Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care

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ABSTRACT

Objectives: To describe hospital and emergency department use in the last year of life by people for whom death from cancer or one of another nine conditions was an expected outcome.

Design, participants and setting: Retrospective cross-sectional study based on death registrations and morbidity data for 1071 Western Australians who died between 1 August 2005 and 30 June 2006. Decedents had an informal primary carer, did not live in residential aged care and died of a condition amenable to palliative care.

Main outcome measures: Total number of hospital admissions; emergency presentations (with and without hospital admission); days spent in hospital by age group at death, sex, metropolitan or rural place of residence and cancer versus non-cancer diagnosis; proportion in hospital on any day in the last 365 days of life; time points of change in the last 365 days of life at which there was an increasing proportion of hospital admissions for those with cancer and non-cancer conditions.

Results: All but 4% of the decedents spent time in hospital with a marked increase in hospitalisations in the last 108 days of life for people who died of cancer and the last 83 days of life for people who died of non-cancer conditions. Those with cancer spent less time in hospital than those with other diagnoses. Seventy per cent of the cohort had at least one emergency presentation. On the last day of life, 61.5% of people were in hospital and 4.0% had been seen in emergency departments.

Conclusions: Western Australian hospitals currently provide extensive and progressively greater care at the end of life. Identifying patterns of emergency and inpatient use for various disease trajectories will assist in the planning of appropriate services for people where death is an expected outcome.

MJA 2011; 194: 570–573

eMJA Rapid Online Publication 23 May 2011

In 2008 the number of Australians who died totalled 143 900, and this annual total will increase as the population grows.[1] At least half of these people died of conditions from which their deaths were clinically expected and where a palliative-care approach was warranted.[2] Yet, surprisingly, little is known about where seriously ill Australians spend their last months of life. Hospital use before death has received little attention,[3] and what is known has been motivated by concern about inpatient costs.[3,4] In contrast, international perspectives provide some insight, particularly those that note an exponential increase in hospitalisations in the last months or weeks of life.[5-7] A recent Canadian study used linked health care data from administrative sources to show that emergency department (ED) use by people dying of cancer may be avoidable in some circumstances.[8]

Inappropriate use of EDs, as well as numerous or long hospital stays, may be indicative of limitations in community services for some people.[7] One study identified a number of potential indicators of poor quality end-of-life cancer care: starting new cancer therapies or continuing ongoing treatments very near death; a high number of ED visits, inpatient hospital admissions, or days in an intensive care unit near the end of life; and a high proportion of patients never enrolled in palliative care services, only admitted in the last few days of life, or dying in an acute-care setting.[9] A more recent systematic review based on organisational, patient and family perspectives has endorsed the importance of these indicators.[10]

"Quality of death" can be enhanced by improving the standards of end-of-life care. This includes providing services to enable people to be cared for and die in the home if that is their wish.[11] For this study, we chose a cohort of people who died from conditions considered amenable to palliative care, and contrasted hospital use for those who had cancer and conditions other than cancer. By charting the incidence of hospital and ED use by this cohort over the last 365 days of life, we aimed to estimate the proportion of people with such conditions in relation to their place of care on any given day in their last year of life.

METHODS

We performed a retrospective cross-sectional study of hospitalisations of people in a cohort identified systematically through death registrations.

Our cohort comprised people who died in Western Australia between 1 August 2005 and 30 June 2006, had an informal primary carer at the time of death, did not reside in a residential aged care facility, and died of one of 10 conditions identified from the underlying cause(s) of death on the death registrations. Cause of death was established for people for whom the primary diagnosis recorded on the death certificate was a condition considered amenable to palliative care. This included cancer, chronic heart failure, chronic renal failure, chronic liver failure, chronic obstructive pulmonary disease, Alzheimer's disease, Parkinson's disease, motor neurone disease/amyotrophic lateral sclerosis, HIV/AIDS and Huntington's disease.[12] Underlying causes of death were grouped according to International Classification of Diseases, 10th revision, Australian modification (ICD-10-AM) codes.

Hospital morbidity administrative data for all admissions and separations, including ED presentations, were linked to death registrations using the Western Australian Data Linkage System. We included planned or unplanned hospital admissions in which the patient stayed at least overnight.

Statistical analysis

Descriptive statistics were used to describe the cohort: age at death (grouped as <65 years, 65–75 years and >75 years); underlying cause of death (grouped as cancer and non-cancer); sex; and usual place of residence (metropolitan or rural, based on postcode). Data were provided for total number of hospital admissions, length of stay, primary reason for admission, deaths in hospital and

the proportion of people who were admitted to hospital directly or through an ED admission. Admission and separation data were used to plot the proportion of people who died of cancer and non-cancer conditions and who were in hospital or were in an ED on any one day of the last year of life.

Non-linear regression models were fitted to these data and used to estimate change points. We then compared these non-linear models with separately predicted linear components of the proportion of decedents in hospital. This allowed us to define a change point to be the point at which the linear component of the proportion of decedents in hospital was substantially less than the overall non-linear curve. We used a 5% deviation from the fitted linear component as indication of change. Approximate 95% bootstrap confidence intervals for these change points were calculated based on 1000 bootstrap samples. All statistical analyses were carried out using the R statistical computing language.[13]

Ethics approval

Ethics approval was obtained from Curtin University Ethics Committee and the Confidentiality of Health Information Committee of the Health Department of Western Australia.

RESULTS

Cohort characteristics

The cohort comprised 1071 people, 63.2% of whom were men. Three-quarters of the cohort (75.8%) lived in the metropolitan area of Perth, WA; their age distribution was one-quarter (25.3%) aged less than 65 years, one-quarter (24.5%) aged 65–75 years and half (50.2%) aged over 75 years. Over two-thirds (746; 69.7%) had died of a cancer condition, and the remainder (325; 30.3%) had died of one of another nine conditions considered amenable to palliative care. Box 1 provides a summary of the demographic characteristics of the cohort by death from cancer and non-cancer conditions.

Hospital admissions and emergency department visits in the last year of life

Forty-two decedents (4%) were not admitted to hospital in their last year of life. Of these, 25 were men, 30 were aged over 75 years, 20 had cancer and 38 lived in the metropolitan area. Although they were not admitted to hospital in the last year of life, 12 of these decedents did present at an ED during that time: eight were male, 10 had a non-cancer diagnosis, eight were aged over 75 years and 11 lived in the metropolitan area.

1 Demographic characteristics of the cohort by death from cancer and non-cancer conditions

	Diagnostic groups	
	Non-cancer	Cancer
Age group at death		
< 65	36 (13.3%)	235 (86.7%)
65–75	62 (23.7%)	200 (76.3%)
> 75	227 (42.2%)	311 (57.8%)
Sex		
Male	216 (31.9%)	461 (68.1%)
Female	109 (27.7%)	285 (72.3%)
Place of residence		
Metro	253 (31.2%)	559 (68.8%)
Rural	72 (27.8%)	187 (72.2%)
Total	325 (30.4%)	746 (69.7%)

There were a total of 8350 hospital admissions for the 1071 decedents during the last year of life. The mean number of hospital admissions per decedent was 7.8 (SD, 15.3; median, 4) and the mean number of days in hospital per admission was 5.6 (SD, 14.2; median, 1). Decedents with cancer had a mean number of hospital admissions of 7.6 (SD, 10.2; median, 5) with the mean number of days in hospital per admission of 41.3 (SD, 35.2; median, 34). Decedents with non-cancer diagnoses had a mean number of hospital admissions of 8.1 (SD, 23.1; median, 3) with the mean number of days in hospital per admission of 49.6 (SD, 60.0; median, 30).

For all decedents, those aged less than 65 years (younger age group) and 65–75 years (middle age group) had mean numbers of hospital admissions in the last year of life of 9.8 (SD, 9.3; median, 8) and 9.6 (SD, 20.4; median, 5), respectively, while those aged over 75 years (older age group) had a mean number of admissions of 5.9 (SD, 14.6; median, 3). The mean number of hospital admissions for men and women were 7.9 (SD, 17.1; median, 4) and 7.6 (SD, 11.5; median, 4), respectively. Decedents from rural and metropolitan areas had mean numbers of admissions of 8.9 (SD, 18.1; median, 4) and 7.4 (SD, 14.3; median, 4), respectively.

Almost two-thirds of decedents (61.5%) were in hospital on the final day of life (excluding those in ED). A greater proportion of decedents in hospital on the final day of life had non-cancer diagnoses (65.5% v 59.8% for decedents with cancer), were women (64.5% v 59.8% men) and came from rural areas (68.7% v 59.2% from the metropolitan area). Increasing age did not substantially influence the proportion in hospital, with 60.5% of decedents under 65 years, 61.1% of decedents aged 65–75 years and 62.3% of decedents aged over 75 years being in hospital on the final day of life. Another 42 decedents (4.0%) visited an ED on the final day of life.

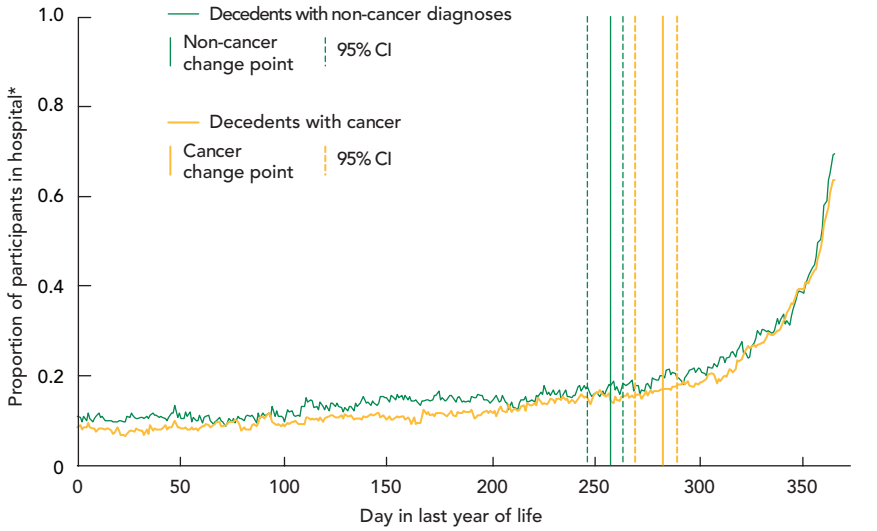
Seventy per cent of the 1071 decedents had at least one emergency presentation, and made a total of 2068 visits to an ED (mean, 1.9 visits) during the final year of life. Decedents with cancer averaged 1.7 visits and those with non-cancer diagnoses averaged 2.5 visits. Women and rural decedents had similar numbers of visits to men and people living in the metropolitan area (2.0 v 1.9 and 2.0 v 1.9, respectively). Increasing age did not substantially influence the proportion of decedents visiting EDs, with a mean number of visits of 1.9 for decedents aged under 65 years, 2.0 for decedents aged 65–75 years and 1.9 for decedents aged over 75 years. Two-thirds of all 2068 presentations to an ED (1379; 67.0%) resulted in decedents being admitted to hospital; a slightly higher proportion of decedents admitted from EDs were those who had non-cancer conditions, women, those from the metropolitan area and those older than 75 years.

The estimated change point for hospitalisations of decedents who died of cancer was 257 days (95% CI, 246–263) into the last year of life, or 108 days before death (Box 2). The change point for decedents who died of non-cancer diagnoses was 282 days (95% CI, 255–270 days) into the last year of life or 83 days before death (Box 2). The estimated change point for ED visits for all decedents was 311 days (95% CI, 232–339 days) or 54 days before death. The change point for decedents who died of a cancer condition (272 days; 95% CI, 111–329 days; 93 days before death) was earlier than for those who died of a non-cancer condition (326 days; 95% CI, 277–340; 39 days before death).

DISCUSSION

In this study, a novel use of death registrations enabled us to identify people who died of conditions from which their deaths were clinically expected and where a palliative-

2 Change points for hospitalisation in the last 365 days of life (excluding emergency department presentations) for decedents with cancer and non-cancer diagnoses



* Proportion of decedents admitted to hospital on any one day of their last year of life. ◆

care approach would have been warranted. Linking these deaths to hospital morbidity data provided an insight into inpatient and ED use during the last year of life and at the time of death for these people. Change points mark an exponential rise in hospital use at the end of life and can be used in health service and policy planning.

The data provide a crucial baseline for modelling ways in which care at the end of life can be modified. Total number of bed-days, length of stay for individual admissions and total number of admissions per person are interrelated. Any decrease in any of these will relieve pressure on the hospital system. The number of admissions is of particular importance, given that much of the cost in health care is borne in the initial clinical assessment at the time of admission.[14] Reduction in the number of short admissions is likely to have a long-term impact on health resource utilisation.

Differences in the course of different diseases, in part, help to explain the period of time towards the end of life when the increase in the prevalence of hospital admission occurs. People with cancer, on average, do not have as many admissions to hospital as those without cancer. However, the change point at which the proportion of hospital admissions increases is closer to death for those with cancer. The physical debility of people with cancer appears to have a much more precipitous drop, and patients' families and community services have often not prepared adequately for this eventuality.[15,16] Without building extensive support networks over time, care may, by default, move to acute-care hospital inpatient beds.

Our study illustrates the dual use of EDs for people for whom death is clinically expected, with a third of ED presentations for such patients not resulting in them subsequently being admitted to hospital. Many presentations among this group of patients are undoubtedly warranted, but it is questionable whether EDs should also be expected to be a substitute for around-the-clock community care. Distinguishing between "emergencies" and service substitution is complex, given that emergencies in this setting have a subjective component and community care may not always be available. Insufficient attention to appropriate community care for people whose deaths are clinically expected will lead to increasing numbers of ED presentations in the future.

A limitation of our study is that the cohort chosen was not representative of the whole population. To enable us to identify those whose deaths were clinically expected, the study was limited to those who had died of one of 10 conditions identified from the underlying cause(s) of death on the death registrations. Each cohort member had a primary family carer who had participated in a survey, and the cohort had a larger proportion of women than men. The presence of a carer may also have influenced decisions about whether or not patients attended hospitals. Nevertheless, despite our cohort not being representative of the general population, our data enabled a highly relevant and informative analysis of hospital use.

We intentionally excluded those who lived in a residential aged care facility before death from the study. There is a decrease in the use of hospital beds among older people compared with those of younger ages in the last year of life, which has been partially explained by the threshold for hospital admission being higher for those receiving care in aged care facilities.[4] The long-term care sector is likely to absorb some of the economic burden from the hospital sector but only for those residing in residential aged care facilities.

In future this study could be repeated, not just for those living in the community and who have primary family carers, but for all people dying of a condition potentially amenable to palliative care, including those residing in aged care facilities. Further research needs to be conducted to help uncover the difference between emergencies that could have been foreseen, those that could have been adequately dealt with by primary care if available around the clock, and those that required the expertise and resources of prehospital and hospital emergency services. How primary, community and palliative care services may be used to alleviate inappropriate use of inpatient and ED services should be examined systematically over time.

Our study confirms that there is extensive use of inpatient services and EDs in the last year of life by people whose deaths are clinically expected. Clinical contact for this group should include early referral to appropriate community and allied health services, contingency planning, and discussion about potential symptom problems within the context of social and environmental circumstances. This requires an intimate knowledge of the trajectory of each disease, comorbid conditions and the social circumstances in which that care is being provided.

Given the potential for inappropriate use of hospitals for people whose deaths are clinically expected, more careful consideration must be given to service design and delivery for this group of vulnerable people. The heavy reliance on the acute-care system does not necessarily reflect the most appropriate use of resources for patients at the end of life. Planning should cover a continuum of care, and should involve the patients and their families together with their general practitioners.

ACKNOWLEDGEMENTS

This article is based on research funded by the National Health and Medical Research Council to determine indicators for palliative care provision in the life-limiting illness pathway in the last year of life (Grant No. 425554). We acknowledge Linda Kristjanson of Curtin University and Stephen Carmody of Silver Chain Nursing Association for their clinical, ethical and epidemiological advice.

COMPETING INTERESTS

None identified.

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Provenance: *Not commissioned; externally peer reviewed.*

(Received 23 Sep 2010, accepted 17 Feb 2011)

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