

Trends, prevalence and factors associated with dying in critical care and hospice settings in Scotland: a national decedent cohort study

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Key messages

- What was already known?
 - There are limited data comparing factors associated with deaths in critical care and hospices.
- What are the new findings?
 - Deaths in critical care are younger (1 in 8 <40 years), with greater social deprivation occurring in more traumatic circumstances compared with deaths in hospices.
- What is their significance?
 - There is a need for a specific focus on end-of-life and bereavement support services in critical care units.

Abstract

Objectives

End-of-life and bereavement care support services differ in critical care and inpatient hospice settings. There is limited population-level data comparing deaths in these two locations. We aimed to compare characteristics of people who die in critical care units and in hospices, identify factors associated with place of death, and report 12-year trends in Scotland.

Methods

We undertook a cohort study of decedents aged ≥ 16 years in Scotland (2005-2017). Location of death was identified from linkage to the Scottish Intensive Care Society Audit Group database and NRS Death Records. We developed a multinomial logistic regression model to identify factors independently associated with location of death.

Results

There were 710,829 deaths in Scotland, of which 36,316 (5.1%) occurred in critical care units and 42,988 (6.1%) in hospices. As a proportion of acute hospital deaths, critical care deaths increased from 8.0% to 11.2%. Approximately 1 in 8 deaths in those aged under 40 years occurred in critical care. Factors independently associated with hospice death included living in less deprived areas, cancer as the cause of death, and presence of comorbidities. In contrast, liver disease and accidents as the cause of death and absence of comorbidities were associated with death in critical care.

Conclusions

Similar proportions of deaths in Scotland occur in critical care units and hospices. Given the younger age profile and unexpected nature of deaths occurring in critical care units, there is a need for a specific focus on end-of-life and bereavement support services in critical care units.

INTRODUCTION

Dying in critical care and dying in an inpatient hospice are frequently positioned as polar ends of dying scenarios. Being in a critical care unit at the end of life is associated with a more medicalised death, greater focus on active treatments and a high level of medical interventions.(1, 2) Conversely, families reported greater satisfaction around quality of care and dignity when death occurred in hospital ward settings.(3) While good quality end-of-life care is possible in critical care even without formal palliative care input, it remains variable.(2, 4) Moreover, the opportunities for timely end-of-life care provision are reduced by virtue of the clinical characteristics of patients who die in critical care, particularly when death is unexpected.(5) Hospice care centres on providing end-of-life care that is consistent with the values and priorities of patients and their families. (6) Hospice admission is only available to certain patients who are triaged using eligibility criteria and, as with critical care, these criteria vary widely across and within countries.(7, 8) The COVID-19 pandemic has demonstrated this starkly in critical care.(9)

In England, approximately 46.9% of all deaths occur in hospital.(10) Of the proportion admitted to critical care in England, Wales and Northern Ireland, 14.5% (23,401) died in critical care and 19.6% (31,673) in total died before leaving hospital, with similar data reported in Scotland.(11, 12) These figures are not dissimilar to those reported for people dying in hospices in England and Wales (25,673), equating to around 5.2% for intensive care unit (ICU) deaths and 5.7% for hospice deaths respectively.(13) Disparity in place of death for people in Scotland differs according to the primary diagnosis, with cancer being the most common reason for hospice referral. For cancer patients, socio-economic status and ethnicity were factors and older, white Scottish groups were more likely to die at home and in their preferred place than other ethnic groups.(14)

Introduction of timely palliative care, which incorporates planning for preferred place of death, is a global health goal.(15) The current Scottish Government Strategic Framework for Action on Palliative and End of Life Care aims to offer improved access to palliative care and so reduce ‘medicalisation of death’ in Scotland.(16) Reducing harm associated with medical interventions of low benefit and unwarranted variations in practice, improving access to equitable care and aligning evidence with individual preferences for treatment, are the key focus of the Chief Medical Officer for Scotland’s ‘Realistic Medicine’ initiative. (17) Promoting a palliative care infrastructure that spans health (acute and community) and social care would support greater equity of access to care for dying patients consistent with their preferred choices.(18) Universal access to palliative care on the basis of need is echoed in a recent White Paper from the European Association of Palliative Care. (8)

Place and cause of death are well-reported in the UK. What remains unclear are the specific characteristics of people dying at the most acute end of the spectrum in critical care and how this differs from those dying in hospices. Importantly, no direct comparisons have been made between the characteristics of people dying in critical care or in a hospice despite representing a similar proportion of all deaths. We therefore aimed to make this comparison by examining differing individual factors, and trends over time using population-based information in Scotland.

METHODS

Study setting and databases

Three main data sources were used: National Records Scotland (NRS) Death Records, the Scottish Intensive Care Society Audit Group (SICSAG) (11) database of critical care activity and the Scottish acute hospital discharge database (SMR01). The SICSAG database captures all adult general intensive care (ICU) and high dependency unit (HDU) activity within Scotland and is subject to regular validation assessments.(11) Data sources were linked using the Community Health Index (19) number, a unique identifier used across all Scottish health services.

Participants

We used a cohort study design of decedents. NRS Death Records were used to identify all people aged ≥ 16 years old who died in Scotland over the 12 years from 2005 to 2017. Non-Scottish residents who died in Scotland were excluded. Scottish residents who died outside of Scotland were not identifiable from the databases.

Variables

The primary outcome was location of death which was identified from SICSAG and NRS death records linkage. Critical care deaths were identified from the SICSAG database and included deaths in high dependency and intensive care units. Deaths occurring in other locations were grouped in a single category, which included deaths in acute hospitals, a private residence, care homes and other institutions (prisons, schools, hostels and hotels).

Other variables included in analyses were age (divided into 10 year bands), gender and socioeconomic status as defined by the Scottish Index of Multiple Deprivation (SIMD) grouped into quintiles. (20) SIMD is an area-based ranking index based on postcode of residence. It is a weighted score combining 7 domains (income, employment, health, education, skills and training, housing,

geographic access and crime). The main underlying cause of death was derived from NRS deaths using International Classification of Diseases–Revision 10 (ICD-10) codes (see supplement). Causes of death were mutually exclusive. Comorbidities were derived from ICD-10 codes using the cause of death field in NRS death records and SMR01 discharge diagnoses using “comorbid” function in R. The Charlson classification was used with the addition of the Elixhauser categories of drugs, alcohol and obesity.(21)

Statistical analyses

We used R Version 3.6.1 statistical software for analyses.(22) . Baseline characteristics and number of annual deaths were presented for hospice and critical care cohorts before and after direct standardisation using the age-sex structure of the combined cohorts. A complete case analysis was undertaken. A multivariable multinomial logistic regression model was developed to examine independent predictors of location of death (critical care, hospice, other locations). The baseline comparison group was death occurring in other locations. Predictors included in the model were age, gender, SIMD quintile, cause of death, number of comorbidities and year of death. Exponentiated coefficients from multinomial regression are interpreted as relative risk, as these represent the probability of having an outcome relative to the probability of having the baseline outcome. For example (with reference to Figure 4), the relative probability of dying in critical care compared with other locations is 3% lower for females than for males, whereas the relative probability of dying in hospices compared with other locations is 9% lower overall for females than for males.

Approvals

The study was approved by the Public Health Scotland Public Benefit and Privacy Panel for Health and Social Care (1718-0342) and SICSAG steering group. All data were de-identified before release to researchers and analysed in a Trusted Research Environment.

RESULTS

During the 12 years of the study, there were 710,829 deaths in Scotland, of which 36,316 [5.1%] occurred in critical care units and 42,988 [6.1%] in hospices. The other locations included home, care homes, acute hospitals and other places of death [631,525; 88.84%]. Deaths in both study settings increased over time, from 2,514 in 2005 to 3,098 in 2017 in critical care and from 2,978 in 2005 to 3,636 in 2017 in hospices (Figure 1). Following direct standardisation for the age-sex structure of the

two combined cohorts, similar trends over time were demonstrated (eFigure 1). In contrast, deaths in acute hospitals reduced over time from 28,959 in 2005 to 24,521 in 2017. As a proportion of hospital deaths, critical care deaths increased from 8% to 11.2% (eTable 1).

Compared with critical care unit decedents, people dying in hospices were older, lived in less deprived areas, and were more likely to have a comorbidity (Table 1). The cause of death was cancer in 90.6% of hospice decedents compared with 11.3% in critical care decedents. The most common cause of death in critical care was respiratory disease [18.9%]. Further comparisons with other deaths in acute hospitals are presented in eTable 2. Directly standardising these characteristics for the age-sex structure of the two cohorts demonstrated similar findings (eTable 3).

Table 1. Characteristics of deaths occurring in critical care and hospices in Scotland during study period.

	Critical Care (N=36316)	Hospice (N=42988)	Total (N=79304)
Gender			
Female	16535 (45.5%)	21674 (50.4%)	38209 (48.2%)
Male	19781 (54.5%)	21314 (49.6%)	41095 (51.8%)
Age (years)			
Mean (SD)	66.3 (14.9)	70.3 (12.5)	68.5 (13.8)
Median [Q1, Q3]	69.0 [58.0, 77.0]	72.0 [63.0, 79.0]	70.0 [60.0, 78.0]
Age Groups			
16-30	912 (2.5%)	185 (0.4%)	1097 (1.4%)
31-40	1414 (3.9%)	584 (1.4%)	1998 (2.5%)
41-50	3087 (8.5%)	2417 (5.6%)	5504 (6.9%)
51-60	5484 (15.1%)	5782 (13.5%)	11266 (14.2%)
61-70	9069 (25.0%)	10872 (25.3%)	19941 (25.1%)
71-80	10477 (28.8%)	13720 (31.9%)	24197 (30.5%)
81-90	5487 (15.1%)	8313 (19.3%)	13800 (17.4%)
91-115	386 (1.1%)	1115 (2.6%)	1501 (1.9%)
Cause of Death			
Accident	1278 (3.5%)	62 (0.1%)	1340 (1.7%)
Cancer	4115 (11.3%)	38934 (90.6%)	43049 (54.3%)
Dementia	57 (0.2%)	201 (0.5%)	258 (0.3%)
Liver Disease	2760 (7.6%)	96 (0.2%)	2856 (3.6%)
MI	3650 (10.1%)	400 (0.9%)	4050 (5.1%)
Other	15188 (41.8%)	2381 (5.5%)	17569 (22.2%)
Respiratory Disease	6881 (18.9%)	715 (1.7%)	7596 (9.6%)
Stroke	2048 (5.6%)	199 (0.5%)	2247 (2.8%)

	Critical Care (N=36316)	Hospice (N=42988)	Total (N=79304)
Suicide	339 (0.9%)	0 (0%)	339 (0.4%)
Socio-Economic Group			
1 - Most Deprived	10652 (29.3%)	10283 (23.9%)	20935 (26.4%)
2	8899 (24.5%)	9275 (21.6%)	18174 (22.9%)
3	7014 (19.3%)	8170 (19.0%)	15184 (19.1%)
4	5357 (14.8%)	7024 (16.3%)	12381 (15.6%)
5 - Least Deprived	4394 (12.1%)	8236 (19.2%)	12630 (15.9%)
Number of comorbidities			
0	10128 (27.9%)	990 (2.3%)	11118 (14.0%)
1	16361 (45.1%)	25323 (58.9%)	41684 (52.6%)
2+	9827 (27.1%)	16675 (38.8%)	26502 (33.4%)
Critical care admission within 30 days of death			
No	NA	42334 (98.5%)	42334 (53.4%)
Yes	36316 (100%)	654 (1.5%)	36970 (46.6%)
Critical care admission within 1 year of death			
No	NA	38745 (90.1%)	38745 (48.9%)
Yes	36316 (100%)	4243 (9.9%)	40559 (51.1%)

Location of death as a proportion of specific groups defined by gender and age is presented in Figure 2. In younger age groups, death was more common in critical care than in hospices, which reversed in older age groups. This was more pronounced in males than in females. The likelihood of dying in critical care was highest in those aged 41-50 years for males [10.8%] and those aged 31-40 years for females [15.6%]. In contrast, the proportion dying in a hospice was highest in those aged 41-50 years for females [13.6%] and in those aged 61-70 years for males [9.2%]. Similar patterns of age-specific location of death was seen when combining males and females (eFigure 2).

There was a socioeconomic gradient in location of death which differed between the groups. People living in the most deprived areas of Scotland were more likely to die in critical care than those living in the least deprived areas [6.0% of those living in most deprived quintile vs 4.4% least deprived quintile; Figure 3). This gradient was reversed for deaths occurring in hospices [5.8% most vs 8.2% least deprived quintile]. A similar pattern was seen when stratified by gender (eFigure 3) and by year of death (eFigure 4).

In the multivariable analysis, factors independently associated with hospice death (relative to death in other locations) were age, living in a less deprived area, cancer as the cause of death, and presence of comorbidities. These differed from factors associated with death in critical care (relative

to death in other locations): liver disease and accidents as the cause of death and absence of comorbidities increased the risk of dying in critical care (Figure 4).

DISCUSSION

This nationwide study of all 710,829 deaths registered in Scotland from 2005 to 2017 has demonstrated that there were similar proportions of deaths occurring in critical care units and hospices over the twelve-year study period. Approximately 1 in 8 deaths in those aged under 40 years occurred in critical care units. Compared with critical care unit decedents, those dying in hospices were older, lived in less deprived areas, and were more likely to have comorbid conditions.

There is minimal literature comparing the epidemiology of decedents in critical care and in hospices. Our results highlighted that one of the most marked differences between the two population groups was the socioeconomic status of decedents. A recent population-level study relating to patients admitted to ICU with COVID-19, reported a higher frequency of admission and risk of death in those living in socially deprived communities.(23) In contrast, a study of end-of-life care for people with cancer in Scotland found that hospice patients were more likely to be of white ethnicity, older and less likely to be from an area of socioeconomic deprivation.(24) Those who live in more deprived areas are less likely to receive hospice care and more likely to die in hospital, with possible reasons being less suitable housing where end-of-life care can be provided and that more affluent people can pay for supplemental care.(25) People living in more deprived areas may have worse experiences at the end-of-life and have reported less support available.(25) Furthermore, the National Survey of Bereaved People found those in the most deprived areas were less likely to describe their overall quality of care for their loved one in the last 3 months of life as 'outstanding' or 'excellent' in comparison to the least deprived.

We have demonstrated that a similar proportion of deaths across Scotland occur in critical care units and hospices. Patients and bereaved family members describe completely different experiences of end-of-life care in these settings. Hospice care is associated with anticipated death. Although unexpected death can occur in this setting, it is rare at less than 5% of deaths.(26) Managing anticipated or expected death is a defining feature of hospice care, and means that bereavement infrastructure is well organised, with trained staff and volunteers offering targeted bereavement care and support.(27)

In contrast, deaths in critical care more often occur suddenly, in younger people and with a wider variety of causes. The proportion of unexpected deaths in critical care has been described as reaching 32% of all deaths, predicated on anticipated deaths occurring following withdrawal of life-sustaining treatment.(19) However, the determinants of anticipated and unexpected death are based on critical care staff definitions and do not necessarily reflect the lived experiences of families in what is regarded as 'sudden'.

Sudden or violent death and a lack of time to prepare increase the risk of complicated grief in the bereaved.(28) Bereavement is known to be associated with changes in physiology, particularly cardiovascular health, and increased risks for mental health, morbidity and mortality.(29, 30) Critical care death is also a risk factor for prolonged grief and is associated with poorer quality of life for a dying person, as evaluated by carers.(31) For this reason, patients and their families in critical care may have even greater need for high quality end-of-life care and bereavement care.

One recent study of 237,989 Medicare-insured individuals in the US identified that 18.5% were admitted to an ICU in the last 30 days, and 16.9% received late hospice care. Where advance care planning (ACP) discussions had taken place, this was associated with fewer hospital admissions overall and fewer ICU admissions, but hospice use was unaffected.(32) Hospice care in the US is generally accessed when all other treatments have been discontinued in contrast with broader UK hospice referral criteria. A high proportion of critical care deaths were from respiratory causes or 'other', whereas cancer deaths constituted over 90% of hospice deaths in our study. Advance care planning occurs much less often with people who have non-cancer conditions although this is improving.(33) Interventions to improve timely end-of-life care planning may reduce critical care use as well as hospital admissions, but a recent UK study found few patients had this information when referred to acute care settings. (34) Planned ACP discussions are not always possible, particularly in context of sudden illness or deterioration, but can be part of shared decision-making conversations about interventions and outcomes in critical care settings. (19, 34).

Provision of bereavement support around the time of death and afterwards is integral to the philosophy of palliative care. This comprehensive provision has focused largely on hospice and primary care settings.(35) Bereavement support and grief counselling forms part of the palliative medicine training curriculum in the UK.(36) In contrast, bereavement support in critical care units is informal, sporadic and rudimentary. This is despite families and healthcare providers stating they would like bereavement support services and the clear need for these services, particularly in relation to dealing with unexpected death.(5, 37) A national survey of UK critical care units found a

paucity of bereavement support services; a leaflet is the standard method of bereavement support in most units.(38)

The key strengths of this study included the complete, national ascertainment of all deaths in Scotland, and the ability to link these accurately to identify all deaths occurring in critical care units as well as hospices. Our study also had a number of limitations. Prevalence of comorbidities was likely to be underestimated due to the method used to derive these relying on data from previous hospitalisations and death records. We were unable to ascertain whether any advance care planning discussions took place with these patients before they reached the end of life, as these national datasets do not currently record this information. In addition, we were unable to capture other factors which might have impacted on location of death during the 13-year study period, such as changes in healthcare policy and practice, and financial pressures affecting NHS services and those hospices which rely on charitable donations and fundraising. Place of death data does not capture whether people's preferences were achieved nor how the different illness trajectories of dying in ICU or an inpatient hospice unit impact on the best place of care.

Our study has implications for policy and clinical practice. The differing socioeconomic status of people dying in critical care and hospices highlight potential inequities in access to palliative care and bereavement support. Our data demonstrate the need for national initiatives to address this imbalance.(39) Furthermore, this study underlines the importance of a specific emphasis on providing high quality bereavement support for families after a death in critical care units. There is real potential for collaboration and mutual learning with palliative care services and spiritual care providers as well as across organisations and settings. This has been brought into sharp focus during the COVID-19 pandemic. Having clear guidelines for bereavement standards and care pertinent to the unique environment of critical care that is integrated with broader community support would also enhance care and may mitigate long-term adverse outcomes. Complicated grief is known to be more prevalent in families bereaved after a critical care death than in the general population.(40)

In conclusion, our study has demonstrated that a similar proportion of deaths in Scotland occur in critical care units as in hospices. Given the younger age profile, greater social deprivation and unexpected nature of deaths in critical care units, there is a pressing need for a specific focus on end-of-life care that includes bereavement support services.

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Authorship statement

All authors made substantial contributions to the conception or design of the work; JM/SM/NL undertook analyses; JM/SM/NL/NP drafted the work; all authors revised the work critically for important intellectual content; all authors grant final approval of the version to be published. NL gives agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Competing Interests

None.

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Figure Legends

Figure 1. Number of annual deaths occurring in hospices and critical care units 2005-2017.

Figure 2. Age-specific proportions of deaths in hospices compared with critical care stratified by sex.

Figure 3. Social deprivation-specific proportions of deaths in critical care compared with hospices.

Figure 4. Factors associated with death occurring in critical care and hospice relative to deaths occurring in other settings adjusted for year of death.