ORIGINAL RESEARCH ARTICLE

Specialist Palliative Care and Health Care Costs at the End of Life

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Abstract

Background/Aims The use and costs of health care rise substantially in the months prior to death, and although the use of palliative care services may be expected to lead to less costly care, the evidence is mixed. We analysed the costs of care over the last year of life and the extent to which these are associated with the use and duration of specialist palliative care (SPC) for decedents who died from cancer or another life-limiting illness.

Methods The decedents were participants in a cohort study of older residents of the state of New South Wales, Australia. Using linked survey and administrative health data from 2007 to 2016, two cohorts were identified: $n = 10,535$ where the cause of death was cancer; and $n = 11,179$ where the cause of death was another life-limiting illness. Costs of various types were analysed with separate risk-adjusted linear regression models for the last 1, 3, 6, 9 and 12 months before death and for both cohorts. SPC was categorised according to time to death from first contact with the service as 1–7 days, 7–30 days, 30–180 days and more than 180 days.

Results SPC use was higher among the cancer cohort (30.0%) relative to the non-cancer cohort (4.8%). The mean costs over the final year of life were AU$55,037 (SD 45,059) for the cancer cohort and AU$35,318 (SD 41,948) for the non-cancer cohort. Earlier use of SPC was associated with higher costs over the last year of life but lower costs in the last 1 and 3 months for both cohorts. Initiating SPC use more than 180 days before death was associated with a mean difference relative to the no SPC group of AU$15,590 (95% CI 10,617 to 20,562) and AU$13,739 (95% CI 733 to 26,746) over the last year of life for those dying from cancer and another illness, respectively. The same differences over the last month of life were − AU$2810 (95% CI − 3945 to − 1676) and − AU$4345 (95% CI − 6625 to − 2066). Admitted hospital care was the major driver of costs, with longer SPC associated with lower rates of death in hospital for both cohorts.

Conclusion Early initiation of SPC was associated with higher costs over the last year of life and lower costs over the last months of life. This was the case for both the cancer and non-cancer cohorts, and appeared to be largely attributed to reduced hospitalisation. Although further investigation is required, our results suggest that expanding the availability of SPC services to provide more equitable access could enable patients to spend more time at their usual place of residence, reduce pressure on inpatient services and facilitate death at home when that is preferred.

1 Introduction

The cost of health care generally increases toward the end of life [1–4], driven largely by increasing hospitalisation [3–6]. Higher costs have been associated with multimorbidity [7] and previous health care expenditure [6], while variation in costs has been identified by geographic region [8] and by cause of death. People dying from cancer were found to have higher costs than those dying from other conditions over the last 6 [5, 9] and 12 months of life [9], while people with

dementia have been found to have lower costs over the last 6 [9, 10] and 12 months of life [9].

Palliative care aims to relieve suffering and improve quality of life for people with life-limiting health conditions, as well as provide support for families and informal carers. It can be provided by generalist or specialist palliative care providers in both inpatient and community settings, with those with more complex needs generally requiring specialist care. Despite limitations of research studies in the end-of-life context, there is evidence to support the effectiveness of specialist palliative care programmes which have been found to improve quality of life [11–15] and relieve symptoms [11, 16, 17] for patients with advanced disease. In many

Key Points for Decision Makers

Differences identified suggest that referral to specialist palliative care services is not equitable across health conditions, location and socio-economic status.

Early referral to specialist palliative care was associated with lower costs nearer death for some patients, but further research is required to establish causality.

Design of palliative care services requires a nuanced approach to accommodate the different trajectories and needs of different patients at the end of life.

countries (including Australia), government palliative care policies have emphasised the need to achieve the patient's preferred place of death and a need to avoid unnecessary hospitalisation, noting the potential cost savings that might be achieved [18].

Reviews have found the evidence for the effects of specialist palliative care on resource use, costs or cost effectiveness to be mixed [19] or inconclusive [11]. A meta-analysis found early palliative care for hospitalised patients with serious illness was associated with lower hospital costs within that hospitalisation but did not investigate other health care costs [20]. Larger reductions were found for those with cancer and those with multiple comorbidities. Recent observational studies using administrative health data and focusing on the utilisation of acute health care services at the end of life have found reductions in hospitalisation attributable to palliative care programmes [21–23] and lower rates of in-hospital death among those receiving the palliative care programme [21, 22]. These studies used different end-of-life periods, including the last 1 [22], 6 [21] and 12 [23] months of life. Lower health system expenditures have also been found using administrative health data [9, 24]. Hung et al. [9] found lower USA Medicare expenditures in the last year of life associated with longer durations of hospice care for people with cancer, but this was less clear for other health conditions where lower costs were seen only in the last 1–3 months. Using a cohort of decedents with pooled cancer and non-cancer diagnoses, Seow et al. [24] found lower health system costs in the last month of life for those accessing specialist community palliative care.

As patients with more complex palliative care needs may be more likely to be referred to specialist palliative care services at an earlier stage [25, 26] and may also be higher users of health services [21], observational studies in this context must use measures to address potential confounding. The above studies used either propensity matching [21, 22, 24] or a range of control variables [9, 23]. Both approaches may be constrained by the adequacy of the variables in the administrative data, which may account for some of the mixed results found in the reviews. Pooling of cohorts with different chronic diseases may also contribute to the mixed results as cancer patients are more likely to access specialist palliative care [27, 28] and typically have a different and more predictable end of life trajectory of decline [29] relative to people dying from other chronic diseases.

We used linked survey and administrative health data to investigate the costs of health care in the last year of life and the extent to which these are associated with the use of specialist palliative care (SPC) services. Our analysis used two cohorts of older decedents where the cause of death is cancer or another chronic disease. It also considered costs over different time periods to death for groups with different durations of SPC contact and a large range of control variables to account for selection into SPC. The main study aim was to investigate the association between the duration of SPC use and health care costs at the end of life. The study also included two related secondary aims to: (1) investigate the patient characteristics associated with the duration of SPC use in the final year of life and (2) investigate associations between the duration of SPC use and the place of death.

2 Materials and Methods

2.1 Sample

We identified a cohort of decedents who had been participating in the Sax Institute's 45 and Up study [30, 31] conducted in New South Wales (NSW) Australia. Between 2005 and 2009, the 45 and Up Study recruited 267,357 people aged 45 or more and resident in NSW. The study population was a random sample identified from the Services Australia Medicare enrolment database, with oversampling (by a factor of 2) of people aged over 80 and rural residents [30, 31]. Approximately 19% of those invited participated and participants included roughly 11% of the NSW population aged 45 and over. The 45 and Up Study participants complete surveys every 5 years and have provided consent for linkage of their survey data to routinely collected health data for research purposes. From 266,756 participants who had not withdrawn from the 45 and Up Study at the time of data provision (99.8% of study recruits), we identified a cohort of 21,714 participants who died between 2007 and 2016 from cancer ($n = 10,535$) or another advanced chronic disease ($n = 11,179$) deemed likely to require palliative care [28, 32]. The chronic diseases were those identified among patients using palliative care services [32, 33] and included the diseases deemed likely to require palliative care identified in previous

studies involving literature reviews and focus groups or interviews with health care professionals involved in end-of-life care [34, 35]. The above sample sizes resulted after exclusion of some decedents due to potential data gaps, including those in border regions with shared cross-state services and Department of Veterans Affairs (DVA) clients as we did not have access to interstate hospital data or DVA specific health data such as Repatriation PBS. As some data sources commenced in 2005, we excluded deaths in 2006 to ensure availability of all data sources in the year prior to death and decedents with missing data for one or more covariates were also excluded. The online supplementary material includes a flowchart of included and excluded participants (Online Resource Fig. S1) and a list of International Classification of Diseases 10th Revision (ICD-10) codes used to identify relevant causes of death (Online Resource Page 3).

2.2 Data

The study used the 45 and Up baseline and follow-up surveys linked to Medicare claims data, Pharmaceutical Benefits Scheme (PBS) data, the NSW Emergency Department Data Collection (EDDC), the NSW Admitted Patient Data Collection (APDC), the NSW Registry of Births Deaths and Marriages death data (RBDM) and the NSW Cause of Death Unit Record File (COD-URF). Medicare claims and PBS data were provided by Services Australia. Linkage of the 45 and Up Study cohort data to these datasets is facilitated by the Sax Institute using a unique identifier and deterministic matching. The 45 and Up Study baseline data were linked to other datasets by the Centre for Health Record Linkage (CHeReL) using a probabilistic procedure to link records, where records with an uncertain probability of being true matches are checked by hand. Its current estimated false positive rate is 0.5% [36]. Further information on the linked datasets is available in the online supplementary file (Online Resource Page 4). The ICD-10 coded underlying cause of death variable in the COD-URF data was used to determine the cause of death for cohort identification. The non-cancer cohort included 3281 people (29%) with a recorded prior diagnosis of cancer, although this was not the underlying cause of death. Cancer was considered a contributing cause of death for 845 (7.7% of the non-cancer cohort) and 2784 (24.9% of the non-cancer cohort) received cancer treatment in the final year of life. These participants were retained in the non-cancer cohort, and sensitivity analysis was conducted to assess any impact on the results for the non-cancer cohort.

2.2.1 Outcome Variables

The main outcome was total cost of health care, which was examined over multiple time periods including the last 30, 90, 180, 270 and 365 days of life. Costs were estimated taking a health sector perspective. Total costs were constructed using the resource use identified in the administrative data alongside the costs associated with each resource item. Costs for privately provided medical and diagnostic services were identified from the Medicare data as the fees charged by providers. The costs of pharmaceuticals were identified from PBS data as the gross price of a prescription which is the sum of the patient contribution and the benefit paid by government. The costs for emergency department (ED) attendances which did not result in admission (DRG costs for inpatient episodes include ED costs) were assigned using the EDDC data and the national average cost by urgency related group (URG) from the National Hospital Costs Data Collection (NHCDC) [37]. The APDC data were used to identify utilisation of inpatient episodes in public and private hospitals and costs were assigned to these episodes using diagnosis-related group (DRG) except where the care type was identified as palliative. DRG costs were identified from the NHCDC [37] for public inpatient episodes and from the Hospital Casemix Protocol (HCP) data for private inpatient episodes [38]. Where care type was classified as palliative, costs were taken from the subacute table of the NHCDC report [37] using the national average cost for palliative care. These public hospital costs were applied to all episodes classified as palliative as almost all were in public hospitals. Adjustments to allocated costs were made to account for extremely long or short hospital stays relative to the mean for each DRG by applying the relevant short or long stay price weights to lengths of stay beyond the lower or upper cut, using data from the National Efficient Price (NEP) price weight tables [39]. Hospital costs were assigned using the relevant tables from 2016 to 2017. All costs were subsequently adjusted to 2020–2021 Australian dollars [40].

2.2.2 Explanatory Variables

Use of SPC services in the last year of life was identified from two sources: (1) the use of any services in the Medicare data where the provider was a palliative care specialist and (2) any episode in the APDC data where the person was admitted or transferred to a palliative care unit or where the person was referred to palliative care on separation. Although we do not directly observe the use of community palliative care services, we expect that most people using these services will be captured through referral on separation from an inpatient episode or from outpatient specialist medical services identified in the Medicare data. The use of SPC was then classified into five categories according to

the time between first contact with SPC and death: Cat1 7 days or less, Cat2 8–30 days, Cat3 31–180 days, Cat4 more than 180–365 days and Cat5 no SPC use identified. The categories were determined based on the distribution of SPC duration and clinical advice. Our method for identification of SPC may not capture some users of a community palliative care programme where care was provided in conjunction with a general practitioner and there was no SPC physician visit billed to Medicare and no admitted episode. However, we expect the number of episodes missed to be small as 60–70% of patients seen by community programmes in NSW are referred from an inpatient episode [41, 42] and others will have at least one inpatient episode prior to death, with the majority dying in a hospital or hospice in NSW [41, 42].

A range of control variables were used to account for demographic and health factors which may affect both cost and use of SPC including: cause of death (including cancer type for the cancer cohort) from COD-URF, Rx-Risk comorbidity score [43] (based on PBS data from the penultimate year of life), inpatient days in the penultimate year of life (calculated from APDC data), self-rated health as good/very good/excellent at the most recent survey, use of chemotherapy (identified from PBS, MBS and APDC data) or radiation therapy (from MBS data) in the last year of life, admission to intensive care in the last year of life, one or more inpatient episodes where the intent of care is palliative in the last year of life, death in hospital where the care type was classified as acute care, age, sex, living in residential aged care, annual household income at the most recent survey, private health insurance, year of death and regional variables including Local Health District (LHD) of residence and decile of the Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socioeconomic Advantage (IRSA) [44]. Further information about the survey variables and their coding is provided in the online supplementary file (Online Resource Page 4). Although some of the treatment related variables are potentially in the causal pathway between SPC and cost, they are also likely to be factors in referral to SPC. People attending hospital for cancer therapies may be more likely to be referred to SPC by the radiation or medical oncologist than patients with cancer not seeing an oncologist. People receiving acute care services and not deemed to be palliative care patients will be less likely to be referred to SPC or will be referred when very close to death.

2.3 Analysis

Costs of various types were analysed with separate risk-adjusted linear regression models for each costing period and for those dying from cancer separately from those dying

from another life limiting illness. The regression models all take the same form:

$$y_{id} = \beta_0 + \sum_{j=1}^{4} \beta_{jd} \text{Cat}_{ji} + x_i' \delta_d + u_{id}, \tag{1}$$

where y_{id} represents one of four cost variables (total, hospital, medical services or pharmaceuticals), for individual i over $d = 1, \dots, 5$ durations (representing the last 30, 90, 180, 270 and 365 days of life). The Cat_{ji} represents four dummy indicators for whether individual i was classified as Cat1–Cat4 in terms of SPC use and x_i represents individual specific risk-adjustment controls. Because Cat5 is the omitted category in this specification, the estimated β_{jd} represent risk-adjusted differences relative to a control group with no SPC (Cat5). The sequence of estimates of $\beta_{j1}, \dots, \beta_{j5}$ provide a convenient representation, amenable to graphical presentation, of how a particular cost varies over the last year of life and part-there-of. These can then be compared across different periods of SPC use and between the cancer and non-cancer samples.

Because the analysis relies on risk adjustment, additional analyses using the double selection procedure based on lasso regressions [45] were undertaken to assess robustness of our choice of control variables. These are outlined in detail in the online supplementary material. To assess the sensitivity of the non-cancer models to comorbid cancer or cancer treatment, the risk-adjusted models for the non-cancer cohort in the last 30 and 365 days of life were re-estimated after excluding those with cancer as a contributing cause of death and those receiving cancer treatment.

A multinomial logit (MNL) model was used to examine characteristics predicting the four categories of SPC use relative to no SPC use. Risk-adjusted probabilities (adjusted for the control variables listed at the end of Sect. 2.2) of death at home or in a nursing home relative to hospital for each category of SPC use were also estimated using MNL. Again, separate models were estimated for the cancer and non-cancer groups.

3 Results

SPC use was identified for 17% of the sample overall (3697 of 21,714), with higher use among the cancer cohort (30.0% or 3160 of 10,535) relative to the non-cancer cohort (4.8% or 537 of 11,179). The most prevalent underlying causes of death among the non-cancer cohort were heart failure (47.2%), stroke (15.8%) and dementia (14.9%) (Table 1). Among the cancer cohort, the most frequent cancer types

Table 1 Sample characteristics

Variable	Cancer N = 10,535 %	Non-cancer N = 11,179 %
No SPC	70.0	95.2
First SPC:		
≤ 7 days before death	4.5	1.7
> 7 and ≤ 30 days before death	8.7	1.2
> 30 and ≤ 180 days before death	13.1	1.3
> 180 and ≤ 365 days before death	3.7	0.6
Male	61.2	57.6
Age at death, mean (SD)	77.2 (10.3)	83.9 (9.0)
Living in residential aged care	11.1	20.5
Annual household income ≥ AU$40,000	20.8	11.5
Private health insurance last survey	51.6	46.8
Total days in hospital penultimate year, mean (SD)	8.6 (17.2)	10.9(24.0)
Self-reported health last survey good/very good/excellent	68.5	55.2
Rx-Risk Comorbidity Index (Pratt et al. 2018), mean (SD)	3.4 (3.9)	4.8 (4.4)
Died in hospital	64.7	45.1
Care type "acute" last inpatient episode if in-hospital death	31.3	36.7
Care type "palliative" one or more inpatient episodes final year	36.2	8.5
Any care in ICU in last year of life	13.7	12.1
No inpatient episodes in last year of life	4.9	19.0
Received radiation therapy in last year of life	54.2	24.5
Received chemotherapy in last year of life	33.5	0.8
Underlying cause of death:		
Chronic obstructive pulmonary disease		11.4
Dementia/Alzheimer's disease		14.9
Heart failure/ischaemic heart disease		47.2
Other neurodegenerative disease (Huntington/motor neurone/multiple sclerosis/muscular dystrophy/Parkinson's disease)		5.4
Stroke		15.8
Renal/liver failure		5.3
Lung cancer	15.8	
Colorectal cancer	8.8	
Prostate cancer	10.6	
Breast cancer	7.0	
Pancreatic cancer	5.8	
Melanoma	4.1	
Liver cancer	2.9	
Haematological cancer	13.3	
Other cancer	31.8	

SPC specialist palliative care, *SD* standard deviation, *ICU* intensive care unit

included lung cancer (15.8%), haematological cancers (13.3%) and prostate cancer (10.6%). Relative to the non-cancer cohort, the cancer cohort was younger and had fewer health problems (in terms of comorbidity scores and days in hospital) prior to the final year of life (Table 1). A higher proportion of the non-cancer cohort were in residential aged care during the final year of life, while a higher proportion of the cancer cohort died in hospital (Table 1). A higher proportion of the cancer cohort used hospital inpatient services in the last year of life; 5% of the cancer cohort and 19% of the non-cancer cohort had no inpatient episodes in the final year.

3.1 Duration of SPC

The duration of SPC use differed between the cancer and non-cancer cohorts, where Cat3 (used for between 30 days and 6 months) formed the largest group of SPC users in the

Fig. 1: Mean total costs over the last 1, 3, 6, 9 and 12 months of life by time from first specialist palliative care (SPC) contact: raw mean costs for the cancer and non-cancer cohorts
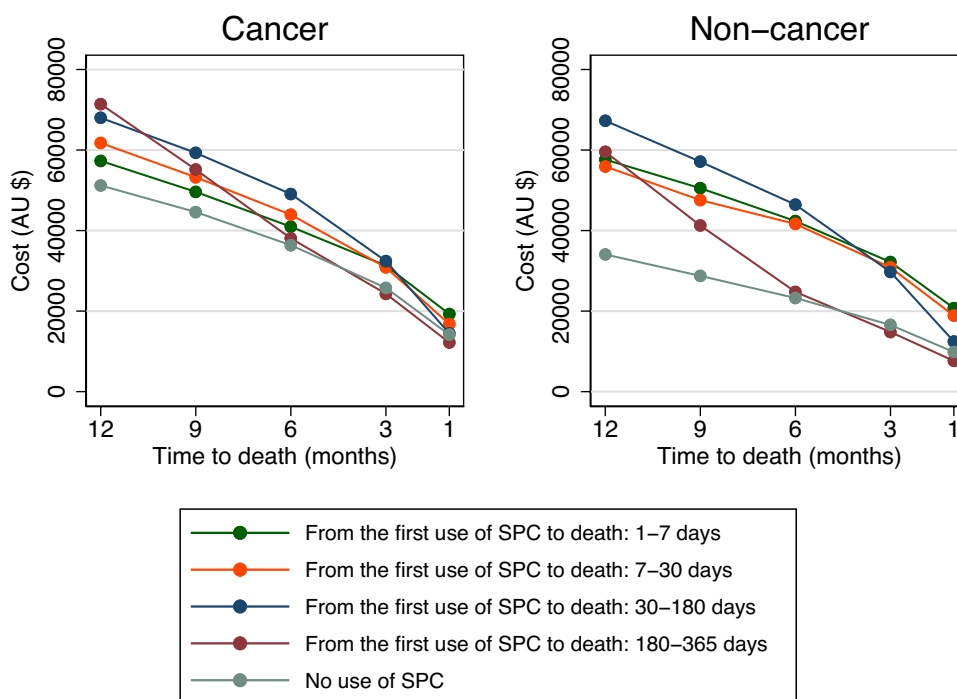
cancer cohort while Cat1 (used for less than 7 days) was the largest group in the non-cancer cohort. Among those in the cancer cohort using SPC, 15% fall into Cat1 (used for less than 7 days), 29% into Cat2 (between 7 and 30 days), 44% into Cat3 (between 30 days and 6 months) and 12% into Cat4 (between 6 months and 1 year). Among those in the non-cancer cohort using SPC, 36% fall into Cat1, 26% into Cat2, 26% into Cat3 and 12% into Cat4.

3.2 Costs of Health Care

Overall, the cancer cohort incurred more costs than the non-cancer cohort over the final year of life; mean costs were AU$55,357 (SD 45,059) for the cancer cohort and AU$35,318 (SD 41,948) for the non-cancer cohort. Among the cancer cohort, the mean total costs for those using SPC at any time in the last year were AU$64,982 (SD 46,354) and AU$51,205 (SD 43,845) for those not using SPC. Among those dying from a non-cancer illness, the same mean costs were AU$59,975 (SD 47,852) for those using SPC and AU$34,074 (SD 41,245) for those not using SPC. The mean total costs of health care over the last year of life were highest for those with longer SPC use and lowest for those with no SPC use (Fig. 1) for both the cancer and non-cancer cohorts. The differences between the groups with different duration of SPC use diminish when we examine the shorter time periods to death (Fig. 1). Without risk adjustment, the group with longer SPC use (Cat4) had the lowest costs over the last month of life expressed as differences from the costs of

those with no SPC use (Fig. 2). Although the costs for all groups increased toward the end of life, the mean total cost in the last month of life as a proportion of the mean cost over the last year of life was lowest for those with longer SPC use. These proportions (calculated from the raw mean costs over the last 1 and 12 months for each SPC category) were: Cat1 0.34, Cat2 0.27, Cat3 0.21, Cat4 0.17 and Cat5 0.28 for the cancer cohort and Cat1 0.36, Cat2 0.34, Cat3 0.19, Cat4 0.13 and Cat5 0.29 for the non-cancer cohort.

Over the last year of life, the mean cost differences between each of the SPC groups and those not using SPC were substantially reduced by risk adjustment, particularly for the non-cancer cohort. However, relative to no SPC use (Cat5), they remained significantly higher for SPC use categories Cat2, Cat3 and Cat4 for the cancer cohort and for categories Cat1, Cat3 and Cat4 for the non-cancer cohort (Fig. 3). The differences were AU$6051 (95% CI 3047–9055), AU$11,351 (95% CI 8673–14,029) and AU$15,590 (95% CI 10,617–20,562) for categories, Cat2, Cat3 and Cat4, respectively, among the cancer cohort and AU$9029 (95% CI 3017–15,042), AU$16,456 (95% CI 8615–24,296) and AU$13,739 (95% CI 733–26,746) for categories Cat1, Cat3 and Cat4, respectively, among the non-cancer cohort. This changes for the costs over shorter time periods to death. After risk adjustment, the mean costs for those using SPC for more than 6 months were significantly lower than for those not using SPC over the last 1 and 3 months of life (Fig. 3). For the cancer group, the differences were − AU$2810 (95% CI − 3945 to − 1676) and − AU$2845 (95% CI − 5025 to − 665) over the last 1 and 3

Fig. 2 Unadjusted mean total cost differences relative to the no specialist palliative care (SPC) group over the last 1, 3, 6, 9 and 12 months of life by time from first SPC contact: estimates for the cancer and non-cancer cohorts
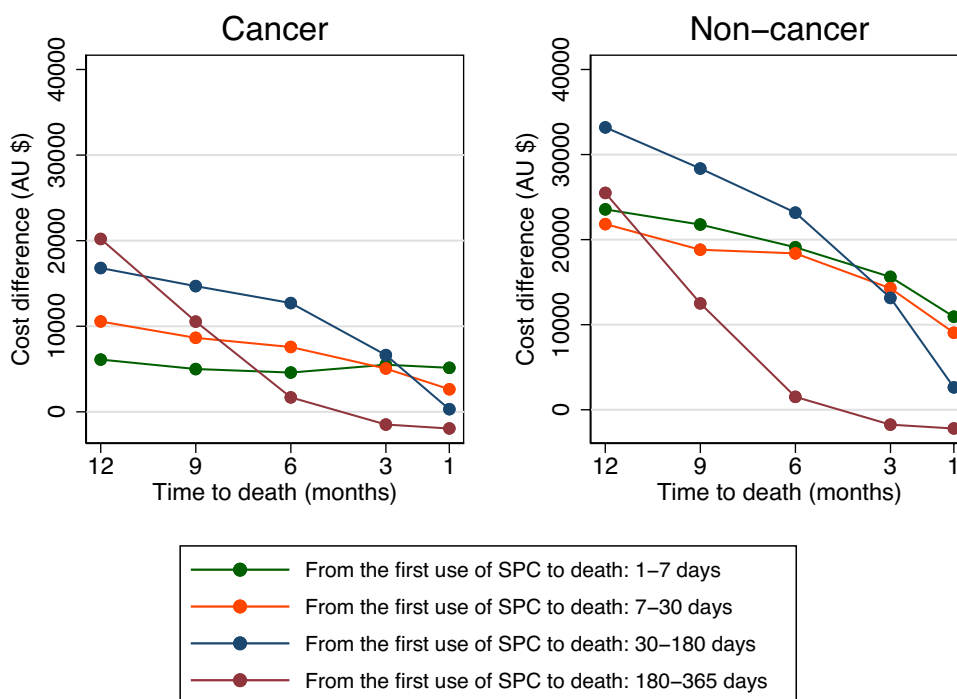
months, respectively, and for the non-cancer group the same differences were − AU$4345 (95% CI − 6625 to − 2066) and − AU$6223 (95% CI − 11,016 to − 1431). Those using SPC for 1–6 months had significantly lower costs relative to the no SPC group over the last month of life with differences of − AU$2395 (95% CI − 3196 to − 1594) and − AU$2778 (95% CI − 4769 to − 787) for the cancer and non-cancer cohorts, respectively (Fig. 3). The relevant models are shown in the supplementary material (Online Resource Tables S1 and S2). Similar differences were found in the robustness checks reported in the supplementary material (Online Resource Tables S4 and S5). The results for the non-cancer cohort were not sensitive to the exclusion of those with cancer as a contributing cause of death or those receiving cancer treatment in the last year of life (Online Resource Table S3).

Inpatient hospital costs comprised the major portion of total costs, particularly over the shorter time periods to death. Over the last year of life, mean hospital costs were 69% of mean total costs for the cancer cohort and 77% for the non-cancer cohort. Over the last month of life, mean hospital costs were 89% of mean total costs for the cancer cohort and 90% for the non-cancer cohort. After risk adjustment, the differences in mean hospital costs showed a similar pattern to the mean total costs with Cat3 and Cat4 having the highest cost over the last year of life and the lowest cost over the last month of life (Fig. 4). Among the non-cancer cohort, lower hospital costs were identified over the last 6 months of life for those with longer SPC use (Cat4) relative to those with no SPC use (difference − AU$6157, 95% CI − 11,677 to − 637). Private medical services (Medicare) and

pharmaceuticals (PBS) were considerably less costly than hospital services, which formed the major portion of total costs. The risk-adjusted cost differences showed a similar pattern to total costs for the cancer cohort but not for the non-cancer cohort where only the Cat3 group showed significantly lower Medicare costs than the no SPC group over the last month (Figs. 5 and 6). Among the cancer cohort, lower Medicare costs were identified over the last 6 months of life for those with longer SPC use (Cat4) relative to those with no SPC use (difference − AU$745, 95% CI − 1297 to − 194). The models are provided in the online supplementary material; see Online Resource Tables S6 and S7 for hospital costs, Tables S8 and S9 for Medicare costs and Tables S10 and S11 for PBS costs. Non-admitted emergency department attendances were less than 1% of total costs and are not shown separately.

3.3 Characteristics Associated with Use of SPC

The use and duration of SPC was associated with a number of decedent socio-demographic and health characteristics. In both cohorts, residents in a non-metropolitan area had a lower probability of using SPC relative to those in the metropolitan area; this was the case for SPC of any duration in the cancer cohort and for Cat1 and Cat3 in the non-cancer cohort (Tables 2 and 3). In the cancer cohort, those with private health insurance and those residing in the most economically advantaged areas had a higher probability of using SPC of any duration, relative to those without insurance or living in the most disadvantaged areas (Table 2).

Fig. 3 Risk-adjusted mean total cost differences relative to the no specialist palliative care (SPC) group over the last 1, 3, 6, 9 and 12 months of life by time from first SPC contact: regression estimates for the cancer and non-cancer cohorts. Models were adjusted for age, sex, residential aged care, previous year hospital days, comorbidity index, private insurance, household income, acute care episode if died in hospital, palliative care inpatient episode, decile of socioeconomic advantage, local health district of residence, year of death and chemotherapy or radiation therapy in the last year. Cancer model was adjusted for the type of cancer, and the non-cancer model was adjusted for the underlying cause of death
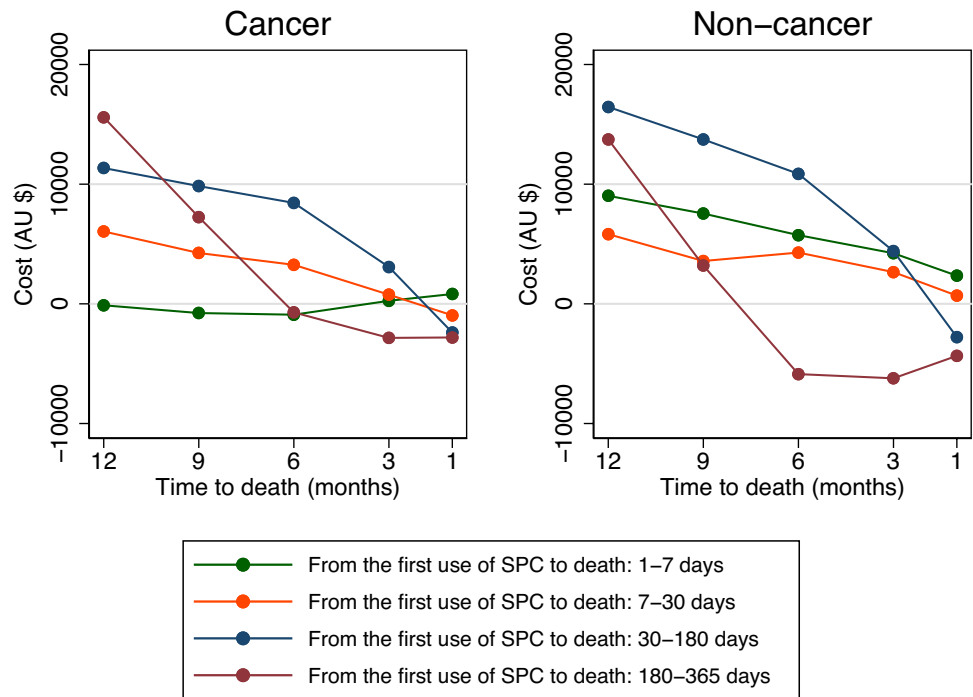

Fig. 4 Risk-adjusted mean hospital cost differences relative to the no specialist palliative care (SPC) group over the last 1, 3, 6, 9 and 12 months of life by time from first SPC contact: regression estimates for cancer and non-cancer cohorts. Models were adjusted for age, sex, residential aged care, previous year hospital days, comorbidity index, private insurance, household income, acute care episode if died in hospital, palliative care inpatient episode, decile of socioeconomic advantage, local health district of residence, year of death and chemotherapy or radiation therapy in the last year. Cancer model was adjusted for the type of cancer, and the non-cancer model was adjusted for the underlying cause of death
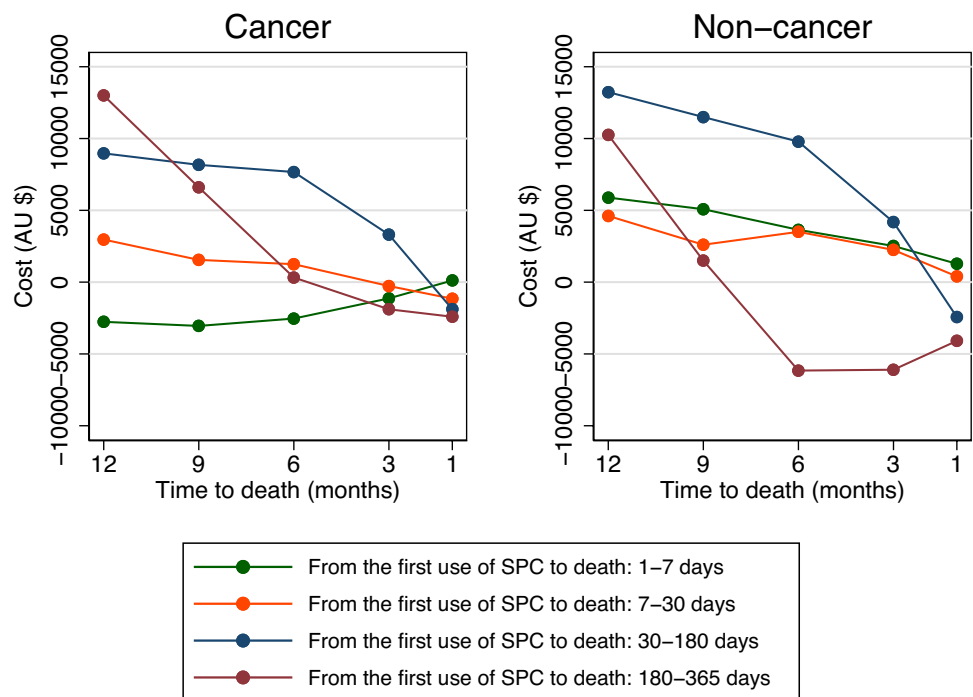

Decedents in both cohorts who lived in residential aged care had a lower probability of late initiation of SPC (1 month or less before death) relative to those living in the community. Residential aged care was also associated with longer use of SPC in the cancer cohort (Table 2) but not in the non-cancer cohort (Table 3).

The health characteristics associated with the use and duration of SPC included indicators of prior poor health and underlying cause of death. Indicators of prior poor health were associated with a higher probability of earlier use of SPC in the final year of life; in the cancer cohort this was the case for those with a higher comorbidity index in the penultimate year of life (Table 2), while it was the case for

Fig. 5 Risk-adjusted mean cost differences for private medical services relative to the no specialist palliative care (SPC) group over the last 1, 3, 6, 9 and 12 months of life by time from first SPC contact: regression estimates for cancer and non-cancer cohorts. Models were adjusted for age, sex, residential aged care, previous year hospital days, comorbidity index, private insurance, household income, acute care episode if died in hospital, palliative care inpatient episode, decile of socioeconomic advantage, local health district of residence, year of death and chemotherapy or radiation therapy in the last year. Cancer model was adjusted for the type of cancer, and the non-cancer model was adjusted for the underlying cause of death
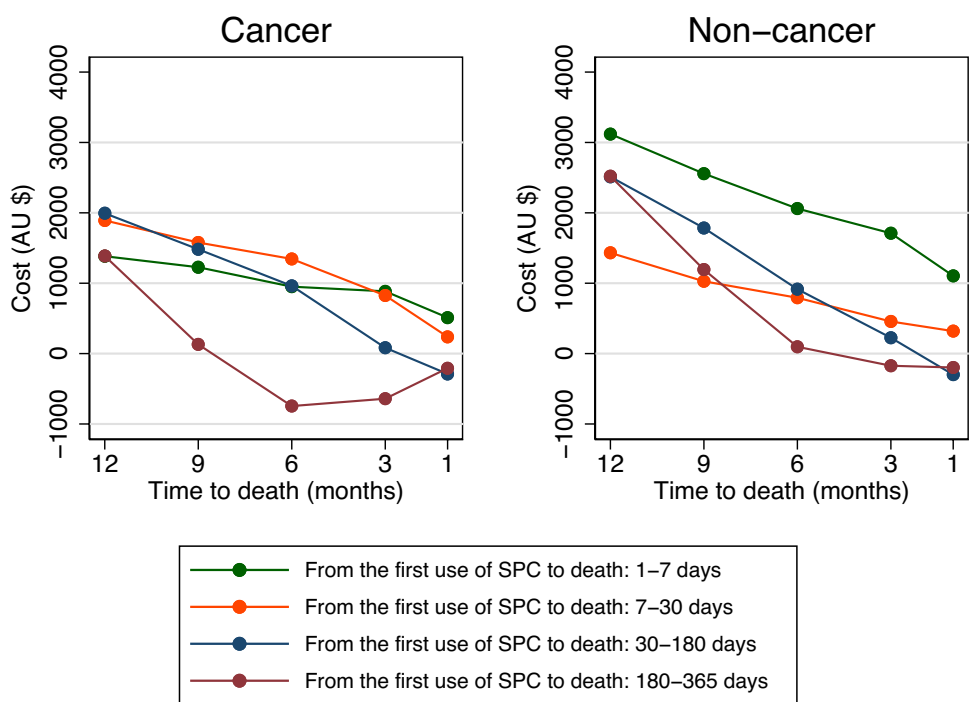
Fig. 6 Risk-adjusted mean cost differences for pharmaceuticals relative to the no specialist palliative care (SPC) group over the last 1, 3, 6, 9 and 12 months of life by time from first SPC contact: regression estimates for cancer and non-cancer cohorts. Models were adjusted for age, sex, residential aged care, previous year hospital days, comorbidity index, private insurance, household income, acute care episode if died in hospital, palliative care inpatient episode, decile of socioeconomic advantage, local health district of residence, year of death and chemotherapy or radiation therapy in the last year. Cancer model was adjusted for the type of cancer, and the non-cancer model was adjusted for the underlying cause of death
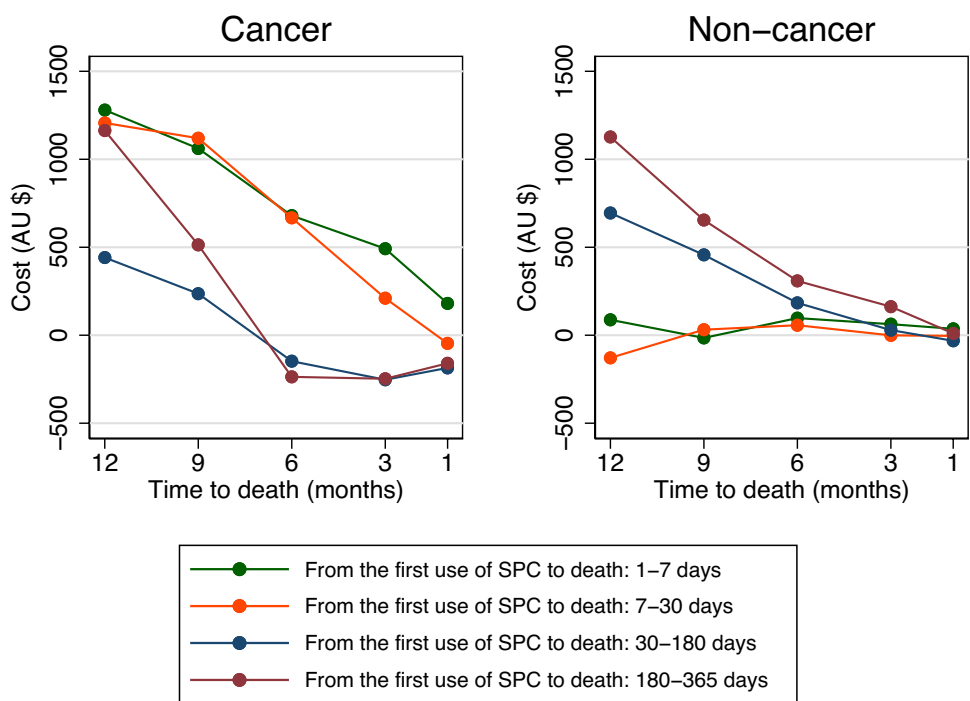

those who had spent more days in hospital in the non-cancer cohort (Table 3). Among the non-cancer cohort, those dying from dementia or stroke were least likely to use SPC of any duration, while those dying from chronic obstructive pulmonary disease (COPD) or a neurodegenerative disease (other than dementia) were most likely to use SPC for more than 6 months before death (Cat4) (Table 3). Among the cancer

cohort, decedents with a haematological cancer were least likely to use SPC for more than 1 month before death (Cat3 and Cat4) and those with liver cancer were most likely to use early SPC (6 months or more before death) (Table 2).

There were also some treatment factors associated with the use of SPC among the cancer cohort where treatment with radiation therapy or chemotherapy in the last year of

Table 2 Multinomial logit model for use of specialist palliative care (SPC) with no use of SPC as reference: cancer

	SPC 1 week or less		SPC 7–30 days		SPC 30–180 days		SPC more than 180 days	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Male	− 0.020	0.115	− 0.052	0.089	− 0.186*	0.078	− 0.237	0.130
Age	− 0.003	0.006	− 0.008	0.005	− 0.011**	0.004	− 0.024***	0.006
Hospital days lag year	0.006*	0.003	− 0.002	0.003	− 0.002	0.002	0.005	0.003
Residential aged care	− 1.005***	0.277	− 0.681***	0.172	0.069	0.117	0.364*	0.172
Health good/very good/excellent	0.289*	0.124	0.104	0.092	0.123	0.080	0.209	0.130
Rx-Risk comorbidity lag year	− 0.004	0.015	− 0.008	0.011	0.018	0.010	0.067***	0.014
Radiotherapy final year	0.257*	0.111	0.156	0.085	0.542***	0.075	0.657***	0.126
Chemotherapy final year	0.228	0.119	0.153	0.093	0.391***	0.080	0.255*	0.129
Private health insurance	0.393***	0.116	0.497***	0.089	0.522***	0.078	0.586***	0.127
Last inpatient episode acute care	0.097	0.199	− 0.251	0.132	− 0.395***	0.105	− 0.852***	0.173
Inpatient palliative care episode	2.871***	0.168	2.358***	0.110	1.974***	0.089	1.368***	0.133
Intensive care final year	− 0.152	0.152	− 0.142	0.117	− 0.227*	0.104	− 0.294	0.174
Household income missing	− 0.089	0.131	0.000	0.098	0.056	0.086	0.100	0.138
Household income > AU$40,000 pa	0.169	0.141	0.012	0.110	0.027	0.094	− 0.079	0.151
Decile of relative socio-economic advantage:								
2	0.167	0.222	− 0.028	0.172	0.184	0.156	− 0.007	0.275
3	0.199	0.223	0.106	0.170	0.189	0.157	0.276	0.261
4	0.171	0.225	− 0.106	0.178	− 0.076	0.165	0.237	0.259
5	− 0.018	0.255	0.175	0.183	0.194	0.168	0.240	0.277
6	0.320	0.240	0.179	0.185	0.171	0.170	0.113	0.285
7	0.140	0.252	0.139	0.188	0.499**	0.163	0.022	0.293
8	0.029	0.258	0.034	0.196	0.236	0.173	0.242	0.279
9	0.246	0.256	0.301	0.191	0.456**	0.170	0.226	0.280
10	0.629*	0.253	0.480*	0.193	0.681***	0.171	0.660*	0.276
Underlying cause of death[a]:								
Lung cancer	− 0.626*	0.281	− 0.430	0.236	− 0.247	0.220	− 0.823*	0.322
Colorectal cancer	− 0.471	0.298	− 0.228	0.249	0.008	0.230	− 0.235	0.330
Prostate cancer	− 1.357***	0.331	− 0.658*	0.256	− 0.213	0.231	− 0.295	0.325
Breast cancer	− 0.550	0.323	− 0.418	0.268	− 0.576*	0.247	− 0.451	0.342
Pancreatic cancer	− 0.369	0.312	− 0.143	0.259	0.098	0.240	− 0.293	0.355
Melanoma	− 0.797*	0.367	− 0.412	0.292	− 0.011	0.256	− 1.089*	0.438
Haematological cancer	− 0.661*	0.286	− 0.556*	0.241	− 0.765***	0.230	− 1.374***	0.351
Other cancer	− 0.605*	0.264	− 0.140	0.221	− 0.081	0.210	− 0.656*	0.301
Local health district of residence:								
Metropolitan 2	0.626*	0.308	0.459	0.240	− 0.443*	0.187	− 0.995**	0.343
Metropolitan 3	0.511	0.299	0.702**	0.227	0.276	0.169	0.402	0.266
Metropolitan 4	0.845**	0.309	0.659**	0.245	0.036	0.189	− 0.079	0.310
Metropolitan 5	− 0.433	0.358	− 0.604*	0.283	− 1.337***	0.229	− 0.959**	0.352
Metropolitan 6	1.280***	0.300	1.452***	0.227	0.858***	0.169	0.966***	0.266
Regional/rural 1	1.315***	0.300	1.344***	0.232	0.745***	0.177	0.758**	0.279
Regional/rural 2	− 0.471	0.380	− 0.654*	0.294	− 1.684***	0.248	− 1.427***	0.388
Regional/rural 3	− 0.626*	0.297	− 0.912***	0.233	− 1.976***	0.187	− 1.542***	0.292
Regional/rural 4	− 3.121***	0.642	− 2.063***	0.339	− 2.506***	0.258	− 3.097***	0.562
Regional/rural 5	− 0.882*	0.368	− 0.598*	0.267	− 1.628***	0.224	− 1.289***	0.346
Regional/rural 6	− 3.703***	1.039	− 2.240***	0.418	− 2.268***	0.281	− 2.891***	0.632
Regional/rural 7	− 1.990***	0.452	− 1.772***	0.323	− 2.513***	0.265	− 4.348***	1.032
Regional/rural 8 and 9	− 2.777***	0.571	− 2.181***	0.352	− 2.125***	0.231	− 2.219***	0.416

Table 2 (continued)

	SPC 1 week or less		SPC 7–30 days		SPC 30–180 days		SPC more than 180 days	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Year of death:								
2007	− 0.739	0.474	− 0.240	0.320	− 0.350	0.308	− 0.818	0.628
2008	− 0.073	0.281	− 0.187	0.226	− 0.283	0.208	− 0.755	0.403
2009	− 0.235	0.213	− 0.226	0.167	− 0.314*	0.153	− 0.060	0.235
2010	− 0.127	0.207	− 0.305	0.168	− 0.015	0.144	0.226	0.216
2011	− 0.392	0.207	− 0.215	0.158	− 0.067	0.139	− 0.331	0.236
2012	− 0.360	0.204	− 0.074	0.153	− 0.046	0.138	− 0.074	0.218
2013	− 0.501*	0.201	− 0.580***	0.161	− 0.298*	0.138	− 0.252	0.217
2014	− 0.348	0.200	− 0.306	0.157	− 0.026	0.134	− 0.189	0.216
2015	− 0.467*	0.205	− 0.207	0.154	− 0.201	0.138	− 0.137	0.211
Constant	− 3.743***	0.629	− 2.340***	0.486	− 1.626***	0.423	− 1.446*	0.654

SE standard error

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$

[a]Reference is liver cancer.

life was associated with a higher probability of early use of SPC (Cat3 or Cat4) than for those who did not receive these treatments in their final year (Table 2). Among the non-cancer cohort, where the cause of death was not cancer, the use of radiation therapy in the last year of life was associated with an increased probability of using SPC for 1–6 months (Cat 3), while the use of chemotherapy was associated with a higher probability of using SPC for any duration (Table 3).

3.4 Death in Hospital

The unadjusted probabilities of dying in hospital were similar for those with no SPC (Cat5) and those with SPC for 6 months or more (Cat4); for the non-cancer cohort this was 0.44 and 0.43, respectively, and for the cancer cohort this was 0.60 for both Cat4 and Cat5. Those with shorter use of SPC (Cat1 and Cat2) had the highest probabilities of death in hospital (Table 4). After risk adjustment, those with longer use of SPC (Cat3 and Cat4) had a significantly higher probability of dying in their own home or a nursing home relative to the no SPC group (Cat5) for the cancer cohort. This was only the case for death in a nursing home for the non-cancer cohort. Among the cancer cohort, the probabilities of dying in hospital were 0.64, 0.56 and 0.71 for Cat3, Cat4 and Cat5, respectively, and 0.31, 0.33 and 0.47 among the non-cancer cohort for the same SPC groups. Those with late initiation of SPC (Cat1) continued to have the highest probability of death in hospital after risk adjustment, 0.84 for the cancer cohort and 0.66 for the non-cancer cohort (Table 4). Indicators of higher socio-economic status (income >AU$40,000 and the highest deciles of relative

socio-economic advantage) were positively associated with death at home for the cancer cohort but this was not the case for the non-cancer cohort. The MNL models used to produce the adjusted probabilities in Table 4 are provided in the online supplementary material (Online Resource Tables S12 and S13).

4 Discussion

The use of SPC which commenced more than 6 months before death was associated with higher costs over the last year of life but lower costs over the last 1 and 3 months of life relative to those who did not use SPC. This was also the case for those commencing SPC use between 1 and 6 months before death except that lower costs were seen for the last 1 month only. Both the cancer and non-cancer cohorts showed this pattern. Use of SPC commencing within 1 week or 1 month of death was associated with similar or larger costs relative to no SPC use. Admitted hospital care was the major driver of costs, and longer use of SPC was associated with lower rates of in-hospital death. People dying from cancer had higher rates of SPC use than those dying from another life-limiting illness. Those living in more advantaged urban areas and those with poor health prior to the final year of life were most likely to use SPC and to use SPC for longer periods prior to death.

Although we cannot be sure of the causal direction, the pattern of costs associated with longer use of SPC where higher costs were identified over the last year of life and lower costs over the last one to three months suggest that

Table 3 Multinomial logit model for use of specialist palliative care (SPC) with no use of SPC as reference: non-cancer

	SPC 1 week or less		SPC 7–30 days		SPC 30–180 days		SPC more than 180 days	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
Male	0.045	0.173	− 0.101	0.196	− 0.124	0.189	− 0.129	0.263
Age	0.007	0.011	0.001	0.012	− 0.033**	0.011	− 0.050***	0.014
Hospital days lag year	− 0.001	0.003	0.005	0.003	0.006*	0.003	0.012***	0.003
Residential aged care	− 0.775**	0.285	− 0.050	0.256	0.423	0.221	0.182	0.308
Health good/very good/excellent	− 0.096	0.175	− 0.015	0.200	− 0.012	0.195	− 0.042	0.277
Rx-Risk comorbidity lag year	− 0.003	0.021	0.011	0.023	0.006	0.021	0.027	0.029
Radiotherapy final year	0.017	0.185	− 0.052	0.220	0.636***	0.190	0.382	0.280
Chemotherapy final year	1.237*	0.522	1.541*	0.602	1.481**	0.490	1.706**	0.645
Private health insurance	0.397*	0.186	0.242	0.209	0.639**	0.216	0.343	0.289
Last inpatient episode acute care	0.502*	0.252	− 0.436	0.332	− 0.304	0.247	− 0.351	0.316
Inpatient palliative care episode	4.114***	0.235	3.876***	0.245	2.691***	0.231	1.280***	0.370
Intensive care final year	0.097	0.235	0.264	0.275	0.136	0.255	− 0.003	0.391
Household income missing	− 0.224	0.193	− 0.162	0.214	− 0.236	0.227	− 0.408	0.303
Household income > AU$40,000 pa	0.083	0.236	− 0.298	0.303	0.400	0.238	− 0.687	0.423
Decile of relative socio-economic advantage:								
2	− 0.110	0.402	− 0.272	0.450	− 0.753	0.530	0.132	0.571
3	0.438	0.350	0.001	0.425	− 0.159	0.470	− 0.673	0.719
4	− 0.286	0.429	− 0.017	0.443	− 0.586	0.531	− 0.455	0.720
5	− 0.845	0.547	− 0.064	0.471	0.296	0.437	0.937	0.530
6	0.106	0.415	− 0.534	0.536	0.407	0.432	− 0.310	0.732
7	0.795*	0.386	0.523	0.434	− 0.168	0.493	0.082	0.685
8	− 0.420	0.509	− 0.092	0.497	0.083	0.472	− 0.062	0.695
9	0.303	0.398	− 0.082	0.458	0.284	0.432	0.430	0.612
10	1.036**	0.389	0.364	0.442	0.423	0.437	0.988	0.604
Underlying cause of death[a]:								
Chronic obstructive pulmonary disease	− 0.044	0.374	− 0.893*	0.412	0.027	0.318	− 0.294	0.424
Dementia/Alzheimer's disease	− 0.928*	0.423	− 1.348**	0.425	− 1.961***	0.458	− 1.744**	0.558
Heart failure/ischaemic heart disease	− 0.384	0.331	− 0.868**	0.329	− 0.926**	0.287	− 1.361***	0.392
Stroke	− 0.639	0.357	− 1.172**	0.365	− 1.812***	0.397	− 1.649**	0.530
Renal/liver failure	0.275	0.395	− 0.263	0.410	− 0.630	0.415	− 1.674*	0.710
Local health district of residence:								
Metropolitan 2	0.388	0.488	0.861	0.841	0.004	0.536	1.252	1.115
Metropolitan 3	− 0.499	0.476	1.541*	0.765	0.176	0.477	1.851	1.058
Metropolitan 4	0.340	0.489	1.396	0.805	0.243	0.535	0.842	1.172
Metropolitan 5	− 2.647*	1.092	− 14.686	806.636	− 1.110	0.676	− 0.234	1.432
Metropolitan 6	1.017*	0.445	2.491**	0.769	1.003*	0.463	1.726	1.068
Regional/rural 1	1.067*	0.458	1.748*	0.787	0.361	0.502	1.604	1.085
Regional/rural 2	− 0.716	0.625	− 0.209	1.037	− 0.512	0.631	1.251	1.126
Regional/rural 3	− 1.274*	0.538	0.280	0.804	− 1.512*	0.596	0.696	1.085
Regional/rural 4	− 2.483**	0.838	− 0.493	0.908	− 1.633*	0.740	− 0.517	1.440
Regional/rural 5	− 0.837	0.590	− 0.387	0.960	− 1.720*	0.753	− 0.595	1.440
Regional/rural 6	− 2.977**	1.096	− 1.711	1.262	− 2.655*	1.128	0.514	1.259
Regional/rural 7	− 1.080	0.579	− 0.187	0.908	− 1.667*	0.843	− 0.256	1.440
Regional/rural 8 or 9	− 2.999**	1.092	− 0.469	0.948	− 1.521*	0.730	− 14.828	1154.303
Year of death:								
2007	− 15.447	1729.274	0.188	1.157	− 0.011	1.081	0.497	1.103
2008	− 1.041	0.577	− 0.169	0.602	− 0.412	0.582	− 0.292	0.807
2009	0.210	0.333	0.641	0.417	− 0.251	0.454	0.246	0.570

Table 3 (continued)

	SPC 1 week or less		SPC 7–30 days		SPC 30–180 days		SPC more than 180 days	
	Coefficient	SE	Coefficient	SE	Coefficient	SE	Coefficient	SE
2010	− 0.074	0.323	0.608	0.377	0.136	0.360	0.334	0.510
2011	− 0.327	0.314	0.074	0.384	− 0.714	0.447	− 0.273	0.560
2012	− 0.202	0.293	0.449	0.343	− 0.123	0.347	− 0.948	0.666
2013	− 0.774*	0.320	0.329	0.339	0.293	0.304	0.121	0.465
2014	− 0.634*	0.319	0.126	0.361	0.058	0.312	0.171	0.443
2015	− 0.414	0.276	− 0.472	0.378	− 0.275	0.319	0.081	0.439
Constant	− 5.400***	1.006	− 5.980***	1.273	− 1.889	0.985	− 1.883	1.566

SE standard error

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$

[a]Reference is other neurodegenerative disease.

early referral to SPC may be occurring for higher users of health care services who subsequently become lower users close to death, relative to non-users of SPC. It is possible that earlier use of SPC contributed to relatively higher costs over the last year of life in this group; however, lower costs relative to other groups over the last 1–3 months would not be in keeping with this scenario, given more intensive palliative and supportive care is likely to be required during this period. Lower use of hospital inpatient care appeared to be the main mechanism for lower costs closer to death in both cohorts. It is plausible that longer involvement of the SPC team meant that better symptom management along with planning for and coordination of care at the end of life may have reduced the need for hospitalisation and provided better support for death in the usual place of residence. Seow et al. [46] found patients with advanced cancer receiving early specialist palliative care (6–12 months before death) were more likely to use supportive care at home at the end of life and less likely to use in-hospital care and less likely to die in hospital. Given the differences in the typical trajectory of functional decline between different health conditions (including among different cancer types), it is possible that for some conditions there is a longer period to adjust to the diagnosis and plan for the final stages which would also facilitate death at home. However, as we did not have complete data on date of diagnosis and had no information on the palliative phase, we were unable to examine this in the current analysis.

Socio-economic status was a factor in the use of SPC among those dying from cancer. The association between use of SPC and socio-economic factors in the cancer cohort is not only related to the location of services, given the models also included local health district of residence. It is possible that referral patterns differ for more socio-economically advantaged areas and that patients and their supporters may be more proactive in accessing services. Further research is required to better understand the factors influencing referral to SPC and how that may be made more equitable. A Danish study [47] recently used national data on patients with cancer and found higher use of specialist palliative care among those with higher income and education levels. The Danish health system is largely publicly funded, as is the Australian health system (despite its mixed public and private provision of services). We also found that socio-economic status was a factor in death at home among those dying from cancer. A review of studies examining associations between socio-economic status and place of death [48] found those living in more deprived areas had a higher probability of death in hospital while those in a better financial position were more likely to die at home.

Among the cancer cohort, the cost of pharmaceuticals and private medical services for those with earlier use of SPC were also lower than those who did not use SPC in the last months of life, but these differences were small relative to the overall cost differences. Some of the difference in pharmaceuticals and private medical services may be attributable to the cessation of cancer therapies which may have occurred prior to, or as a result of, SPC consultation. The use of cancer therapies in the last year of life was associated with use of SPC in both cohorts, which may reflect a higher propensity for medical and radiation oncologists to refer patients to SPC. We did not examine the extent to which cancer therapies continued after initiation of SPC as we were unable to distinguish their use for palliation. The cancer cohort had higher costs on average than those dying from other conditions, which has been identified in previous research.[5, 9]

The existing evidence on the costs associated with SPC programs is mixed,[11, 19] reflecting the difficulty in disentangling the complexity of care needs, the duration of serious ill health before death, and the timing of referral to SPC. By observing differences in costs across multiple

Table 4 Probability of death in hospital, at home or in a nursing home by category of specialist palliative care (SPC) use for the cancer and non-cancer cohorts

	Cancer			Non-cancer		
	Hospital	Home	NH	Hospital	Home	NH
Unadjusted						
SPC ≤ 7 days before death	0.893	0.095	0.013	0.834	0.145	0.021
> 7 and ≤ 30 days before death	0.815	0.157	0.029	0.727	0.173	0.101
> 30 and ≤ 180 days before death	0.709	0.220	0.071	0.529	0.271	0.200
> 180 and ≤ 365 days before death	0.603	0.282	0.115	0.431	0.354	0.215
No SPC	0.600	0.301	0.099	0.439	0.402	0.159
Risk-adjusted[a][b]						
SPC ≤ 7 days before death	0.839	0.144	0.017	0.662	0.301	0.037
> 7 and ≤ 30 days before death	0.751	0.216	0.033	0.423	0.393	0.184
> 30 and ≤ 180 days before death	0.637	0.283	0.081	0.311	0.381	0.308
> 180 and ≤ 365 days before death	0.563	0.314	0.123	0.329	0.424	0.247
No SPC	0.711	0.222	0.067	0.47	0.377	0.153

NH nursing home

[a]Adjusted for age, sex, previous year hospital days, comorbidity index previous year, chemotherapy or radiation therapy in last year, private insurance, household income, palliative care inpatient episode, decile of socioeconomic advantage, local health district of residence, and year of death. Cancer model also adjusted for type of cancer and non-cancer model also adjusted for underlying cause of death

[b]Predicted probabilities were estimated at the mean level of covariates.

dimensions and how these differences evolve over time, we have a framework that has the capacity to shed some light on the mixed results discussed above. We also used several approaches to assess the robustness of our analyses. We considered time from first SPC consultation in more detail than previous analyses which either did not consider it or considered only shorter periods. We included a further category to Hung et al.[9] who used: no hospice, 1–7 days, 7–30 days and more than 30 days. We included 30–180 days and more than 180 days and found substantial differences for this last group relative to no SPC or those with late initiation of SPC. Consistent with our results, Hung et al.[9] found that those with shorter hospice stays had the highest costs in the last month of life. Like other studies[3–6] we found costs to be largely driven by admitted hospital care.

Our study has some limitations, in that our results identify associations which rely on the variables available for risk adjustment and are not necessarily causal. However, our study included a larger range of patient characteristics than is typically found in administrative health data, and the results were robust to checks using lasso regression to formalise variable selection amongst controls. Further, there is evidence of a mechanism for the lower costs seen in those receiving SPC for longer periods prior to death who appeared to spend less time in hospital before death. We may have underestimated the use of SPC where the patient was seen by nursing and allied health members of the palliative care team but not by a palliative care physician and was not referred through an inpatient episode. This would be more likely in rural areas where palliative care is usually provided by general practitioners but may involve specialist palliative care nurses. Although the administrative data sets used in the analysis are a valuable addition to the survey data, they have some limitations. Data collections primarily designed to manage the health system will not necessarily include all the variables needed for research, and, while they offer a complete record of the health services used, we must assume that non-occurrence in the data means the service was not used (rather than missing). Due to data limitations, we were unable to include the costs of home nursing services provided by general nurses or specialist palliative care nurses. We did not have the appropriate approval to investigate differential use of SPC by people identifying as Aboriginal or Torres Strait Islander who may face more challenges in accessing services, particularly in rural and remote areas. The probabilistic data linkage may have included errors, although the CHeReL report contained extremely low false positive linkages and all datasets used are in the Master Linkage Key, which is regularly checked and updated when false linkages are reported.[36] An extremely small number of 45 and Up cohort participants had withdrawn consent at the time of data provision (0.2%), which is unlikely to impact results. Missing covariate data was also a limitation although also relatively small at 5% and 8% for the cancer and non-cancer cohorts, respectively. Although costing all hospital inpatient episodes at the average for the DRG is a limitation, we adjusted the average DRG costs for outliers which would minimise distortions related to extremely long or short stays. The retrospective nature of the study

design is a limitation in that we were unable to accurately identify patients with the same level of health care needs and the control variables are unlikely to have adequately accounted for this. Further, cohort selection based on time to death may introduce selection bias as it is not able to account for differences related to the differing patterns of survival time for patients with apparently similar clinical characteristics. Thus, while we can identify associations between SPC and the costs of care, they cannot be interpreted as necessarily causal. Despite these limitations, the study provides useful information on the costs of care at the end of life, which is valuable for health services planning. Future research in this area should consider prospective designs which might examine cost trajectories.

SPC is provided to improve the quality of care at the end of life and does not aim to reduce health system costs although it does aim to reduce inappropriate treatment provision which is likely related to costs. The importance of the lower costs observed in the last months before death for those with longer SPC use suggest different management with less reliance on the acute care sector and less disruption for patients and their families. The higher use of SPC found among those in residential aged care in the cancer cohort but not in the non-cancer cohort suggests that policies to enhance the use of SPC among some patients with a non-cancer illness in residential aged care might be beneficial. Further research on the interactions between palliative care, aged care and acute care would also be worthwhile. Our results have implications for the design of palliative care services in that a nuanced approach is required to accommodate the different trajectories and needs of different patients at the end of life, not all of whom will require specialist services. Our results also indicate that the success of palliative care should not be assessed by reductions in health care costs.

5 Conclusion

A small proportion of patients, less than 5%, whose cause of death is not cancer receive specialist palliative care. Although the proportion of patients with cancer receiving specialist palliative care is considerably larger, at 30%, it is still a minority. Furthermore, the use of SPC was higher among those living in wealthier and metropolitan areas, suggesting that there are access issues for those living in rural and less wealthy areas. We found that longer contact with SPC at the end of life was associated with lower costs in the last months of life among those who were previously higher health service users. This was the case for both the cancer and non-cancer cohorts and appeared to be largely attributed to reduced hospitalisation. Although further investigation is required, our results suggest that expanding the availability of SPC services to provide more equitable access could enable patients to spend more time at their usual place of residence, reduce pressure on inpatient services and facilitate death at home when that is preferred.

Declarations

Conflict of Interest All authors have no conflicts of interest to declare.

Availability of Material and Data The ethics and data custodian approvals for this research do not permit sharing of the data. The survey data was used under licence to the 45 and Up Study (https://www.saxinstitute.org.au). The linked administrative health data is not publicly available, but application may be made to the 45 and Up Study and the NSW Centre for Health Record Linkage (https://www.cherel.org.au). Stata code used in the data management and analysis will be made available upon reasonable request to the authors.

Ethics Approval This study was approved by the NSW Population and Health Services Research Ethics Committee (2020/ETH02894) and the University of Technology Sydney Human Research Ethics Committee (ETH21-6090). The 45 and Up Study is run by the Sax Institute and was approved by the University of NSW Human Research Ethics Committee (HC210602).

Consent to Participate Participants in the 45 and Up Study have provided consent for the linkage of their survey responses to routinely collected health data for the purposes of research.

Consent for Publication No individual information will be published, the manuscript includes sample summaries and regression results only.

Author Contributions Conception and design: PK, PH, KvG, JH, DF. Analysis of the data: DL, DF, PK. Interpretation of the findings: SA, JM, KvG, JH, PH, DF, PK Drafting of the manuscript: PK. Critical revision of the manuscript: all authors All authors read and approved the final version.

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