

Manuscript Title: Hospital and emergency department use in the last year of life:
A baseline for future modifications to end of life care

Abstract

Objectives:

To describe hospital and emergency department use for the last year of life for people where death was an expected outcome.

Design, participants and setting:

Retrospective cross sectional study using death registrations and morbidity data for 1071 Western Australians who died between August 2005 and June 2006. Decedents had an informal primary carer, did not reside 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 demographics and cancer/non cancer; proportion in hospital on any day in the last 365 days; points of change where across the cohort there was an increasing proportion of hospital admissions.

Results:

All but 2% of the decedents spent time in hospital with a marked increase in hospitalisations in the last 108 days for people who died of cancer and the last 83 days for people who died of non-cancer conditions. Those with cancer spent less time in hospital than those with other diagnoses. Seventy percent 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:

Hospitals provide extensive care at the end of life. Even a small decrease in hospitalisations or length of stay would offset costs of increased community-based care. With additional support and contingency planning, community-based care may be an appropriate and financially viable substitute for inpatient care.

Abstract word count: 250

Introduction:

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

Inappropriate ED use, as well as numerous or long hospital stays may be indicative for some people of limitations in community services (7). Earle and colleagues (9) 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 intensive care unit days 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. 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 increasing standards of end-of-life care and 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 of conditions considered amenable to a palliative approach, and contrasted hospital use for those who had cancer and non-cancer conditions. By charting the incidence of hospital and ED use over 365 days, this study aims to demonstrate the

proportion of people with such conditions in relation to place of care on any given day in their last year of life.

Methods:

Study design

A retrospective cross sectional study of hospitalisations of a cohort identified systematically through death registrations.

Participants

Inclusion for the cohort was of people who died between 2005 and June 2006, had at the time of death an informal primary carer, did not reside in a Residential Aged Care Facility (RACF) and died of one of ten conditions identified from the underlying cause(s) of death on the death registrations. Cause of death was established where the primary diagnosis recorded on the death certificate was considered a condition amenable to a palliative approach, including 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 Disease version 10, Australian edition (ICD-10-AM) codes.

Data

Hospital morbidity administrative data for all admissions and separations, including ED presentations, were linked to death registrations using the Western Australian Data Linkage System. In this paper, a hospital admission is included if the admission is unplanned or where a planned admission is at least overnight.

Statistical analyses

Descriptive statistics were used to describe the cohort: age at death was grouped into three groups, being less than 65 years, 65 to 75 years and greater than 75 years; underlying cause of death was grouped as cancer and non-cancer; gender; and usual place of residence (metropolitan or rural) based on postcode. Frequencies 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 ED on any one day of the last year of life. Non linear regression models of the form $f(t) = a + bt + c * \exp(dt)$ were fitted to these data and used to estimate change points. Comparing these non-linear models to separately predicted linear components of $f(t)$ allowed us to define a change point to be the point at which the linear component of $f(t)$ 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 1,000 bootstrap samples.

All statistical analyses were carried out using the R environment (16).

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

Results:

Cohort characteristics

The cohort consisted of 1071 people of whom 63.2% were male; three quarters lived in the metropolitan area of Perth, Western Australia (75.8%); one-quarter were aged less than 65 years (25.3%), one-quarter were aged between 65 and 75 years (24.5%) and half were aged over 75 years (50.2%); and 69.6% died of a cancer condition with the remainder dying of one of nine conditions

considered amenable to palliative care. Table 1 provides a summary of the cohort characteristics by cancer (n=746) and non-cancer conditions (n=325).

Hospital admissions and Emergency Department visits in the last year of life

Forty two participants (2%) were not admitted to hospital in their last year of life. Of these, 25 were male, 30 were aged over 75 years, 20 had cancer and 38 lived in the metropolitan area. While not admitted to hospital in the last year of life, 12 of these participants did present at an Emergency Department during that time: eight were male, 10 had a non-cancer diagnosis, eight were over 75 years of age and 11 lived in the metropolitan area.

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 decedent 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 decedent of 49.6 (SD, 60.0; median, 30). For all participants, those people aged less than 65 years (younger age group) and 65 to 75 years (middle age group) had a mean number of hospital admissions of 9.8 (SD, 9.32; median, 8) and 9.6 (SD, 20.39; median, 5) respectively. The older age group (greater than 75 years) had a mean number of admissions in the last year of life of 5.9 (SD, 14.56; median, 3). The mean number of hospital admissions for males and females were 7.9 (SD, 17.1; median, 4) and 7.6 (SD, 11.5; median, 4) respectively. Participants from rural regions had a mean number of admissions of 8.9 (SD, 18.1; median, 4) and metropolitan participants averaged 7.4 (SD, 14.3; median, 4).

Almost two thirds of participants (61.5%) were in hospital on the final day of life (excluding those in ED). A greater proportion of participants in hospital at this time had non-cancer diagnoses compared

to cancer (65.5% vs 59.8%), were female compared to male (64.5% vs 59.8%) and came from a rural area as compared to a metropolitan area (68.7% vs 59.2%). Increasing age did not substantially impact the proportion in hospital with 60.5% of participants under 65 years in hospital, 61.1% of participants aged 65 to 75 years in hospital and 62.3% of participants aged over 75 years in hospital on the final day of life. Another 42 participants (4.0%) visited ED on the final day of life.

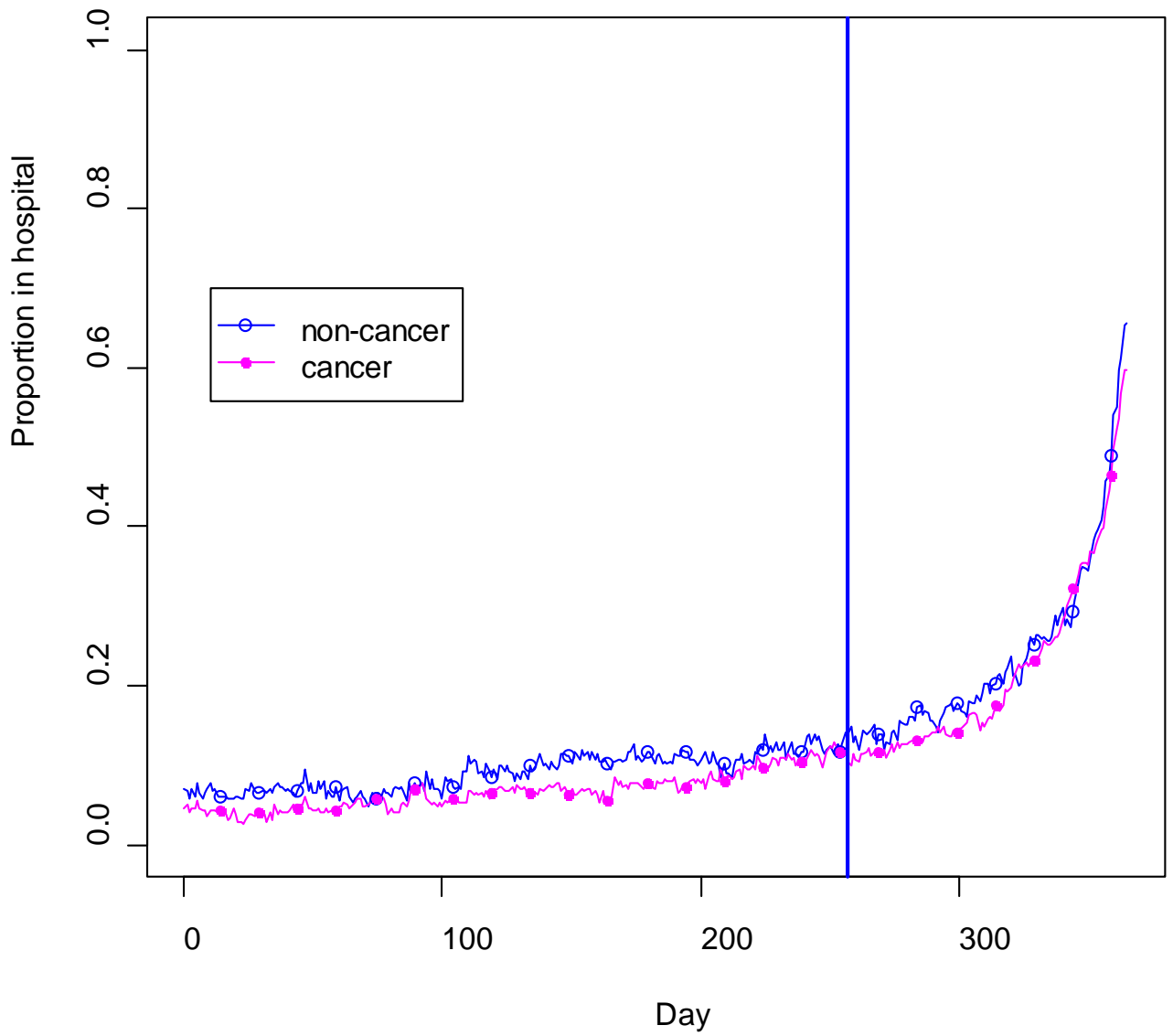
The 1,071 participants had, in total, 2,068 visits to ED (mean, 1.9). Participants with cancer averaged 1.7 visits and those with non-cancer diagnoses averaged 2.5 visits during the final year of life. Females and rural participants had similar numbers of visits to males and people living in metropolitan areas (2.0 vs 1.9 and 2.0 vs 1.9 respectively). Increasing age did not substantially impact the proportion of participants visiting EDs with a mean of 1.9 visits for participants under 65 years, 2.0 visits for participants aged 65 to 75 years and 1.9 visits for participants aged over 75 years. Of all presentations to ED, two thirds of participants were admitted to hospital (67.0%); a slightly higher proportion of the admissions from ED were participants with non-cancer conditions, female, from the metropolitan area and older than 75 years.

The estimated change point for hospitalizations of participants who died of cancer was 257 days (95%CI, 246-263) into the last year of life, or 108 days before death (Figure 1). The change point for participants who died of non-cancer diagnoses was 282 days (95%CI, 255-270) into the last year of life or 83 days before death (Figure 1). The estimated change point (95% CI) for Emergency Department visits for all participants was 311 days (95%CI, 232-339) or 54 days before death, with participants who died of a cancer condition having an earlier change point than those who died of a non-cancer condition (change points 272 days (95%CI, 111-329) compared with 326 days (95%CI, 277-340) or 93 days compared with 39 days before death).

Table 1: Summary of demographics for participants with and without cancer as their life-limiting illness

	Diagnostic groups			
	Non-cancer		Cancer	
	n	Percent	N	Percent
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
Gender				
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

Figure 1: Change points for hospitalization in the last 365 days of life (excluding ED presentations)



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.

The data provide a crucial baseline for modelling ways that 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 will relieve pressure on the hospital system. The number of admissions is of particular impact, given that much of the cost in health care is borne in the initial clinical assessment at the time of admission (13). Reduction in the number of short admissions is likely to have long term impact on health resource utilisation.

Differences in disease trajectories, in part, help to explain the period of time towards the end of life where the increase in prevalence of hospital admission occurs. While people with cancer, on average, do not have as many admissions to hospital as those without cancer, the change point where increasing proportion of hospital admissions occurs is earlier for those with cancer. The physical debility of people with cancer appears to have a much more precipitous drop, and often the family and community services have not prepared adequately for this eventuality (14-15). Without extensive support networks built up over time care will, by default, move to acute hospital inpatient beds.

The study illustrates the dual use of ED for people where death is clinically expected, with one third of ED presentations not subsequently admitted to hospital. Undoubtedly, many presentations for this group are warranted; however, it is questionable whether ED should also be expected to be a substitution 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.

The cohort chosen for this study is in some ways limited as it was not representative of the whole population. In order to identify those people whose death was clinically expected the study was limited to those who had died of one of ten conditions identified from the underlying cause(s) of death on the death registrations. Each of the cohort members had a primary family carer who had participated in a survey. A larger proportion of the respondents were female and consequently there was a gender imbalance in the group. The presence of a carer may also have impacted upon decisions around attendance at hospital or otherwise. Nevertheless, these factors enable highly relevant and informative analysis of hospital use.

Those who lived in a residential aged care facility (RACF) prior to death were intentionally excluded from the study. There is a decrease in the use of hospital beds among the elderly, compared with younger ages in the last year of life, which has been partially explained by a higher threshold for hospital admission for those receiving care in RACFs (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 RACFs.

In future this study could be repeated, not just for those with primary family carers living in the community, but for a whole palliative care population including those residing in RACFs. 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 pre-hospital 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.

This study confirms that there is extensive use of inpatient services and EDs in the last year of life for 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 each disease trajectory, co-morbidities and the social circumstances in which that care is being provided.

Given the potential inappropriate hospital use 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.

Word count: 2415

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