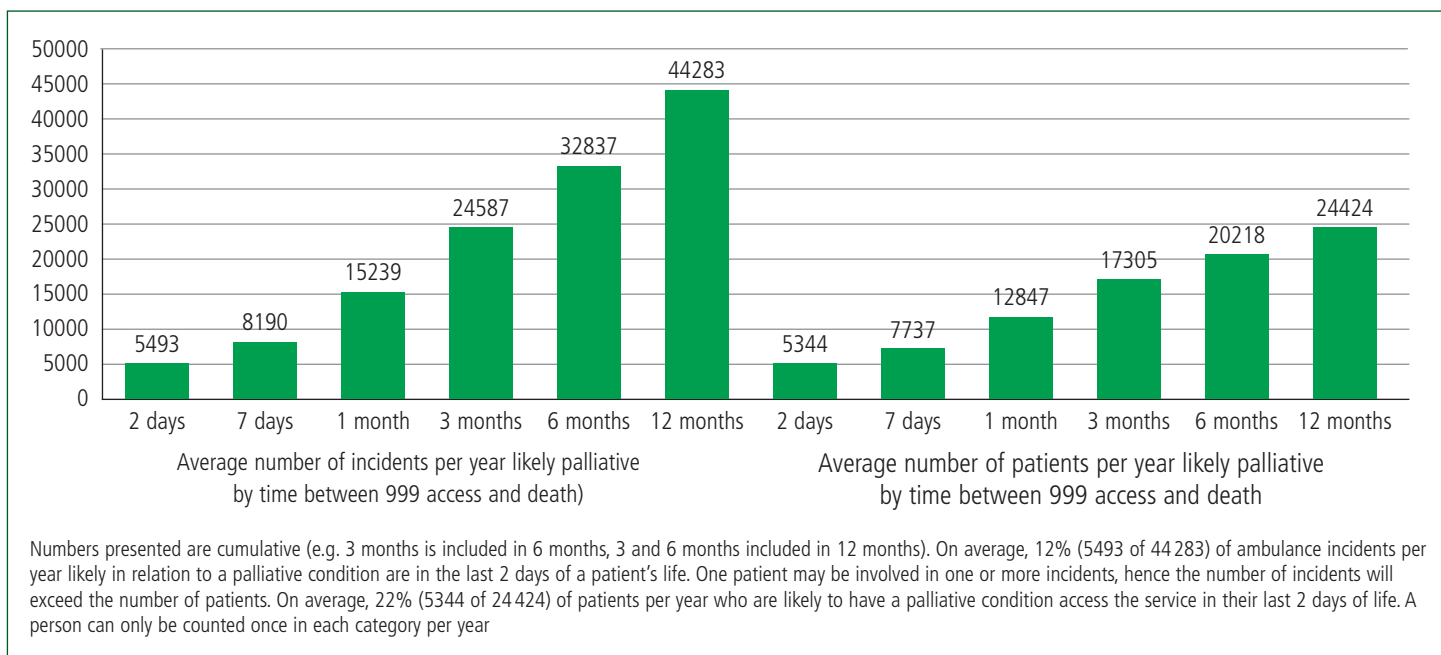


Figure 10. Average number of Welsh Ambulance Services NHS University Trust incidents/patients per year likely palliative by time between 999 access and death

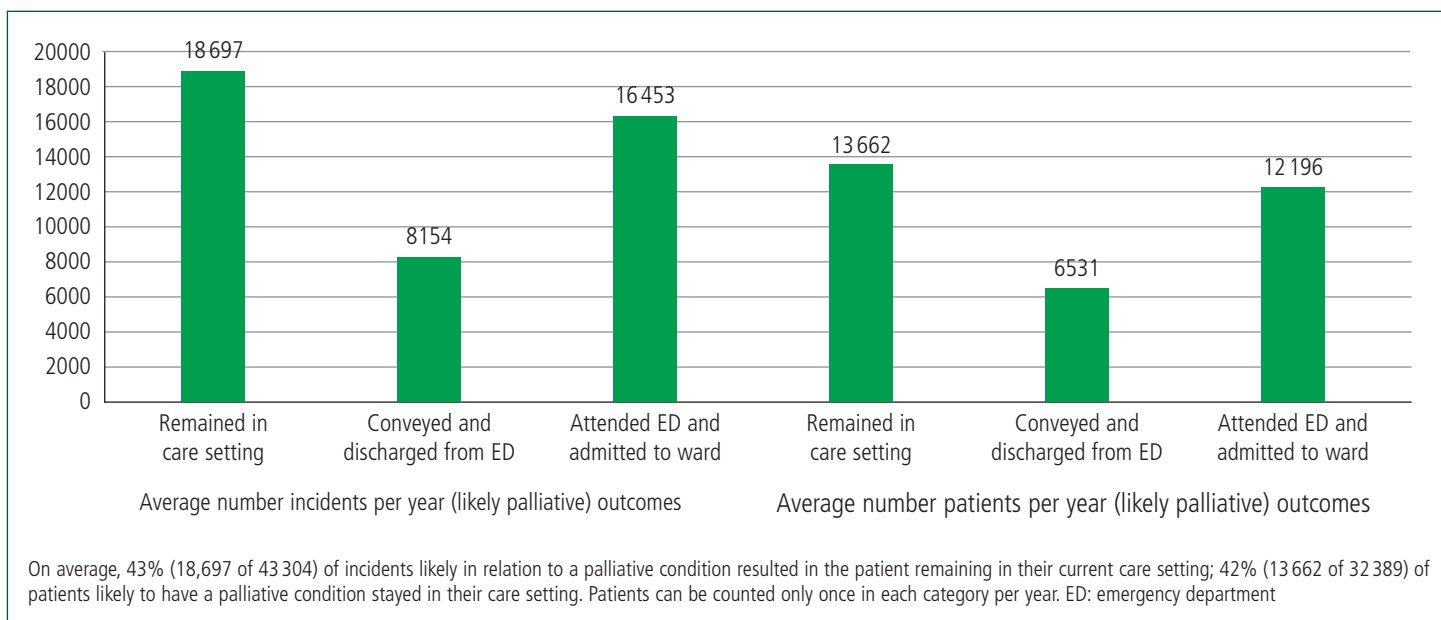


Figure 11. Average number of Welsh Ambulance Services University Trust incidents/patients per year (likely palliative) outcomes

Discussion

Within Wales, over the 4-year study period, an average of 81% of adult deaths per year were in relation to patients with a likely palliative condition. Of this percentage, on average 90% ($n=24$; 424) of patients recognised as likely palliative accessed unscheduled care via WAST in the last year of life during the same time period (Figures 2 and 12).

With regard to patient demographics, on average 55% (14873 of 27006) of adult deaths likely owing

to a palliative condition were in patients aged ≥ 80 years. Deaths were not disproportionate by sex or level of deprivation.

On average, 22% (5975 of 27070) of GP-recorded adult deaths had a palliative event recorded before death. Therefore, it can be concluded that 78% (21095 of 27070) of patients who likely had a palliative condition and were in their last year of life did not have a code in their GP history indicating that they were on the palliative register.

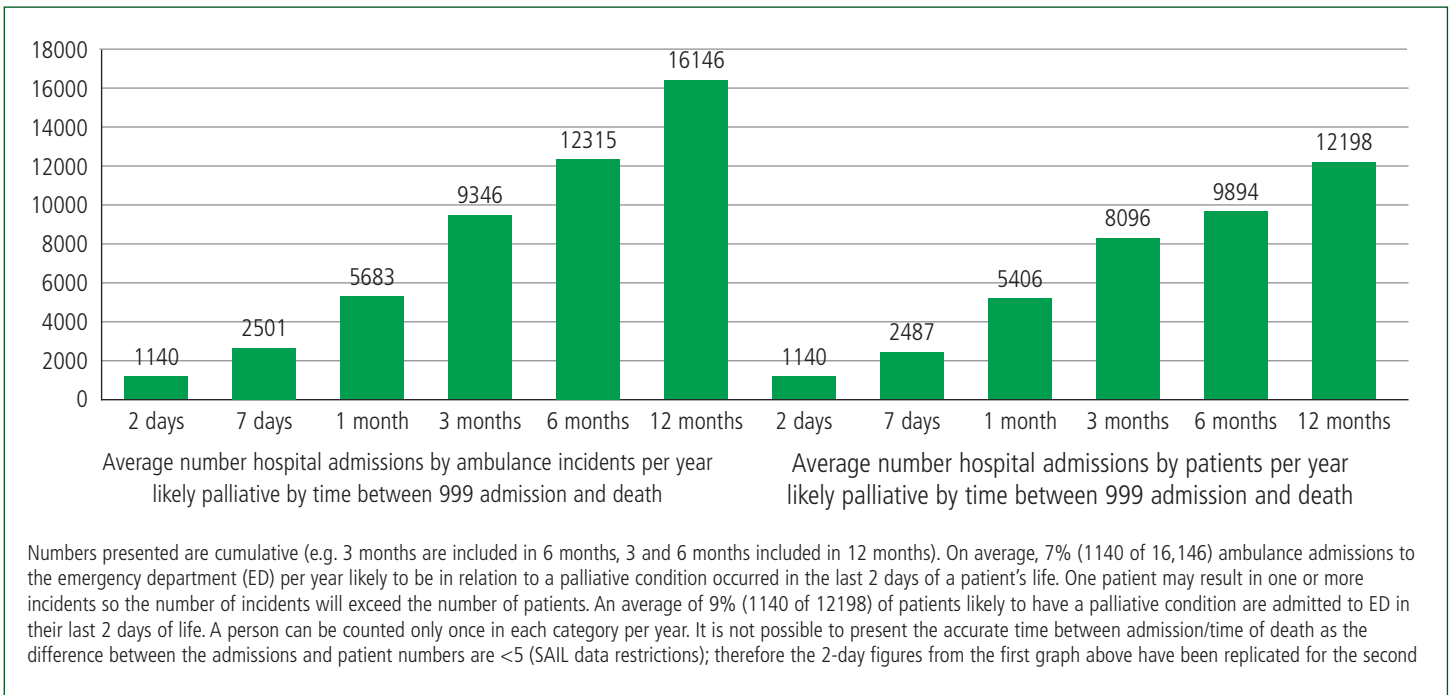


Figure 12. Average number of hospital admissions by Welsh Ambulance Services University NHS Trust (WAST) incidents/patients per year likely palliative, by time between admission and death. This includes only WAST patients admitted to hospital

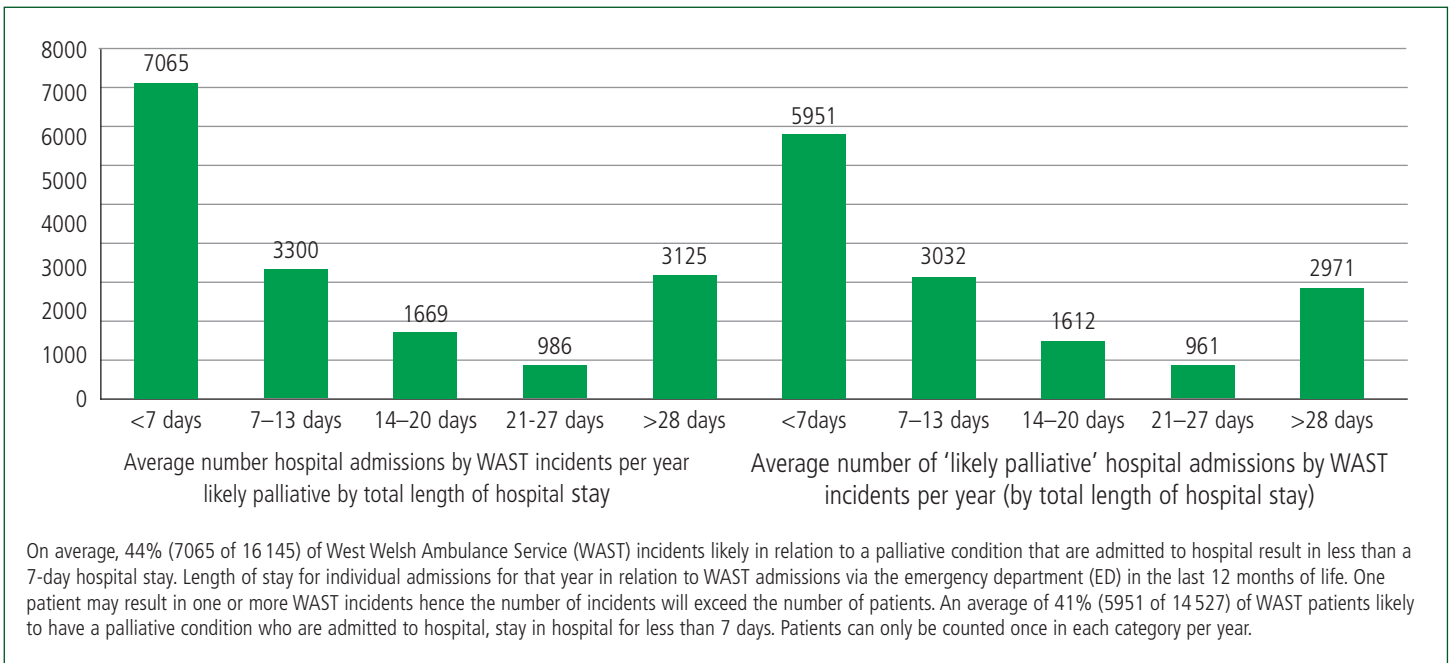


Figure 13. Average number of hospital admissions by incidents/patients per year likely palliative by total length of hospital stay

On average, 9% ($n=44\,283$) of WAST-verified incidents each year over the 4-year period were likely to be in relation to a palliative condition (Figure 15). This would place EoLC/palliative conditions in WAST's top five reasons for patients accessing unscheduled care from the ambulance

service. It should be noted that the reasons for patients accessing WAST are not mutually exclusive, so it is highly probable that other categories in the top 5 reasons, such as falls and breathing problems, will affect palliative patients. With regard to the time between incident and patient death:

- On average, 22% (5344 of 24 424) of patients likely to have a palliative condition accessed unscheduled care via WAST in the last 2 days of life; this accounted for 12% (5493 of 44,283) of incidents.

- On average 32% (7737 of 24 424) of patients likely to have a palliative condition accessed unscheduled care via WAST in the last 7 days of life; this accounted for 18% (8190 of 44,283) of incidents.

In comparison, on average 17% (4206 of 24 424) of patients likely to have a palliative condition accessed unscheduled care via WAST 6–12 months before death.

On average, 57% of incidents (24 607 of 43 304) and 58% of patients (18 727 of 32 389) with a palliative condition accessing unscheduled care via WAST led to hospital admission.

An average of 43% of incidents (3534 of 8190) likely in relation a palliative condition resulted in admission to hospital in the patient's last 7 days of life. A mean of 33% of incidents (1807 of 5493) likely in relation to a palliative condition resulted in admission to hospital in the last 2 days of life.

Per month, this equates to approximately 295 of WAST patients who are in their last 7 days of life likely owing to a palliative condition being admitted to hospital, and 151 patients in the last two days of life.

Conclusion

Findings suggest that the number of WAST incidents increases the proximity to death a palliative care patient becomes. Comparison between incident and patient data indicates that patients with a palliative condition will need to access unscheduled care via WAST more than once in their last year of life.

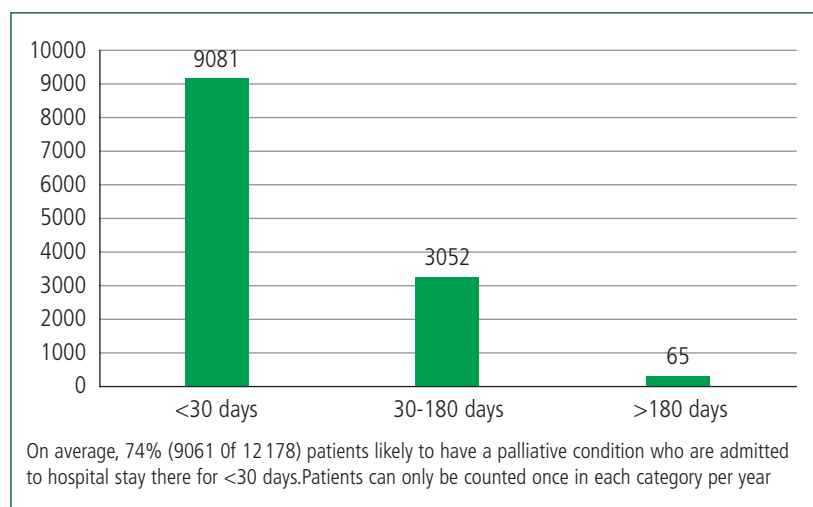


Figure 14. Average number of hospital admissions by Welsh Ambulance Services University NHS Trust (WAST) patients per year likely palliative by total length of hospital stay

The findings also evidence that WAST ambulance clinicians prevent avoidable ED admissions by enabling a high number of patients with a likely palliative condition to be managed in their current care setting (likely to be patient's preferred place of care), the closer to death a patient becomes.

The high number of patients with a likely palliative condition who did not have a palliative care event recorded in their GP records needing to access WAST indicates a lack of advance care planning.

The results demonstrate the crucial role ambulance services play in providing community EoLC. Paramedics may often be the first clinician to identify deterioration and dying. Evidence from

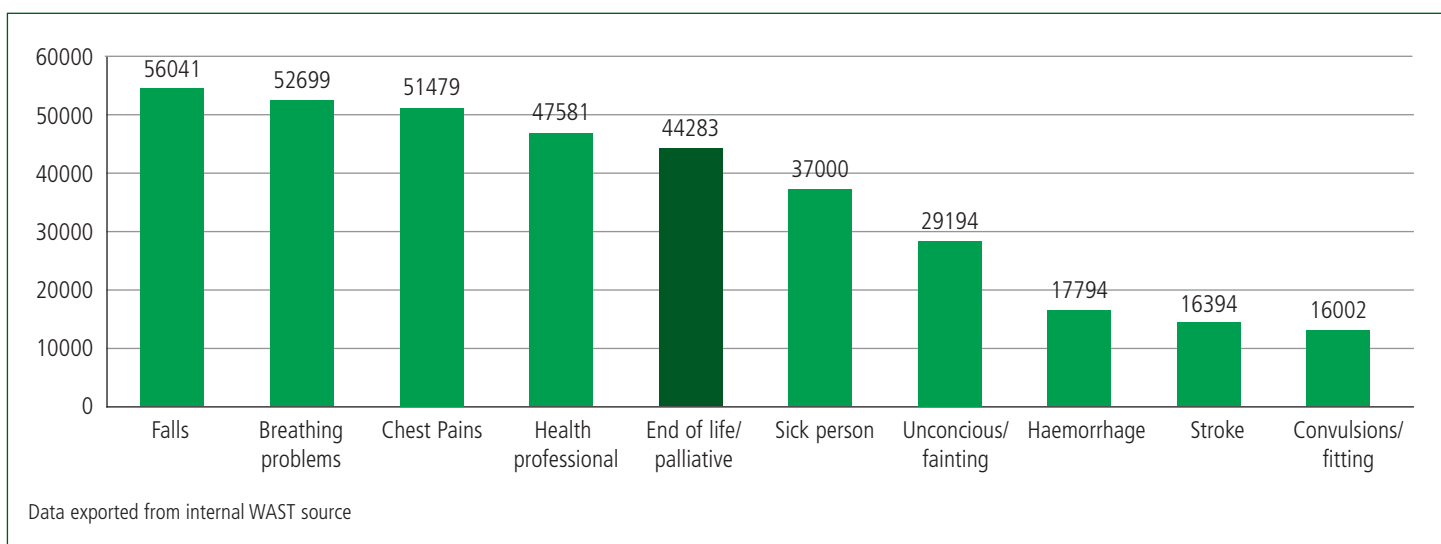


Figure 15. Top 10 reasons patients accessed the Welsh Ambulance Services University NHS Trust in 2019

Key Points

- Most deaths in Wales are likely to be in relation to a palliative condition
- Paramedics provide a crucial role in supporting patients to receive unscheduled care where they live rather than in hospital, particularly in their final days of life
- There is a lack of care planning; of the deaths likely to be in relation to a palliative condition, only 22% patients had a palliative care event recorded in their GP records
- Most patients in Wales likely to have a palliative condition and in their last year of life will access unscheduled care via the ambulance services
- Nearly one in 10 Welsh ambulance incidents are to respond to a patient with a palliative condition who is in their final year of life
- Palliative care patients access 999 at least twice on average in their last year of life. They are most likely to do this in their final 7 days

these findings is suggestive of a need for a specialist paramedic role to manage this cohort of patients. **JPP**

Appendices will be made available as supplementary material online at <https://www.magonlinelibrary.com/toc/jpar/17/6>

Conflict of interest: The authors declare that there are no conflicts of interest.

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Data sharing: data are available from the author upon reasonable request.

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CPD Reflection Questions

- How can the findings of this study regarding the high percentage of end-of-life care patients accessing unscheduled care via the Welsh Ambulance Services University NHS Trust in their last year of life influence your approach to patient care?
- How can the integration of palliative care services within emergency ambulance services be improved to ensure that patients receive timely and appropriate care, as suggested by the study's findings?
- How can ambulance services better support community end-of-life care (EoLC), based on the study's conclusion that paramedics play a crucial role in managing EoLC patients in their preferred care settings?

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