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## Aggressive end-of-life care among chronic disease patients that received early, late, or no specialist palliative care: a retrospective cohort study of eight chronic disease groups

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4 **Aggressive end-of-life care among chronic disease patients that received early, late, or no specialist**  
5 **palliative care: a retrospective cohort study of eight chronic disease groups**  
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## ABSTRACT

**Objective:** For eight chronic diseases, evaluate the impact of specialist palliative care (PC) timing on hospital-based healthcare resource use in the 30 days prior to death (indicative of aggressive end-of-life [EOL] care).

**Design:** Retrospective cohort study using administrative data.

**Setting:** Alberta, Canada between 2007 and 2016.

**Participants:** 47,169 adults deceased from: (1) malignant cancer, (2) heart disease or heart failure, (3) dementia or Alzheimer's disease, (4) stroke, (5) chronic lower respiratory disease (COPD) or respiratory failure, (6) liver disease, (7) neuro-degenerative disease, and (8) reno-vascular disease or renal failure.

**Main outcome measures:** The proportion of decedents who died in hospital or who in the last 30 days of life experienced  $\geq$ two emergency department (ED) visit,  $\geq$ two hospital admissions,  $\geq$ 14 days of hospitalization, or any intensive care unit (ICU) admission.

**Results:** In an analysis of all decedents, early specialist PC ( $\geq$ 90 days before death) was associated with reducing risk of four out of five indicators of aggressive EOL care, including  $\geq$ two ED visit (relative risk [RR] 0.96, 95% confidence interval [CI] 0.95 to 0.96),  $\geq$ two hospital admission (RR 0.98, 95%CI 0.97 to 0.99), any ICU admission (RR 0.90, 95%CI 0.89 to 0.90), and death in hospital (RR 0.84, 95%CI 0.83 to 0.85), as compared to those with no PC. Those exposed to early PC had a 32% reduction in risk of any aggressive EOL care indicator (RR 0.68; 95%CI 0.65 to 0.70); the effect was strongest in cancer (RR 0.52, 95%CI 0.50 to 0.54) and renal disease (RR 0.60, 95%CI 0.43 to 0.84) decedents, but a ~25% risk reduction was observed for each of heart disease, COPD, neuro-degenerative diseases, and stroke.

**Conclusions:** Early specialist PC exposure reduced the risk of aggressive EOL care for all chronic disease groups except dementia. Improving timeliness and access to specialist PC for terminally ill non-cancer chronic disease patients could improve quality of EOL care.

### Strengths and limitations of this study

- A strength is the separate analysis of eight different common chronic disease groups.
- Large population-based cohort from a jurisdiction with a well-established specialist palliative care program operating institutional and in the community.
- Strength is the comprehensive assessment of all specialist palliative care providers (physician, nurses, and allied healthcare professionals) activities in all settings.
- Limitation is that the contribution of non-specialist palliative care providers (e.g. family physician) is not included.

## INTRODUCTION

Palliative care (PC) is a key ingredient to providing the best possible care for many patients nearing the end-of-life (EOL).<sup>1</sup> The World Health Organization defines PC as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.<sup>2</sup> Thus, PC focusses on addressing patients' unmet needs around illness comprehension and coping, advanced care planning and decision making, symptoms and daily functioning, and coordination of care.

In the past, PC has been provided predominantly to terminal cancer patients, in large part because the disease trajectory is easier to predict.<sup>3</sup> However, timely access to PC has been associated with improved quality of life (QoL) for patients with a myriad of chronic diseases.<sup>4-8</sup> Conditions now considered appropriate for palliative care include malignant cancer, heart disease, dementia, stroke, chronic lower respiratory disease (COPD), advanced liver disease, neurodegenerative diseases, and reno-vascular diseases.<sup>9-10</sup> In addition to improving QoL, PC use has been associated with reduced or neutral healthcare cost through reductions in acute care use, e.g. emergency department (ED) visits and hospital and intensive care unit admissions (ICU), near the EOL.<sup>3 11-13</sup> Thus, greater use of PC has the potential to be a "win-win" for patients and administrators of health systems.

Many studies have reported on the relationship between PC exposure and healthcare resource use near the EOL for cancer patients<sup>14-20</sup>; consistently finding that PC exposure reduces risk of hospital-based care near the EOL. Recently, the same was found to be true for patients with many of the commonest chronic diseases, however, questions remain about the role of PC timing on these outcomes.<sup>21</sup> To address this, for eight chronic diseases, we evaluate the impact of specialist palliative care timing (early,  $\geq 90$  days before death; late,  $\geq 8$  but  $< 90$  days before death; very late,  $\leq 7$  days before death; and never) on hospital-based healthcare resource use (ED visits, hospital and ICU admissions, death in hospital) in the 30 days prior to death.

## METHODS

### Setting and design



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3 This study was set in the Calgary Zone (CZ) of Alberta Health Services (AHS). CZ encompasses the city of  
4 Calgary and surrounding semi-rural areas. It contains ~1.6 million people, or ~38% of Alberta, Canada's  
5 population.<sup>22</sup> AHS is the provincial health authority tasked with delivering publicly-funded universal  
6 healthcare to the population, including access to PC in institutional and community settings. The  
7 specialist PC service in CZ is a longstanding (~20 years), mature, integrated program which, including  
8 PC consult teams (PCCTs, institutional and community-based), a tertiary PC unit (TPCU), palliative  
9 home care (PHC) (available within Calgary city limits only), and (4) hospices (institutional and  
10 community-based).<sup>23</sup> The criteria for PC referral in Alberta are like most PC programs with a focus on  
11 symptoms, advance care planning, and general support for patients, caregivers, and providers.  
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### 22 **Cohort Description**

23 This was an administrative data-based retrospective cohort study of CZ decedents who died between 1  
24 January 2007 and 1 December 2016. Regional, provincial, and national healthcare databases were used  
25 to identify palliative, community, and acute care service use before death. A list of the databases  
26 accessed, and the information extracted from each, is available (see **eTable 1**). Patients 18 years or  
27 older and deceased from a PC-amenable condition, including: (1) malignant cancer, (2) heart disease  
28 and heart failure (abbreviated 'heart disease/failure'), (3) dementia, vascular dementia, Alzheimer's  
29 disease, senility (abbreviated 'dementia'), (4) haemorrhagic, ischaemic and unspecified stroke  
30 (abbreviated 'stroke'), (5) COPD and respiratory failure (abbreviated 'COPD'), (6) liver disease, (7)  
31 neurodegenerative diseases, and (8) reno-vascular disease, and renal failure (abbreviated 'renal  
32 disease/failure'), were included.<sup>9 10</sup> These conditions were identified based on International  
33 Classification of Diseases 10<sup>th</sup> Revision (ICD-10) codes for underlying cause of death as recorded on the  
34 death certificate (see **eTable 2** for the ICD-10 codes used).<sup>9 10</sup> Administrative data was linked,  
35 aggregated, and de-identified by the data analytics service within AHS. Ethics permission was granted  
36 by the University of Calgary Human Research Ethics Cancer Committee (17-0445).  
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### 51 **Patient and public involvement**

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3 All patients were deceased, precluding involvement in the design, conduct, reporting, or dissemination  
4 plans of our research. The public were not involved in the design, conduct, reporting, or dissemination  
5 of this research.  
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### 10 **Primary outcome and exposure of interest**

11 The primary outcomes were the proportion of decedents with hospital-based acute use in the last 30  
12 days of life, and death in hospital, indicators aggressive EOL care.<sup>24</sup> Per prior research on aggressive  
13 EOL care<sup>24</sup> these were defined as: (1) death in an acute care hospital, (2) two or more emergency  
14 department (ED) visit, (3) two or more hospital admissions, (4) fifteen or more days of hospitalization,  
15 and (5) any ICU admission. An aggregated EOL aggressive care indicator was also constructed (any  
16 versus no individual indicators found to occur). The primary exposure of interest was specialist PC  
17 (early,  $\geq 90$  days before death; late,  $\geq 8$  but  $< 90$  days before death; very late,  $\leq 7$  days before death; and  
18 never).  
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### 29 **Clinical characteristics**

30 Demographic and clinical characteristics considered included sex, age at death, year of death, rurality,  
31 Charlson comorbidity Index (CCI) score (adjusted for underlying cause of disease), median household  
32 income, use of general home care, and use of long-term care. For rurality, decedents were assigned an  
33 urban or rural designation using a 7-level categorization based on postal code.<sup>25</sup> The “urban”  
34 designation included the levels: metro, moderate metro influence, and urban; the “rural” designation  
35 included all other levels. An overall (longitudinal) CCI score was calculated for each decedent by  
36 collapsing all records of inpatient care from 2002 until death.<sup>26</sup> CCI scores were calculated using  
37 published methodology,<sup>27 28</sup> with ICD-10 codes for decedents underlying cause of death removed.  
38 Median household income income quintiles were derived using 2016 Statistics Canada Dissemination  
39 Area (DA) level data for Alberta.<sup>29</sup> The population was divided into five groups such that ~20% of the  
40 population was in each group (quintile 1 (Q1) \$0 - \$71,680, Q2: \$71,765 - \$90,112, Q3: \$90,197 -  
41 \$108,032, Q4: \$108,083 - \$128,384, Q5: \$128,512 - \$519,168). Household income quintile was then  
42 assigned based on decedents last known residence postal code.  
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## Statistical analysis

The association between specialist PC and the one aggregate and five individual indicators of aggressive EOL care were estimated using multivariable log-binomial regression. For each outcome, one all-decedent analysis, and eight disease-stratified analyses were performed.

All models were adjusted for age at death, year of death, sex, rurality, household income quintile, CCI score, long-term care use (any versus none), and general home care use (any versus none). The all decedent analyses were adjusted for chronic disease category. Relative risks (RR) are reported with 95% confidence intervals (CI). A  $p < 0.05$  was considered the significant. All analyses were performed in R v4.0.0.

## RESULTS

### Characteristics of decedents

A total of 47,169 decedents were identified during the study period. Cancer was the most common underlying cause of death (39%), following by heart disease/failure (32%). The dementia, stroke, and COPD disease groups each accounted for 11%, 7%, and 6% of deaths, respectively (**Table 1**). The liver and neurodegenerative disease groups each made up 2% of decedents; reno-vascular disease/failure 1%. Fifty-one percent of decedents were female, with women making up a larger percentage of the dementia category (65%) and a smaller percentage of the liver disease category (39%) (**eTable 3**). Liver disease patients were on average much younger at death; dementia patients were older at death. Disease groups were similar in their breakdown by rurality, with 12% of decedents living in rural areas. Overall, decedents were more likely to be in the lowest household income quintile (e.g. Q1: expected 20%, observed 28%, an excess of +8%) (**Table 1**). Liver disease and COPD decedents were even more likely to fall in the lowest household income quintile (Q1: 34% and 33%, respectively) (**eTable 3**). Most patients (69%) had a CCI score of 0 (after excluding underlying cause of death). Liver disease, heart disease/failure, and COPD decedents were more likely to have CCI scores  $\geq 1$ . Nineteen percent of decedents had a long-term care admission prior to death; however, this varied considerably by disease category. Dementia patients were most likely be admitted to long-term care (61%); cancer and liver

disease patients were the least likely, 4% and 6%, respectively. Two-thirds of decedents (68%) had a home care visit prior to death; 55% had only non-palliative home care visits.

### Specialist PC exposure prior to death

Overall, 49% of decedents received one or more specialist PC service prior to death (**Table 1**). Cancer patients were most exposed (86%); heart disease patients least exposed (20%). For the other chronic disease categories, the proportion of PC exposed decedents was: neurodegenerative disease, 48%; reno-vascular disease, 47%; liver disease, 44%, COPD and respiratory failure, 38%; stroke, 30%; and dementia, 22%. A higher proportion of patients who received specialist PC were younger at death, lived in urban areas, were from higher income quintiles (Q2-Q5), died in the second half of the study period, and were not admitted to LTC (**Table 1**). From 2007-2016, we observed a significant increase in the proportion of decedents exposed to specialist PC, overall, and independently for each disease category except reno-vascular disease (**eTable 4**). Overall, PC exposure increased by 10%, from 43% of decedents in 2007/2008 (years combined) to 53% of decedents in 2015/2016 (years combined). The biggest changes occurred for liver disease (+29%; 26% to 62% from 2007 to 2016) and COPD (+25%, 22% to 46% from 2007 to 2016).

Regarding the timing of first specialist PC exposure, 16% of decedents experienced early specialist PC exposure, 24% had late exposure, and 9% had very late exposure. Across all decedents, the median number of days from first PC exposure to death was 43 (IQR 12-140). However, timing was highly variable by disease category. The duration was shortest for stroke (median 8 days, IQR 6-143) and liver disease (median 12 days, IQR 4-40) patients, and longest for cancer (median 55 days, IQR 20-148), neuro-degenerative disease (median 33 days, IQR 9 - 214) and COPD (median 32 days, IQR 5-244) patients. The remaining chronic disease groups each had a median PC exposure timing of 18-19 days before death. From 2007-2016, early specialist PC exposure increased by 4.7%, from 14% of decedents in 2007/2008 (years combined) to 19% of decedents in 2015/2016 (years combined). The biggest changes occurred for COPD (+14%, 7% to 20% from 2007 to 2016). Finally, patients received specialist PC primarily through PC consult team visits (47%), followed by hospice stay (21%), PHC visits (13%), and TPCU stay (6%) (**eTable 6**).

### Death in hospital and hospital-based acute care in the last 30 days of life

Overall, 42% of decedents died in an acute care hospital or bed (**Table 2**). Twenty-one percent of decedents spent > 14 days in hospital in last 30 days of life. Fewer than 10% of patients experience the remaining indicators of aggressive EOL: >1 ED visit in last 30 days in last 30 days of life (9%), >1 hospital admission in last 30 days in last 30 days of life (8%), and any ICU admission care in last 30 days of life (7%). Overall, 48% percent of decedents experienced one or more indicators of aggressive EOL care. The average number of positive indicators per patient was 1.8 (of 5). Liver disease patients were notable in being much more likely to experience aggressive EOL care (78% of all liver patients); a greater proportion died in hospital (76%) and used the ICU (26%). Dementia patients were least likely to experience aggressive EOL care (25%), and least likely to die in hospital (20%).

Over the studied years there was a significant linear decrease in the proportion of decedents who died in hospital (-2.9%), spent  $\geq 14$  days in hospital in the last 30 days of life (-2.0%) or were admitted to the ICU (-1.3%) in the last 30 days of life. However, there was a linear increase in the proportion of decedents with >1 hospitalization (+0.5%) and >1 ED visit (+0.8%) in the last 30 days of life (**eTable 6**). Combining these indicators in the aggregate "aggressive" EOL care indicator, changes over time were not significant.

### Association between specialist PC and indicators of aggressive EOL care

#### All decedents

In the analysis of all decedents, early specialist PC exposure (reference: no specialist PC exposure) was associated with reducing risk for four out of five of the indicators of aggressive EOL care, including: (1) >1 ED visit (relative risk [RR] 0.96; 95% confidence interval [CI] 0.95 to 0.96), (2) >1 hospital admission (RR 0.98; 95%CI 0.97 to 0.99), (3) any ICU admission (RR 0.90; 95%CI 0.89 to 0.90), and (4) death in hospital (RR 0.84; 95%CI 0.83 to 0.85) (**Figure 1A, eTable 7**). It was not associated with having spent >14 days in hospital in the last 30 days of life. Altogether, those exposed to early PC had a 32% reduction in the risk of any aggressive EOL care indicator (indicators aggregated as any or none) compared to those who had no PC (RR 0.68; 95%CI 0.65 to 0.70) (**Figure 1B, eTable 8**). Among all decedents, late specialist PC exposure was associated with reduced risk for three indicators or aggressive EOL care (>1 ED visit, any ICU admission, and death in hospital), but increased risk for two

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3 other indicators (>1 hospital admission, and >14 days in hospital) as compared to those who had no  
4 specialist PC. Finally, very late specialist PC exposure was associated with increased risk for all  
5 indicators of aggressive EOL care except ICU admission.  
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### 10 **Disease-specific analysis**

11 For all disease groups except dementia, early specialist PC exposure was associated with reduced risk  
12 of any aggressive EOL care indicator compared to those who had no PC exposure (**Figure 1B**). The  
13 effect was strongest in cancer (RR 0.52, 95%CI 0.50 to 0.54) and renal disease (RR 0.60, 95%CI 0.43 to  
14 0.84) decedents, but a ~25% risk reduction was observed for each of heart disease, COPD,  
15 neurodegenerative disease, and stroke. The effect in liver disease patient was smaller but significant  
16 (RR 0.81, 95%CI 0.66 to 0.99). Late specialist PC exposure was associated with reduced risk of any  
17 aggressive EOL care indicator for cancer (RR 0.76, 95%CI 0.74 to 0.79) and liver disease patients (RR  
18 0.89, 95%CI 0.81 to 0.98), but increased risk for dementia patients (RR 1.66, 95%CI 1.46 to 1.88), and  
19 was not associated in the other disease groups (**Figure 1B**). Relative to no PC exposure, very late PC  
20 exposure was associated with increased risk of any aggressive EOL care for all disease categories.  
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30 Of particular interest was death in hospital (inconsistent with most patients preferred location  
31 of death) and ICU admission (costly and likely inappropriately aggressive care) (**Figure 1A**). Examining  
32 death in hospital alone, early specialist PC exposure reduced risk of this outcome for all disease  
33 categories, while late PC exposure significantly reduced risk of death in hospital for all disease  
34 categories except dementia and neurodegenerative disease. Examining ICU admission, liver disease is a  
35 notable in the effect of specialist PC exposure, regardless of timing, on reducing risk of this outcome. In  
36 general, ICU admissions are the only aggressive EOL care indicator for which very late specialist PC  
37 reduces risk for some disease groups.  
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## 47 **DISCUSSION**

### 48 **Principal findings**

49 Our analysis of 47,169 chronic disease decedents in Alberta, Canada from 2007-2016 shows that that  
50 early specialist PC exposure is associated with reduced risk of any aggressive EOL care (indicators  
51 aggregated) compared to those with no PC exposure. Four of five individual indicators of aggressive  
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3 EOL care showed this relationship. And, this association was independently observed in all disease  
4 groups except of dementia (the latter was not significant). In contrast, the effect of late PC exposure  
5 was not consistent across disease groups and individual indicators or aggressive EOL care. For most  
6 disease categories, late PC exposure was associated with decreased risk of death in hospital and ICU  
7 admission, but increased risk of >1 hospital admission and >14 days in hospital in the last month of life.  
8 We hypothesize this result is explained by patients whose first exposure to specialist PC occurs in the  
9 last month of life (but >7 days), likely triggered by a hospital admission in the last month life. Specialist  
10 PC would be highly correlated with hospital admission (i.e. increase risk) for these patients.  
11 Importantly however, late specialist PC was still beneficial in reducing risk of ICU admission and death  
12 in hospital for these patients. Finally, very late PC was consistently associated with increased risk of  
13 aggressive EOL care for all indicators (except ICU admission) across all disease groups. Specialist PC  
14 initiated this late would not be expected to reduce healthcare resources use in the last 30 days of life,  
15 nor provide sufficient time to organize the healthcare resources needed to enable death at home.  
16 These patients likely only receive specialist PC because they were in hospital in the last 7 days of life,  
17 explaining the observed increase in risk.  
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### 32 **Comparison with other studies**

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34 Many studies have reported on the relationship between PC exposure and aggressive EOL care in  
35 cancer patients<sup>14-20</sup>; consistently finding that PC exposure reduces risk of hospital-based care near the  
36 EOL. Fewer studies have focussed on non-cancer patients, and results have been limited to the disease  
37 categories examined (heart failure,<sup>30 31 32 33</sup> dementia,<sup>34 35</sup> end stage renal disease [ESRD],<sup>36 37</sup> and end-  
38 stage liver disease.<sup>38</sup>) In these prior studies, PC exposure has not been consistently associated with  
39 indicators of healthcare resource use (often not significant). However, a recent well-powered study of  
40 seven chronic disease, looking at the impact of physician-delivered PC on hospital-based acute care,  
41 found results similar to ours.<sup>21</sup> Indeed, Quinn *et al.* 2020 found PC exposure (any versus none) was  
42 associated with reduced rates of ED visits, hospital and ICU admissions, and death in hospital for  
43 cancer, COPD, ESRD, stroke, and cirrhosis (liver) decedents.<sup>21</sup> Our study extends these results by  
44 showing the impact of PC timing on these outcomes and demonstrates the importance of early  
45 exposure to fully realize the benefits of PC. These studies are notably different in how PC is measured;  
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3 newly initiated (in last 6 months of life but excluding the last 7 days) physician-delivered PC based on  
4 physician billing data,<sup>21</sup> compared to here, any specialist PC service (physician or nursing consultants,  
5 palliative home care, hospice) at any time (after diagnosis of underlying cause of death) based on data  
6 from specialist PC operational databases, yet the overall results are the same with clarity now on the  
7 impact of PC timing. Similar to this study, Rosenwax *et al.*<sup>39</sup> observed increased PC exposure over time  
8 for non-cancer chronic disease patients in Australia<sup>39</sup>, as did a recent study of Ontario decedents  
9 (2004-2014).<sup>40</sup> In both, as in our study, the biggest increases occur for liver disease and COPD patients.  
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### 18 **Strengths and limitations**

19 While this study was large and population-based, it had several important limitations. First, the quality  
20 of EOL care indicators used in this study were developed and validated based on cancer patients use of  
21 healthcare resources.<sup>24</sup> Indicators specific to non-cancer chronic diseases are not well developed or  
22 validated. As a result, the aggressive EOL care outcome examined may not be as appropriate for the  
23 non-cancer chronic diseases categories. Not all aggressive EOL care is inappropriate, and we do not  
24 mean to imply that healthcare interventions should solely focus on reducing aggressive EOL care.  
25 Ultimately, patient and caregiver preferences for care are of greatest importance. Unfortunately, such  
26 data is not readily available in healthcare administrative databases. Second, unlike some prior studies,  
27 we did not evaluate PC provided by non-PC specialist providers. Our approach is anticipated to result in  
28 underreporting of PC use. Finally, this study examined one region in one province, and questions  
29 naturally remain about the generalizability of the findings. Encouragingly, our results are largely  
30 consistent with those of a recent well-powered study of chronic disease patients in Ontario, Canada.<sup>21</sup>  
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### 44 **Implications for clinicians and policymakers**

45 More work is needed to address differences in PC access observed here and elsewhere.<sup>39 40</sup> Further,  
46 more work is needed to ensure earlier timing of first PC exposure. We know PC benefits non-cancer  
47 chronic disease patients through QoL improvements<sup>41-43</sup>. Our current result shows that PC is also  
48 associated with reducing risk of aggressive EOL across most chronic disease categories. Sufficient  
49 follow-up time is necessary for the benefits of specialist PC to be realized, hence the call for earlier PC,  
50 however, late PC is still better than none in terms of reducing death in hospital and ICU admissions.  
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3 Given finite healthcare resources, chronic disease groups with lower PC exposure, particularly early  
4 exposure, but more likely to experience aggressive EOL care, could be prioritized for focussed efforts to  
5 improve access. For example, 78% of liver disease and 59% of COPD decedents experience aggressive  
6 EOL care, but only 44% (6% early) and 38% (15% early), respectively, receive specialist PC. Patients  
7 dying from these conditions still lag far behind cancer patients both in terms of PC access and timing  
8 (86% get specialist PC, 31% early). Given our results, it is our that view that the proportion of terminally  
9 ill non-cancer chronic diseases patients receiving specialist PC should be the same as cancer patients,  
10 i.e. the proportions observed for cancer are an appropriate benchmark to aim for.  
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### 20 **Unanswered questions and future work**

21 Questions remain on the role, the location and model of PC delivery play in improving patient QoL and  
22 optimizing healthcare resource use near the EOL. For example, how do the different specialist PC  
23 services (e.g. palliative home care, palliative consult team) compare in their impact on QoL and EOL  
24 resource use outcomes, and does it differ by chronic disease (underlying cause of death). At the level  
25 of individual specialist PC services, is there a difference in timing for each? For many patients, specialist  
26 PC is a complex, multifaceted intervention, and determining what aspect of the care have the greatest  
27 impact on outcomes could help in determining how to deliver the highest quality and highest value  
28 EOL care.  
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3 **Contributor and guarantor information:** ME, AS, PC, AF contributed to the study concept and design.  
4 PC, AF, KB, T-MP, LS were responsible for acquisition of data. ME, AF, KB, PC, AS were responsible for  
5 data processing and interpretation of the data. ME performed all statistical analyses and drafted the  
6 manuscript. AS, PC, AF, KB, T-MP, LS contributed to the critical revision of the manuscript for important  
7 intellectual content. AS obtained funding and is the guarantor. The corresponding author attests that  
8 all listed authors meet the authorship criteria and that no other authors meeting the criteria have been  
9 omitted.  
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23 **Competing Interests:** All authors have completed the ICMJE uniform disclosure form at  
24 [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare: support from a research grant AS received from the  
25 MSI Foundation to perform this work; no financial relationships with any organizations that might have  
26 an interest in the submitted work in the previous three years; no other relationships or activities that  
27 could appear to have influenced the submitted work.  
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34 **Ethical Approval:** Ethics approval was granted by the University of Calgary Human Research Ethics  
35 Cancer Committee (17-0445).  
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40 **Data Sharing:** The dataset from this study is held securely in coded form at the University of Calgary.  
41 While the conditions of our ethics approval prohibit making the dataset publicly available, access to  
42 anonymized summary-level (aggregate data) may be granted upon request by emailing  
43 [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca). The full dataset creation plan and underlying analytic code are available from  
44 upon request by emailing [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca), understanding that the programmes may rely on  
45 coding templates or macros that are unique AHS and this study.  
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3 The corresponding author (AS) affirms that the manuscript is an honest, accurate, and transparent  
4 account of the study being reported; that no important aspects of the study have been omitted; and  
5 that any discrepancies from the study as planned (and, if relevant, registered) have been explained.  
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11 **Dissemination to participants and related patient and public communities:**

12 The results of this study will be disseminated to the academic community through presentation of the  
13 findings at relevant national and international meetings (eg, the annual International Congress on  
14 Palliative Care, European Association for Palliative Care, and Canadian Hospice Palliative Care  
15 Conference); presenting the findings at local rounds (Tom Baker Cancer Centre, Cumming School of  
16 Medicine), and disseminating the results to networks of researchers associated with primary care,  
17 palliative care, and health services research (including the O'Brien Institute for Public Health).

18 Strategies to disseminate the findings to healthcare organisations and policy makers include presenting  
19 the study findings to policy makers at the local, provincial (eg, Alberta Health Services, Alberta Health,  
20 Covenant Health, Cancer Control Alberta), and national levels.  
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## TABLES

**Table 1:** Summary characteristics of decedents at the time of death.

	Overall (n=47,169)	Specialist palliative care exposure prior to death				
		Never (n=23,931)	Ever (n=23,931)	Early (n=7,736)	Late (n=11,373)	Very Late (n=4,129)
All decedents	47169 (100)	23931 (51)	23238 (49)	7736 (16)	11373 (24)	4129 (9)
<b>Cause of death</b>						
Cancer	18263 (39)	2469 (14)	15794 (86)	5743 (31)	8401 (46)	1650 (9)
Heart disease, failure	15206 (32)	12165 (80)	3041 (20)	803 (5)	1257 (8)	981 (6)
Dementia, senility	5010 (11)	3912 (78)	1098 (22)	321 (6)	457 (9)	320 (6)
Stroke	3108 (7)	2166 (70)	942 (30)	121 (4)	353 (11)	468 (15)
COPD	2905 (6)	1787 (62)	1118 (38)	426 (15)	350 (12)	342 (12)
Liver disease	1044 (2)	583 (56)	461 (44)	60 (6)	218 (21)	183 (18)
Neuro-degenerative diseases	1015 (2)	523 (52)	492 (48)	191 (19)	202 (20)	99 (10)
Reno-vascular disease, failure	618 (1)	326 (53)	292 (47)	71 (11)	135 (22)	86 (14)
<b>Gender</b>						
Female	23865 (51)	12025 (50)	11840 (50)	4137 (17)	5647 (24)	2056 (9)
Male	23304 (49)	11906 (51)	11398 (49)	3599 (15)	5726 (25)	2073 (9)
<b>Age at death (years)</b>						
< 61	6749 (14)	2672 (40)	4077 (60)	1699 (25)	1914 (28)	464 (7)
61-70	7066 (15)	2806 (40)	4260 (60)	1591 (23)	2110 (30)	559 (8)
71-80	10449 (22)	4658 (45)	5791 (55)	1838 (18)	2988 (29)	965 (9)
81-90	15355 (33)	8573 (56)	6782 (44)	1957 (13)	3294 (21)	1531 (10)
≥91	7550 (16)	5222 (69)	2328 (31)	651 (9)	1067 (14)	610 (8)
<b>Rurality</b>						
Urban	41664 (88)	20352 (49)	21312 (51)	7171 (17)	10353 (25)	3788 (9)
Rural	5505 (12)	3579 (65)	1926 (35)	565 (10)	1020 (19)	341 (6)
<b>Neighbourhood income quintile</b>						

Q1 - Lowest	13211 (28)	7603 (58)	5608 (42)	1821 (14)	2738 (21)	1049 (8)
Q2	10972 (23)	5371 (49)	5601 (51)	1868 (17)	2776 (25)	957 (9)
Q3	8896 (19)	4324 (49)	4572 (51)	1493 (17)	2253 (25)	826 (9)
Q4	6614 (14)	3099 (47)	3515 (53)	1125 (17)	1734 (26)	656 (10)
Q5 - Highest	7476 (16)	3534 (47)	3942 (53)	1429 (19)	1872 (25)	641 (9)
<b>CCI score</b>						
0	32666 (69)	16787 (51)	15879 (49)	5720 (18)	7857 (24)	2302 (7)
1 (score 1-2)	9399 (20)	4512 (48)	4887 (52)	1336 (14)	2392 (25)	159 (12)
2 (score ≥3)	5104 (11)	2632 (52)	2472 (48)	680 (13)	1124 (22)	668 (13)
<b>Year of death</b>						
2007-2008	8771 (19)	5043 (57)	3728 (43)	1204 (14)	1916 (22)	608 (7)
2009-2010	9032 (19)	4795 (53)	4237 (47)	1347 (15)	2193 (24)	697 (8)
2011-2012	9195 (19)	4490 (49)	4705 (51)	1600 (17)	2259 (25)	846 (9)
2013-2014	9731 (21)	4673 (48)	5058 (52)	1663 (17)	2425 (25)	970 (10)
2015-2016	10440 (22)	4930 (47)	5510 (53)	1922 (18)	2580 (25)	1008 (10)
<b>Community-care use</b>						
LTC admission	8747 (19)	6419 (73)	2328 (27)	1120 (13)	709 (8)	499 (6)
Home care	32265 (68)	13171 (41)	19094 (59)	7184 (22)	9152 (28)	2758 (9)
<i>Non-palliative home care</i>	25943 (55)	13171 (51)	12782 (49)	3968 (15)	6195 (24)	2619 (10)

Counts and percentages are shown. Percentages for the "overall" column are based on column total, percentages for "specialist PC exposure" columns are based on row totals. "Ever" specialist PC exposure and community care use were evaluated from the time of diagnosis of the the underlying cause of death until death. Early PC exposure is defined as ≥90 before death, late as <90 days but >7 days before death, very late as ≤7 days before death. *COPD* chronic lower respiratory disease, *Q* quintile, *CCI* Charlson Comorbidity Index, *LTC* long term care



**Table 2:** Hospital-based acute care use in the last 30-days of life.

	Hospital-based acute care use (indicators of aggressive EOL care)					
	> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital	Death in an acute care hospital or bed	Any "aggressive" EOL care indicator
All decedents	4224 (9)	3861 (8)	3073 (7)	9903 (21)	19679 (42)	22712 (48)
<b>Cause of death</b>						
Cancer	1960 (11)	2007 (11)	607 (3)	4645 (25)	7416 (11)	9281 (51)
Heart disease, failure	1162 (8)	927 (6)	1533 (10)	2418 (16)	6337 (12)	6904 (45)
Dementia, senility	143 (3)	126 (3)	16 (0)	673 (13)	1020 (10)	1259 (25)
Stroke	339 (11)	227 (7)	312 (10)	644 (21)	1846 (19)	1958 (63)
COPD	323 (11)	298 (10)	247 (9)	707 (24)	1590 (15)	1724 (59)
Liver disease	168 (16)	180 (17)	271 (26)	448 (43)	792 (15)	811 (78)
Neuro-degenerative diseases	57 (6)	46 (5)	42 (4)	180 (18)	367 (16)	425 (42)
Reno-vascular disease, failure	72 (12)	50 (8)	45 (7)	188 (30)	311 (10)	350 (57)

*COPD* chronic lower respiratory disease, *EOL* end-of-life, *ED* emergency department, *ICU* intensive care unit.

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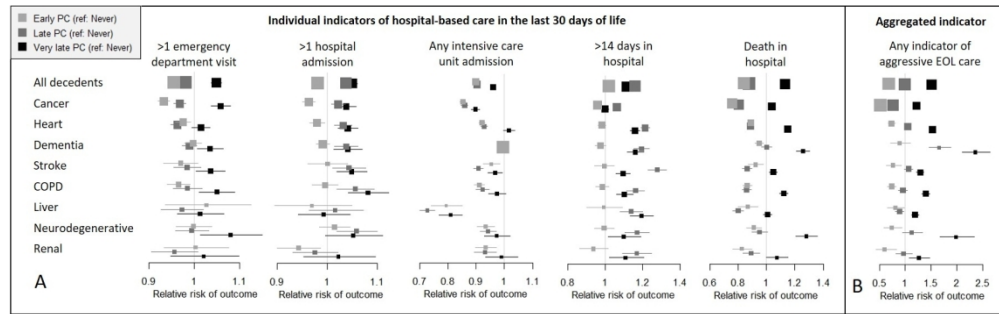


Figure 1: The relative risk of experiencing hospital-based care in the last 30 days of life (indicative of aggressive end-of-life) given exposure to early palliative care early ( $\geq 90$  days before death), late palliative care ( $\geq 8$  but  $< 90$  days before death), and very late palliative care ( $\leq 7$  days before death; and never), compared to no palliative care. Models were adjusted for age at death, year of death, sex, rurality, household income quintile, Charlson Comorbidity Index score, long-term care use (any versus none), general home care use (any versus none), and chronic disease category (for the "all decedent" analysis only). Estimates box size is based on precision (sample size). Plots were constructed using the R package forestplot v1.10. Exact values of estimates (relative risk and 95% confidence intervals) are provided in eTable 7). Abbreviations used: COPD chronic obstructive pulmonary disease, PC palliative care, EOL end-of-life.

305x95mm (150 x 150 DPI)

## ELECTRONIC SUPPLEMENTARY MATERIAL

eTable 1: Data sources for each variable in the study

Variables	Database-level	Database Name
<b>Specialist PC</b>		
Receipt of PC consult team visit (institutional, community-based)	Regional, CZ	Sunrise Clinical Manager & PallD
Receipt of palliative home care visit	Regional, CZ	PARIS
Admission to a tertiary PC unit	Regional, CZ	Sunrise Clinical Manager
Admission to a PC hospice bed	Regional, CZ	Sunrise Clinical Manager & Pathways Continuing Care Application Data
<b>Hospital-based acute care at the end-of-life</b>		
Death in an acute care hospital or bed (including ED)	National, CIHI	Discharge Abstract Database & National Ambulatory Care Reporting System
Emergency department visits in the last 30 days of life	National, CIHI	National Ambulatory Care Reporting System
Hospital admissions in the last 30 days of life	National, CIHI	Discharge Abstract Database
Days of hospitalization in the last 30 days of life	National, CIHI	Discharge Abstract Database
Intensive care unit admissions in the last 30 days of life	National, CIHI	Discharge Abstract Database
<b>Covariates</b>		
Long term care use (based on admission date)	Regional, CZ	Ambulatory Continuing Care Information System
General home care use (based on start date)	Regional, CZ	PARIS
Sex	Provincial, Alberta Health	Longitudinal Demographic Profile
Rurality (urban versus rural)	Provincial, Alberta Health	Longitudinal Demographic Profile
Age at death, in 5 year groups (for anonymity purposes)	Provincial, Alberta Health	Longitudinal Demographic Profile
Median neighbourhood income quintiles based on postal code	National & Provincial	Census 2016 & Longitudinal Demographic Profile (for most recent postal code)
Year of death	Provincial, Alberta Health	Vital Statistics
Underlying cause of death	Provincial, Alberta Health	Vital Statistics

PC palliative care, CZ Calgary Zone, CIHI Canadian Institute for Health Information.

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**eTable 2:** ICD-10 codes used to assign chronic disease categories.

Conditions included	ICD-10 Codes
All deaths from malignant neoplasms	C00-C97
Heart disease and heart failure	I00-I52 (excluding I12/I13-renal)
Dementia, vascular dementia, Alzheimer’s disease, senility	F01, F03, G30, R54
Haemorrhagic, ischaemic and unspecified stroke	I60-I69
Chronic lower respiratory disease, respiratory failure	J40-J47 & J96
Liver Disease	K70-K77
Neurodegenerative	G10, G20, G35, G122, G90.3, G23.1
Reno-vascular disease, renal failure	I12, I13, N17, N18, N28

**eTable 3:** Summary characteristics of decedents at the time of death *by underlying cause of death*

	Cancer (N=18,263)	Heart disease, failure (N=15,206)	Dementia, senility (N=5,010)	Stroke (N=3,108)	COPD (N=2,905)	Liver disease (N=1,044)	Neuro- degenerative diseases (N=1,015)	Renal-vascular disease, failure (N=618)
<b>Gender</b>								
Female	8813 (48)	7250 (48)	3275 (65)	1848 (59)	1476 (51)	407 (39)	469 (46)	327 (53)
Male	9450 (52)	7956 (52)	1735 (35)	1260 (41)	1429 (49)	637 (61)	546 (54)	291 (47)
<b>Age at death (years)</b>								
< 61	3969 (22)	1635 (11)	16 (0)	256 (8)	151 (5)	512 (49)	176 (17)	34 (6)
61-70	4052 (22)	1829 (12)	95 (2)	213 (7)	376 (13)	269 (26)	185 (18)	47 (8)
71-80	4843 (27)	3021 (20)	566 (11)	603 (19)	861 (30)	162 (16)	275 (27)	118 (19)
81-90	4382 (24)	5424 (36)	2435 (49)	1306 (42)	1134 (39)	87 (8)	307 (30)	280 (45)
≥91	1017 (6)	3297 (22)	1898 (38)	730 (23)	383 (13)	14 (1)	72 (7)	139 (22)
<b>Rurality</b>								
Urban	16164 (89)	13401 (88)	4505 (90)	2710 (87)	2532 (87)	898 (86)	897 (88)	557 (90)
Rural	2099 (11)	1805 (12)	505 (10)	398 (13)	373 (13)	146 (14)	118 (12)	61 (10)
<b>Neighbourhood income quintile</b>								
Q1 - Lowest	4560 (25)	4656 (31)	1335 (27)	919 (30)	968 (33)	355 (34)	246 (24)	172 (28)
Q2	4504 (25)	3462 (23)	1003 (20)	701 (23)	698 (24)	265 (25)	185 (18)	154 (25)
Q3	3455 (19)	2875 (19)	947 (19)	594 (19)	524 (18)	178 (17)	207 (20)	116 (19)
Q4	2698 (15)	2005 (13)	757 (15)	428 (14)	353 (12)	132 (13)	160 (16)	81 (13)
Q5 - Highest	3046 (17)	2208 (15)	968 (19)	466 (15)	362 (12)	114 (11)	217 (21)	95 (15)
<b>CCI score</b>								
0	14088 (77)	8881 (58)	4264 (85)	2068 (67)	1703 (59)	644 (62)	767 (76)	251 (41)
1 (score 1-2)	3186 (17)	3435 (23)	591 (12)	721 (23)	764 (26)	293 (28)	194 (19)	215 (35)
2 (score ≥3)	989 (5)	2890 (19)	155 (3)	319 (10)	438 (15)	107 (10)	54 (5)	152 (25)
<b>Year of death</b>								
2007-2008	3464 (19)	2892 (19)	722 (14)	649 (21)	562 (19)	192 (18)	170 (17)	120 (19)
2009-2010	3588 (20)	2975 (20)	850 (17)	642 (21)	508 (17)	181 (17)	169 (17)	119 (19)
2011-2012	3556 (19)	3016 (20)	950 (19)	610 (20)	565 (19)	200 (19)	199 (20)	99 (16)
2013-2014	3697 (20)	3135 (21)	1172 (23)	578 (19)	586 (20)	224 (21)	215 (21)	124 (20)
2015-2016	3958 (22)	3188 (21)	1316 (26)	629 (20)	684 (24)	247 (24)	262 (26)	156 (25)
<b>Community-care use<sup>a</sup></b>								
Home care	14410 (79)	8688 (57)	3557 (71)	2152 (69)	1692 (58)	795 (76)	493 (49)	478 (77)

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<i>Non-palliative</i>								
<i>home care</i>	8455 (46)	8511 (56)	3543 (71)	2073 (67)	1668 (57)	789 (76)	474 (47)	440 (71)
LTC admission	3068 (17)	2789 (18)	806 (16)	797 (26)	650 (22)	427 (41)	152 (15)	58 (9)

Counts and percentages are shown. Percentages are based on column totals. *COPD* chronic lower respiratory disease, *Q* quintile, *CCI* Charlson Comorbidity Index, *LTC* long term care

<sup>a</sup> Evaluated at any time prior to death.

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**eTable 4:** The proportion of decedents exposed to specialist palliative care (at any time) by year.

Year	Overall	Cancer	Heart disease, failure	Dementia, senility	Stroke	COPD	Liver disease	Neuro-degenerative diseases	Renovascular disease failure
2007	41.5	80.7	11.7	10.3	19.1	21.7	26.1	34.6	48.1
2008	43.3	83.9	13.4	13.2	21.3	24.3	26.0	32.6	45.6
2009	46.1	84.9	14.7	17.9	26.4	30.4	44.8	57.8	42.1
2010	47.6	85.1	17.0	18.9	30.0	33.9	36.5	41.9	41.9
2011	50.0	88.1	20.4	25.2	29.7	40.1	39.2	61.0	37.3
2012	52.2	87.6	21.7	27.0	40.1	42.9	45.6	51.5	56.3
2013	51.0	87.6	23.6	20.7	34.4	43.2	51.8	54.3	49.2
2014	52.9	89.3	25.2	25.7	34.8	47.5	51.8	43.6	44.3
2015	53.3	87.8	25.5	27.1	35.7	49.6	48.4	56.4	48.6
2016	52.1	87.4	25.3	23.7	32.9	45.7	62.0	47.4	56.0
% $\Delta^a$	<b>+10.2</b>	<b>+5.3</b>	<b>+12.8</b>	<b>+13.5</b>	<b>+14.1</b>	<b>+24.6</b>	<b>+29.1</b>	<b>+17.6</b>	+5.9

<sup>a</sup> Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear increase in the proportion of decedents with any specialist PC exposure prior to death (Chi-squared Test for Trend in Proportions was  $p < 0.05$ ).



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**eTable 5:** The proportion of decedents exposed to specialist palliative care early (≥90 days before death) by year.

	Overall	Cancer	Heart disease, failure	Dementia, senility	Stroke	COPD	Liver disease	Neuro-degenerative diseases	Reno-vascular disease, failure
2007	13.1	29.0	1.7	0.9	0.9	7.1	2.2	7.4	1.7
2008	14.4	30.6	3.4	2.5	3.3	6.5	1.0	14.6	1.9
2009	14.1	29.4	3.4	3.0	2.7	7.4	3.1	18.1	1.3
2010	15.7	29.9	4.3	4.0	4.8	15.5	4.7	24.4	1.5
2011	17.6	34.1	5.9	7.4	3.1	15.2	7.2	20.0	1.8
2012	17.2	32.1	5.5	7.7	3.5	15.7	5.8	23.2	1.8
2013	16.5	31.5	6.1	5.1	5.1	16.9	7.9	21.0	1.4
2014	17.7	32.3	7.1	8.4	5.3	17.3	9.1	16.4	1.8
2015	18.1	31.6	7.1	10.5	4.9	22.1	5.6	26.4	1.9
2016	18.7	33.7	7.7	8.7	5.6	19.7	9.1	15.8	1.1
%Δ <sup>a</sup>	<b>4.7</b>	<b>2.8</b>	<b>4.8</b>	<b>7.8</b>	<b>3.1</b>	<b>14.2</b>	<b>5.7</b>	9.1	1.8

<sup>a</sup> Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear increase in the proportion of decedents with any specialist PC exposure prior to death (Chi-squared Test for Trend in Proportions was p<0.05).

**eTable 6:** The proportion of the decedents with hospital-based acute care use indicative of aggressive end-of-life care.

Hospital-based acute care use (indicators of aggressive end-of-life care)						
Year	> 1 ED visit in last 30 days of life	> 1 hospital admission in last 30 days of life	> 14 days in hospital in last 30 days of life	Any ICU/SCU admission in last 30 days of life	Death in an acute care hospital or bed	Any "aggressive" end-of-life care indicator
2007	8.2	7.8	21.8	7.8	44.1	49.3
2008	9.0	6.7	21.5	7.0	41.8	48.2
2009	8.3	6.7	19.8	7.2	41.6	48.0
2010	8.5	7.7	21.0	6.1	41.1	46.5
2011	8.3	9.1	21.9	6.0	40.0	47.4
2012	8.8	9.1	21.3	6.6	41.6	48.9
2013	9.3	9.6	21.8	6.5	44.6	50.1
2014	9.9	9.6	22.0	6.0	42.7	49.5
2015	9.6	8.4	20.6	6.0	40.1	47.5
2016	9.3	7.2	18.6	6.2	39.9	46.3
% $\Delta^a$	<b>+0.8</b>	<b>+0.5</b>	<b>-2.0</b>	<b>-1.3</b>	<b>-2.9</b>	-1.8

<sup>a</sup>Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear change (increase or decrease) in the proportion of decedents who experienced the acute care use indicator indicated (Chi-squared Test for Trend in Proportions was  $p < 0.05$ ). ED emergency department, ICU intensive care unit.

**eTable 7:** The association between specialist PC and aggressive EOL care indicators (n=47,169)

	Individual hospital-based acute care use indicators								Death in an acute care hospital or bed		Aggregated aggressive EOL care indicator	
	> 1 ED visit		> 1 hospital admission		Any ICU admission		> 14 days in hospital		RR	95% CI	RR	95% CI
	RR	95% CI	RR	95% CI	RR	95% CI	RR	95% CI				
<b>All decedents</b>												
Early	0.96	(0.95-0.96)	0.98	(0.97-0.99)	0.9	(0.89-0.9)	1.02	(1.01-1.03)	0.84	(0.83-0.85)	0.68	(0.65-0.70)
Late	0.98	(0.97-0.99)	1.04	(1.03-1.04)	0.9	(0.9-0.91)	1.16	(1.15-1.17)	0.88	(0.87-0.89)	0.98	(0.96-1.01)
Very Late	1.05	(1.04-1.06)	1.05	(1.04-1.06)	0.96	(0.95-0.97)	1.11	(1.1-1.13)	1.13	(1.12-1.14)	1.51	(1.48-1.54)
<b>Cancer</b>												
Early	0.93	(0.92-0.95)	0.96	(0.95-0.98)	0.85	(0.84-0.86)	0.96	(0.94-0.98)	0.76	(0.75-0.77)	0.52	(0.5-0.54)
Late	0.97	(0.96-0.98)	1.02	(1.01-1.04)	0.86	(0.85-0.87)	1.06	(1.05-1.08)	0.8	(0.79-0.81)	0.76	(0.74-0.79)
Very Late	1.06	(1.04-1.08)	1.04	(1.02-1.06)	0.9	(0.88-0.91)	1	(0.98-1.02)	1.04	(1.02-1.06)	1.21	(1.17-1.26)
<b>Heart disease and heart failure</b>												
Early	0.98	(0.96-0.99)	0.98	(0.97-0.99)	0.92	(0.91-0.93)	0.98	(0.96-1.01)	0.89	(0.87-0.91)	0.73	(0.67-0.8)
Late	0.96	(0.95-0.98)	1.03	(1.01-1.05)	0.93	(0.92-0.94)	1.21	(1.19-1.24)	0.89	(0.87-0.91)	1.05	(1-1.1)
Very Late	1.02	(1-1.03)	1.04	(1.02-1.06)	1.02	(1-1.04)	1.16	(1.13-1.19)	1.15	(1.13-1.17)	1.53	(1.47-1.58)
<b>Dementia</b>												
Early	1	(0.98-1.02)	0.99	(0.98-1)	1	(0.99-1)	0.98	(0.95-1)	0.95	(0.92-0.98)	0.88	(0.71-1.1)
Late	0.99	(0.97-1.01)	1.04	(1.01-1.06)	1	(0.99-1.01)	1.19	(1.15-1.24)	0.99	(0.97-1.04)	1.66	(1.46-1.88)
Very Late	1.04	(1.01-1.06)	1.04	(1.01-1.07)	0.99	(0.99-1)	1.16	(1.12-1.21)	1.26	(1.21-1.3)	2.35	(2.1-2.64)
<b>Stroke</b>												
Early	0.97	(0.93-1.01)	1	(0.96-1.04)	0.95	(0.93-0.98)	1	(0.95-1.05)	0.92	(0.87-0.98)	0.76	(0.63-0.92)
Late	0.98	(0.95-1.02)	1.04	(1.01-1.08)	0.91	(0.89-0.92)	1.28	(1.23-1.33)	0.86	(0.83-0.9)	1.06	(0.98-1.15)
Very Late	1.04	(1-1.07)	1.05	(1.02-1.08)	0.97	(0.94-0.99)	1.1	(1.06-1.14)	1.05	(1.02-1.08)	1.29	(1.22-1.36)
<b>COPD</b>												
Early	0.97	(0.94-0.99)	1	(0.97-1.02)	0.91	(0.89-0.93)	0.99	(0.95-1.02)	0.87	(0.84-0.9)	0.74	(0.66-0.82)
Late	0.99	(0.95-1.02)	1.06	(1.02-1.09)	0.92	(0.9-0.95)	1.16	(1.12-1.21)	0.86	(0.83-0.9)	0.95	(0.87-1.04)

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2	Very Late	1.05	(1.01-1.09)	1.08	(1.04-1.12)	0.97	(0.94-1)	1.1	(1.06-1.15)	1.2	(1.09-1.15)	1.4	(1.32-1.48)
3	Liver disease												
4													
5	Early	1.03	(0.94-1.13)	0.97	(0.89-1.05)	0.79	(0.74-0.85)	0.99	(0.9-1.09)	0.97	(0.8-0.94)	0.81	(0.66-0.99)
6	Late	0.97	(0.93-1.02)	1.02	(0.96-1.07)	0.73	(0.7-0.75)	1.14	(1.08-1.2)	0.98	(0.76-0.84)	0.89	(0.81-0.98)
7	Very Late	1.01	(0.96-1.07)	0.99	(0.94-1.05)	0.81	(0.77-0.85)	1.19	(1.13-1.26)	1.01	(0.98-1.04)	1.19	(1.12-1.26)
8	Neuro-degenerative diseases												
9													
10	Early	1	(0.96-1.04)	1.01	(0.98-1.05)	0.93	(0.9-0.97)	0.99	(0.94-1.05)	0.91	(0.86-0.97)	0.74	(0.59-0.94)
11	Late	0.99	(0.96-1.03)	1.06	(1.02-1.1)	0.94	(0.91-0.97)	1.17	(1.11-1.24)	0.95	(0.9-1.01)	1.13	(0.95-1.34)
12	Very Late	1.08	(1.01-1.15)	1.05	(1-1.11)	0.97	(0.93-1.02)	1.1	(1.02-1.19)	1.08	(1.21-1.36)	1.98	(1.67-2.34)
13	Reno-vascular disease, failure												
14													
15	Early	1	(0.93-1.08)	0.94	(0.9-0.99)	0.93	(0.9-0.97)	0.94	(0.86-1.02)	0.83	(0.76-0.9)	0.6	(0.43-0.84)
16	Late	0.96	(0.91-1.01)	0.98	(0.93-1.02)	0.93	(0.89-0.97)	1.17	(1.09-1.25)	0.99	(0.84-0.95)	0.96	(0.82-1.13)
17	Very Late	1.02	(0.95-1.1)	1.02	(0.95-1.1)	0.99	(0.93-1.05)	1.11	(1.02-1.21)	1.07	(1-1.15)	1.26	(1.08-1.47)

PC palliative care, RR relative risk, CI confidence interval, COPD chronic lower respiratory disease, EOL end-of-life, ED emergency department, ICU intensive care unit

Early PC exposure is defined as  $\geq 90$  before death, late as  $\geq 8$  but  $< 90$  days, very late as  $\leq 7$  days before death.

**eTable 8:** The relative risk of experiencing any aggressive EOL care for all decedents (n=47,169)

	All decedent log-binomial model	
	RR	95% CI
<b>Specialist PC exposure</b>		
Early	<b>0.68</b>	<b>(0.65-0.70)</b>
Late	0.98	(0.96-1.01)
Very Late	<b>1.51</b>	<b>(1.48-1.54)</b>
Never	1.00	ref
<b>Chronic disease causing death</b>		
Cancer	1.00	ref
Heart disease, failure	0.83	<b>(0.81-0.85)</b>
Dementia, senility	0.75	<b>(0.71-0.79)</b>
Stroke	1.24	<b>(1.20-1.28)</b>
COPD	1.09	<b>(1.06-1.13)</b>
Liver disease	1.18	<b>(1.13-1.22)</b>
Neuro-degenerative disease	0.96	(0.89-1.02)
Reno-vascular disease	0.97	(0.91-1.03)
<b>Sex</b>		
Male	<b>1.06</b>	<b>(1.04-1.08)</b>
Female	1.00	ref
<b>Age at death</b>		
< 61	<b>1.21</b>	<b>(1.17-1.24)</b>
61-70	<b>1.11</b>	<b>(1.08-1.13)</b>
71-80	<b>1.06</b>	<b>(1.03-1.08)</b>
81-90	1.00	ref
≥91	<b>0.86</b>	<b>(0.83-0.88)</b>
<b>Rurality</b>		
Rural	<b>1.19</b>	<b>(1.16-1.22)</b>
Urban	1.00	ref
<b>Household income quintile</b>		
Q1	1.00	ref
Q2	0.99	(0.97-1.02)
Q3	0.98	(0.95-1.00)
Q4	0.98	(0.95-1.01)
Q5	0.97	(0.94-1.00)

<b>CCI score</b>		
0	1.00	ref
1 (score 1-2)	<b>1.52</b>	<b>(1.49-1.55)</b>
2 (score ≥3)	<b>1.70</b>	<b>(1.66-1.74)</b>
<b>Year of death</b>		
2007-2008	1.00	ref
2009-2010	1.02	(0.99-1.05)
2011-2012	<b>1.10</b>	<b>(1.07-1.13)</b>
2013-2014	<b>1.13</b>	<b>(1.10-1.16)</b>
2015-2016	<b>1.07</b>	<b>(1.04-1.10)</b>
<b>Long term care use</b>		
No	1.00	ref
Yes	<b>0.48</b>	<b>(0.46-0.50)</b>
<b>Non-palliative home care use</b>		
No	1.00	ref
Yes	<b>1.13</b>	<b>(1.11-1.15)</b>

RR relative risk, CI confidence interval, Q quintile, CCI Charlson comorbidity index, ref reference group. RR's whose 95%CI's do not contain 1 are bolded, indicating p<0.05.

**STROBE Statement**

Checklist of items that should be included in reports of observational studies

Section/Topic	Item No	Recommendation	Reported on Page No
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	3
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up and data collection	6
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6
		<i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls	
		<i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	
Variables	7	(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed	6,7, eTable 1,2
		<i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Data sources/measurement	8*	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6,7, eTable 1,2
Bias	9	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6,7, eTable 1,2
Study size	10	Describe any efforts to address potential sources of bias	7,8
Quantitative variables	11	Explain how the study size was arrived at	6
Statistical methods	12	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7,8
		(a) Describe all statistical methods, including those used to control for confounding	7,8
		(b) Describe any methods used to examine subgroups and interactions	7,8
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed	NA
		<i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	NA
		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy	NA
		(e) Describe any sensitivity analyses	NA

Section/Topic	Item No	Recommendation	Reported on Page No
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	8
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8, Table 1, eTable 3, eTable 4, eTable 5
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	9,10, Table 2, eTable 6
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	10,11, Figure 1, eTable 7, eTable 8
		(b) Report category boundaries when continuous variables were categorized	
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	11
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	11,12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11,12,13
Generalisability	21	Discuss the generalisability (external validity) of the study results	13
<b>Other Information</b>			



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1	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14
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3 *\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.*

4 **Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is

5 best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and

6 Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

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# BMJ Open

## Hospital-based acute care in the last 30 days of life among chronic disease patients that received early, late, or no specialist palliative care: a retrospective cohort study of eight chronic disease groups

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<b>Primary Subject Heading</b>:	Palliative care
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4 **Hospital-based acute care in the last 30 days of life among chronic disease patients that received**  
5 **early, late, or no specialist palliative care: a retrospective cohort study of eight chronic disease**  
6 **groups**  
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## ABSTRACT

**Objective:** For eight chronic diseases, evaluate the association of specialist palliative care (PC) exposure and timing with hospital-based acute care in the last 30 days of life.

**Design:** Retrospective cohort study using administrative data.

Setting: Alberta, Canada between 2007 and 2016.

**Participants:** 47,169 adults deceased from: (1) cancer, (2) heart disease, (3) dementia, (4) stroke, (5) chronic lower respiratory disease (COPD), (6) liver disease, (7) neuro-degenerative disease, and (8) reno-vascular disease.

**Main outcome measures:** The proportion of decedents who experienced high hospital-based acute care in the last 30 days of life, indicated by  $\geq$ two emergency department (ED) visit,  $\geq$ two hospital admissions,  $\geq$ 14 days of hospitalization, any intensive care unit (ICU) admission, or death in hospital. Relative risk and risk difference of hospital-based acute care given early specialist PC exposure ( $\geq$ 90 days before death), adjusted for patient characteristics.

**Results:** In an analysis of all decedents, early specialist PC exposure was associated with a 32% reduction in risk of any hospital-based acute care as compared to those with no PC exposure (relative risk [RR] 0.69, 95%CI 0.66 to 0.71; risk difference [RD] 0.16, 95%CI 0.15-0.17). The association was strongest in cancer-specific analyses (RR 0.53, 95%CI 0.50 to 0.55; RD 0.31, 95% CI 0.29-0.33) and renal disease-specific analyses (RR 0.60, 95%CI 0.43 to 0.84; RD 0.22, 95%CI 0.11-0.34), but a ~25% risk reduction was observed for each of heart disease, COPD, neuro-degenerative diseases, and stroke. Early specialist PC exposure was associated with reducing risk of four out of five individual indicators of high hospital-based acute care in the last 30 days of life, including  $\geq$ two ED visit,  $\geq$ two hospital admission, any ICU admission, and death in hospital.

**Conclusions:** Early specialist PC exposure reduced the risk of hospital-based acute care in the last 30 days of life for all chronic disease groups except dementia.

### Strengths and limitations of this study

- A strength is the separate analysis of eight different common chronic disease groups.
- Large population-based cohort from a jurisdiction with a well-established specialist palliative care program operating institutional and in the community.
- Strength is the comprehensive assessment of all specialist palliative care providers (physician, nurses, and allied healthcare professionals) activities in all settings.
- Limitation is that the contribution of non-specialist palliative care providers (e.g. family physician) is not included.
- Caution is needed when generalizing results to other jurisdictions, particularly those that do not have a well-developed specialist palliative care program.

## INTRODUCTION

Palliative care (PC) is a key ingredient to providing the best possible care for many patients nearing the end-of-life (EOL).<sup>1</sup> The World Health Organization defines PC as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.<sup>2</sup> Thus, PC focusses on addressing patients' unmet needs around illness comprehension and coping, advanced care planning and decision making, symptoms and daily functioning, and coordination of care.

In the past, PC has been provided predominantly to terminal cancer patients, in large part because the disease trajectory is easier to predict.<sup>3,4</sup> However, timely access to PC has been associated with improved quality of life (QoL) for patients with a myriad of chronic diseases.<sup>5-9</sup> Conditions now considered appropriate for PC include malignant cancer, heart disease, dementia, stroke, chronic lower respiratory disease (COPD), advanced liver disease, neurodegenerative diseases, and renal-vascular diseases.<sup>10,11</sup> In addition to improving QoL, PC use has been associated with reduced or neutral healthcare cost through reductions in acute care use, e.g. emergency department (ED) visits and hospital and intensive care unit admissions (ICU), near the EOL.<sup>3,12-14</sup> Thus, greater use of PC has the potential to be a "win-win" for patients and administrators of health systems.

Many studies have reported on the relationship between PC exposure and healthcare resource use near the EOL for cancer patients<sup>15-21</sup>; consistently finding that PC exposure reduces risk of hospital-based care near the EOL. Recently, the same was found to be true for patients with many of the commonest chronic diseases, however, questions remain about the role of PC timing on these outcomes.<sup>22</sup> To address this, for eight chronic diseases, we evaluate the impact of specialist PC timing (early,  $\geq 90$  days before death; late,  $\geq 8$  but  $< 90$  days before death; very late,  $\leq 7$  days before death; and never) on hospital-based healthcare resource use (ED visits, hospital and ICU admissions, death in hospital) in the 30 days prior to death.

## METHODS

### Setting and design



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3 This study was set in the Calgary Zone (CZ) of Alberta Health Services (AHS). CZ encompasses the city of  
4 Calgary and surrounding semi-rural areas (88% urban, 12% rural). It contains ~1.6 million people, or  
5 ~38% of Alberta, Canada's population.<sup>23</sup> AHS is the provincial health authority tasked with delivering  
6 publicly-funded universal healthcare to the population, including access to PC in institutional and  
7 community settings. The specialist PC service in CZ is a longstanding (~20 years), mature, integrated  
8 program which includes PC consult teams (institutional and community-based), a tertiary PC unit  
9 (TPCU), palliative home care (PHC) (available within Calgary city limits only), and hospices (institutional  
10 and community-based).<sup>24</sup> All services provided by and activities performed by the CZ specialist PC  
11 program/providers are captured in operational databases (Sunrise Clinical Manager, PallD, PARIS, and  
12 Pathways Continuing Care Application Data, see **eTable 1**) managed by AHS, which are used to manage  
13 workflows, admission, consultation, and discharge. The criteria for PC referral in Alberta are like most  
14 PC programs with a focus on symptoms, advance care planning, and general support for patients,  
15 caregivers, and providers.  
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### 29 **Cohort Description**

30 This was an administrative data-based retrospective cohort study of CZ decedents who died between 1  
31 January 2007 and 1 December 2016. Regional, provincial, and national healthcare databases were used  
32 to identify palliative, community, and acute care service use before death. A list of the databases  
33 accessed (including the specialist PC databases), and the information extracted from each, is available  
34 (see **eTable 1**). Patients 18 years or older and deceased from a PC-amenable condition, including: (1)  
35 malignant cancer, (2) heart disease and heart failure (abbreviated 'heart disease/failure'), (3)  
36 dementia, vascular dementia, Alzheimer's disease, senility (abbreviated 'dementia'), (4) haemorrhagic,  
37 ischaemic and unspecified stroke (abbreviated 'stroke'), (5) COPD and respiratory failure (abbreviated  
38 'COPD'), (6) liver disease, (7) neurodegenerative diseases, and (8) reno-vascular disease, and renal  
39 failure (abbreviated 'renal disease/failure'), were included.<sup>10 11</sup> These conditions were identified based  
40 on International Classification of Diseases 10<sup>th</sup> Revision (ICD-10) codes for underlying cause of death as  
41 recorded on the death certificate (see **eTable 2** for the ICD-10 codes used).<sup>10 11</sup> Administrative data was  
42 linked, aggregated, and de-identified by the data analytics service within AHS. Ethics permission was  
43 granted by the University of Calgary Human Research Ethics Cancer Committee (17-0445).  
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## Patient and public involvement

All patients were deceased, precluding involvement in the design, conduct, reporting, or dissemination plans of our research. The public were not involved in the design, conduct, reporting, or dissemination of this research.

## Outcomes

The outcomes were the number of decedents with high hospital-based acute care use in the last 30 days of life. Five indicators of this were defined: (1) death in an acute care hospital, (2) two or more emergency department (ED) visit, (3) two or more hospital admissions, (4) fifteen or more days of hospitalization, and (5) any ICU admission. An aggregate indicator (primary outcome) was constructed as: any individual indicators found to occur versus none. This study reports relative risk (RR) and risk difference (RD) of these indicator outcomes given specialist PC exposure and timing, adjusting for covariates.

## Exposure of interest

The exposure of interest was specialist PC use. This was categorized as: no specialist PC use (reference category), early specialist PC occurring  $\geq 90$  days before death, late specialist PC occurring  $\geq 8$  but  $< 90$  days before death, and very late specialist PC occurring  $< 8$  days before death. Unlike previous reports that excluded patients with very late PC,<sup>22</sup> we chose to include these patients (modelled as a separate group) as we were interested in evaluating associations with our outcome and covariates. PC timing cut-offs (i.e.  $\geq 8$  and  $< 90$  days) were selected based on prior research into PC timing and healthcare resource use.<sup>15 25-27</sup>

In secondary analyses examining only decedents that received specialist PC, the exposure of interest was categorized as: late specialist PC occurring  $\geq 8$  but  $< 90$  days before death (reference category) versus early specialist PC occurring  $\geq 90$  days before death.

## Covariates

Our statistical analyses controlled for covariates previously shown to be associated with either hospital-based acute care use in the last 30 days of life or specialist PC use. These included underlying chronic disease causing death (categories: cancer [reference], heart disease/failure, dementia, stroke, COPD, liver disease, neurodegenerative diseases, renal disease/failure), sex (categories: female [reference], male), age at death (categories: <61, 61-70, 71-80, 81-90 [reference], ≥91 years old), year of death (categories: 2007-2008 [reference], 2009-2010, 2011-2012, 2013-2014, 2015-2016), rurality of primary residence (categories: urban [reference], rural), Charlson comorbidity Index (CCI) score adjusted for underlying cause of disease (categories: 0 [reference], 1-2, ≥3), estimated household income based on postal code (categories: \$0 - \$71,680 [reference], \$71,765 - \$90,112, \$90,197 - \$108,032, \$108,083 - \$128,384, \$128,512 - \$519,168 per year), days spent in hospital in the 90-365 days before death (categories: 0 [reference], 1-10, 11-275), general home care visits before death (categories: 0 [reference], ≥1), and admissions to long-term care before death (categories: 0 [reference], ≥1). For rurality, decedents were assigned an urban or rural designation using a 7-level categorization based on postal code.<sup>28</sup> The “urban” designation included the levels: metro, moderate metro influence, and urban; the “rural” designation included all other levels. An overall (longitudinal) CCI score was calculated for each decedent by collapsing all records of inpatient care from 2002 until death.<sup>29</sup> CCI scores were calculated using published methodology,<sup>30 31</sup> with ICD-10 codes for decedents underlying cause of death removed. Median household income quintiles were derived using 2016 Statistics Canada Dissemination Area (DA) level data for Alberta.<sup>32</sup> The population was divided into five groups such that ~20% of the population was in each group. Household income quintile was then assigned based on decedents last known residence postal code. Categorization of days spent in hospital in the 90-365 days before death reflects the quartiles observed among all decedents (0 days for quartile 1 and 2).

## Statistical analysis

### *Relative risk (RR)*

To determine the likelihood of hospital-based acute care in the last 30 days of life being associated with specialist PC we ran modified Poisson regression models<sup>33</sup> adjusting for underlying chronic disease causing death, sex, age at death, year of death, rurality, income, CCI score, long-term care admission,

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3 general home care use, and days spent in hospital before death. All analyses were performed in R  
4 v4.0.0. The general model formula used was:  $\text{glm}(O \sim E + \text{covariates}, \text{family}=\text{Poisson}(\text{link}=\text{log}))$ , where  
5 “O” is the outcome, one of the indicators of hospital-based acute care in the last 30 days of life (with  
6 the levels ‘no’ [reference], ‘yes’), and where “E” is the exposure of interest, specialist PC use (with the  
7 levels ‘no’ specialist PC use [reference] versus early specialist PC occurring  $\geq 90$  days before death, late  
8 specialist PC occurring  $\geq 8$  but  $< 90$  days before death, and very late specialist PC occurring  $< 8$  days  
9 before death in the main analysis, and in secondary analyses late specialist PC [reference] versus early  
10 specialist PC). Covariates adjusted for are as listed in the “covariates” section. Robust standard errors  
11 were estimated using the covariance matrix of model parameters, obtained using the *vcovHC* function  
12 implemented in the R package *sandwich*.<sup>34</sup> A separate Poisson regression model was run for each of  
13 the six outcomes listed in the “Outcome” section. RRs are reported with 95% confidence intervals (CI)  
14 based on robust standard errors.

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16 We additionally ran modified Poisson regression models on our data subset by chronic disease  
17 condition (8 sub-analyses in total), as it was of interest to determine if the associations between  
18 specialist PC and hospital-based acute care in the last 30 days of life varies by chronic disease.  
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### 21 *Absolute RD*

22 Reporting of RD is recommended for clinical and epidemiological studies. To report RD’s for our  
23 outcomes and exposure while adjusting for covariates, both binomial and Poisson models with an  
24 identity link function were attempted. Both failed to converge, a known problem.<sup>35</sup> Given this, RD’s  
25 were estimated from linear regression models (i.e. normal or Gaussian distribution with identity link  
26 function), an approach supported by simulation-based assessments of model performance when  
27 estimating RD given a binary outcome.<sup>35</sup> The general model formula used to obtain RD’s was:  $\text{glm}(O \sim E$   
28  $+ \text{covariates}, \text{family}=\text{gaussian}(\text{link}=\text{identity}))$ . “O”, “E”, and covariates are as described for RR’s. RRs are  
29 reported with 95% confidence intervals (CI) based on robust standard errors.  
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## 32 **RESULTS**

### 33 **Characteristics of decedents**

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3 A total of 47,169 decedents were identified during the study period. Cancer was the most common  
4 underlying cause of death (39%), following by heart disease/failure (32%). The dementia, stroke, and  
5 COPD disease groups each accounted for 11%, 7%, and 6% of deaths, respectively (**Table 1**). The liver  
6 and neurodegenerative disease groups each made up 2% of decedents; reno-vascular disease/failure  
7 1%. Fifty-one percent of decedents were female, with women making up a larger percentage of the  
8 dementia category (65%) and a smaller percentage of the liver disease category (39%) (**eTable 3**). Liver  
9 disease patients were on average much younger at death; dementia patients were older at death.  
10 Disease groups were similar in their breakdown by rurality, with 12% of decedents living in rural areas.  
11 Overall, decedents were more likely to be in the lowest household income quintile (e.g. Q1: expected  
12 20%, observed 28%, an excess of +8%) (**Table 1**). Liver disease and COPD decedents were even more  
13 likely to fall in the lowest household income quintile (Q1: 34% and 33%, respectively) (**eTable 3**). Most  
14 patients (69%) had a CCI score of 0 (after excluding underlying cause of death). Liver disease, heart  
15 disease/failure, and COPD decedents were more likely to have CCI scores  $\geq 1$ . Nineteen percent of  
16 decedents had a long-term care admission prior to death; however, this varied considerably by disease  
17 category. Dementia patients were most likely be admitted to long-term care (61%); cancer and liver  
18 disease patients were the least likely, 4% and 6%, respectively. Two-thirds of decedents (68%) had a  
19 home care visit prior to death; 55% had only non-palliative home care visits. Over 60% of the cohort  
20 spent 0 days in hospital 90 to 365 days before death, 15% spent between 1 and 10 days, and 24% spent  
21 between 11 and 275 days in hospital for this period (**Table 1**). The COPD, liver disease, and reno-  
22 vascular disease/failure groups were more likely to have more days in hospital 90 to 365 days before  
23 death (**eTable 3**).  
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### 44 **Specialist PC exposure prior to death**

45 Overall, 49% of decedents received one or more specialist PC service prior to death (**Table 1**). Cancer  
46 patients were most exposed (86%); heart disease patients least exposed (20%). For the other chronic  
47 disease categories, the proportion of PC exposed decedents was: neurodegenerative disease, 48%;  
48 reno-vascular disease, 47%; liver disease, 44%, COPD and respiratory failure, 38%; stroke, 30%; and  
49 dementia, 22%. A higher proportion of patients who received specialist PC were younger at death,  
50 lived in urban areas, were from higher income quintiles (Q2-Q5), died in the second half of the study  
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3 period, and were not admitted to LTC (**Table 1**). From 2007-2016, we observed a significant increase in  
4 the proportion of decedents exposed to specialist PC, overall, and independently for each disease  
5 category except reno-vascular disease (**eTable 4**). Overall, PC exposure increased by 10%, from 43% of  
6 decedents in 2007/2008 (years combined) to 53% of decedents in 2015/2016 (years combined). The  
7 biggest changes occurred for liver disease (+29%; 26% to 62% from 2007 to 2016) and COPD (+25%,  
8 22% to 46% from 2007 to 2016).

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14 Regarding the timing of first specialist PC exposure, 16% of decedents experienced early  
15 specialist PC exposure, 24% had late exposure, and 9% had very late exposure. Across all decedents,  
16 the median number of days from first PC exposure to death was 43 (IQR 12-140). However, timing was  
17 highly variable by disease category. The duration was shortest for stroke (median 8 days, IQR 6-143)  
18 and liver disease (median 12 days, IQR 4-40) patients, and longest for cancer (median 55 days, IQR 20-  
19 148), neuro-degenerative disease (median 33 days, IQR 9 - 214) and COPD (median 32 days, IQR 5-244)  
20 patients. The remaining chronic disease groups each had a median PC exposure timing of 18-19 days  
21 before death. From 2007-2016, early specialist PC exposure increased by 4.7%, from 14% of decedents  
22 in 2007/2008 (years combined) to 19% of decedents in 2015/2016 (years combined) (**eTable 5**). The  
23 biggest changes occurred for COPD (+14%, 7% to 20% from 2007 to 2016). Finally, patients first  
24 encountered specialist PC primarily through PC consult team visits (81%), followed by PHC (15%) (**Table**  
25 **1**).

### 36 37 38 **Death in hospital and hospital-based acute care in the last 30 days of life**

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40 Overall, 42% of decedents died in an acute care hospital or bed (**Table 2**). Twenty-one percent of  
41 decedents spent > 14 days in hospital in last 30 days of life. Fewer than 10% of patients experience the  
42 remaining indicators of hospital-based acute care: >1 ED visit in last 30 days in last 30 days of life (9%),  
43 >1 hospital admission in last 30 days in last 30 days of life (8%), and any ICU admission care in last 30  
44 days of life (7%). Overall, 48% percent of decedents experienced one or more indicators of hospital-  
45 based acute care. The average number of positive indicators per patient was 1.8 (of 5). Liver disease  
46 patients were notable in being much more likely to experience hospital-based acute care in the last 30  
47 days of life (78% of all liver patients); a greater proportion died in hospital (76%) and used the ICU  
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(26%). Dementia patients were least likely to experience hospital-based acute care (25%), and least likely to die in hospital (20%).

Over the studied years there was a significant linear decrease in the proportion of decedents who died in hospital (-2.9%), spent  $\geq 14$  days in hospital in the last 30 days of life (-2.0%) or were admitted to the ICU (-1.3%) in the last 30 days of life. However, there was a linear increase in the proportion of decedents with  $>1$  hospitalization (+0.5%) and  $>1$  ED visit (+0.8%) in the last 30 days of life (**eTable 6**). Combining these indicators in the aggregate hospital-based acute care indicator, changes over time were not significant.

### **Association between specialist PC and indicators of hospital-based acute care**

#### **All decedents**

In the analysis of all decedents (**Table 3**), those exposed to early specialist PC had a 31% reduction in the risk of experiencing any hospital-based acute care (indicators aggregated) as compared to those with no specialist PC (RR 0.69; 95%CI 0.66 to 0.71; RD 0.16; 95%CI 0.15-0.17) (**Figure 1, Table 3**). Early specialist PC exposure was associated with reduced risk for four of five of the individual outcome indicators examined (**Figure 2, Table 3**). These included  $>1$  ED visit,  $>1$  hospital admission, any ICU admission, and death in hospital. It was associated with increased risk having spent  $>14$  days in hospital in the last 30 days of life. As compared to no specialist PC exposure, late specialist PC exposure was associated with reduced risk of ED visits, ICU admission, and death in hospital, but increased risk of hospital admission, and spending  $>14$  days in hospital (**Figure 2, Table 3**). Late PC exposure was not associated with the aggregated outcome (**Figure 1**). As compared to no specialist PC exposure, very late specialist PC exposure was associated with increased risk for all outcomes except ICU admission, for which it decreased risk.

In a secondary analysis examining only patients that received specialist PC, where early specialist PC was compared to late specialist PC (**Figure 1, eTable 7**), RR and RD estimates were found to be similar to main models where early specialist PC was compared to no specialist PC. For example, those exposed to early specialist PC (versus late) had a 32% reduction in the risk of experiencing any hospital-based acute care (indicators aggregated) (RR 0.68; 95%CI 0.66 to 0.70; RD 0.16; 95%CI 0.15-0.18).

## Disease-specific analysis

For all disease groups except dementia, early specialist PC exposure was associated with reduced risk of any hospital-based acute care as compared to those who had no PC exposure (**Figure 1, eTable 8**). The effect was strongest in cancer (RR 0.53, 95%CI 0.50 to 0.55; RD 0.31, 95% CI 0.29-0.33) and renal disease (RR 0.60, 95%CI 0.43 to 0.84; RD 0.22, 95%CI 0.11-0.34) decedents, but a ~25% risk reduction was observed for each of heart disease, COPD, neurodegenerative disease, and stroke. The effect in liver disease patient was smaller but significant (RR 0.81, 95%CI 0.66 to 0.99). Late specialist PC exposure was associated with reduced risk of any hospital-based acute care for cancer (RR 0.76, 95%CI 0.74 to 0.79) and liver disease patients (RR 0.89, 95%CI 0.81 to 0.98), but increased risk for dementia patients (RR 1.66, 95%CI 1.46 to 1.88), and was not associated in the other disease groups (**Figure 1**). Relative to no PC exposure, very late PC exposure was associated with increased risk of any hospital-based acute care for all disease categories. In secondary analyses of only patients that received specialist PC (**Figure 1, eTable 9**), RR estimates were found to be similar to main models where early specialist PC was compared to no specialist PC.

Of particular interest was death in hospital (inconsistent with most patients preferred location of death) and ICU admission (**Figure 2**). Examining death in hospital alone, early specialist PC exposure reduced risk of this outcome for all disease categories, while late PC exposure significantly reduced risk of death in hospital for all disease categories except dementia and neurodegenerative disease. Examining ICU admission, liver disease is notable in the effect of specialist PC exposure, regardless of timing, on reducing risk of this outcome. In general, ICU admissions are the only hospital-based acute care indicator for which very late specialist PC reduces risk for some disease groups.

## DISCUSSION

### Principal findings

Our analysis of 47,169 chronic disease decedents in Alberta, Canada from 2007-2016 shows that that early specialist PC exposure is associated with reduced risk of hospital-based acute care in the last 30 days of life when compared to those with no specialist PC exposure, or when compared to those with late specialist PC. Four of five outcome indicators showed this relationship (**Table 3**). And, this



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3 association was independently observed in all disease groups except of dementia (the latter was not  
4 significant). The association between late PC exposure (versus no exposure) was inconsistent across  
5 disease groups and outcomes. For most disease categories, late PC exposure was associated with  
6 decreased risk of death in hospital and ICU admission, but increased risk of >1 hospital admission and  
7 >14 days in hospital in the last month of life. We hypothesize this result is explained by patients whose  
8 first exposure to specialist PC occurs in the last month of life (but >7 days), likely triggered by a hospital  
9 admission in the last month life. Specialist PC would be highly correlated with hospital admission (i.e.  
10 increase risk) for these patients. Importantly however, late specialist PC was still associated with  
11 reduced risk of ICU admission and death in hospital for these patients. Finally, very late PC (versus no  
12 exposure) was consistently associated with increased risk of hospital-based acute care indicators (all  
13 except ICU admission) across all disease groups. Specialist PC initiated this late would not be expected  
14 to reduce healthcare resources use in the last 30 days of life, nor provide sufficient time to organize  
15 the healthcare resources needed to enable death at home. These patients likely only receive specialist  
16 PC because they were in hospital in the last 7 days of life, explaining the observed increase in risk.  
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### 31 **Comparison with other studies**

32 Many studies have reported on the relationship between PC exposure and hospital-based acute care  
33 near the EOL in cancer patients<sup>15-21</sup>; consistently finding that PC exposure reduces risk of hospital-  
34 based care near the EOL. Fewer studies have focussed on non-cancer patients, and results have been  
35 limited to the disease categories examined (heart failure,<sup>36 37 38 39</sup> dementia,<sup>40 41</sup> end stage renal  
36 disease [ESRD],<sup>42 43</sup> and end-stage liver disease.<sup>44</sup>) In these prior studies, PC exposure has not been  
37 consistently associated with indicators of healthcare resource use (often not significant). However, a  
38 recent well-powered study of seven chronic disease, looking at the impact of physician-delivered PC on  
39 hospital-based acute care, found results similar to ours.<sup>22</sup> Indeed, Quinn *et al.* 2020 found PC exposure  
40 (any versus none) was associated with reduced rates of ED visits, hospital and ICU admissions, and  
41 death in hospital for cancer, COPD, ESRD, stroke, and cirrhosis (liver) decedents.<sup>22</sup> Our study add to  
42 these results by showing the association of PC timing on these outcomes. We show early PC exposure,  
43 over late, is associated with reductions in risk of hospital-based acute care in the last 30 days of life.  
44 These studies are notably different in how PC is measured. Quinn *et al.* 2020 defined PC exposure as  
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3 newly initiated (in last 6 months of life but excluding the last 7 days), physician-delivered, and based on  
4 billing data.<sup>22</sup> Here, PC is defined as any specialist PC service (physician or nursing consultants,  
5 palliative home care, hospice) at any time (after diagnosis of underlying cause of death), based on data  
6 from specialist PC operational databases. Yet, the overall results are similar, with additional clarity now  
7 on the association of early versus late PC timing. Similar to our study, Rosenwax *et al.*<sup>45</sup> observed  
8 increased PC exposure over time for non-cancer chronic disease patients in Australia<sup>45</sup>, as did a recent  
9 study of Ontario decedents (2004-2014).<sup>46</sup> In both, as in our study, the biggest increases occur for liver  
10 disease and COPD patients.  
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### 20 **Strengths and limitations**

21 While this study was large and population-based, it had several important limitations. First, the  
22 outcome indicators used in this study were developed and validated based on cancer patients use of  
23 healthcare resources.<sup>47</sup> Indicators specific to non-cancer chronic diseases are not well developed or  
24 validated. As a result, the outcomes examined may not be as appropriate for measuring quality of EOL  
25 care for the non-cancer chronic diseases categories. Patient and provider preferences for EOL care may  
26 differ by chronic disease condition and requires further exploration to interpret the associations  
27 reported here. Development of disease-specific quality of EOL care indicators would help ensure the  
28 right outcomes (those that matter to patients) are the focus of future work. As it is, not all hospital-  
29 based acute care in the last 30 days of life is inappropriate, and we do not mean to imply that  
30 healthcare interventions should solely focus on reducing such care. Some hospital-based interventions  
31 at the EOL are likely appropriate and in line with patient and caregiver preferences. Unfortunately,  
32 data on patient preferences is not available in our healthcare administrative data and is beyond the  
33 scope of this study.  
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45 Second, unlike prior studies based on billing claims data,<sup>18 19 22</sup> here we only evaluated care  
46 provided by *specialist* PC providers (as recorded in institutional specialist PC databases). As the latter  
47 databases are used to manage all day-to-day specialist PC team-patient activities (e.g., consultation,  
48 admission), there should be very little misclassification in terms of who received *specialist* PC (and  
49 when), however this has not been formally measured and reported on. Importantly, there is no  
50 specialist PC provision outside of this in our jurisdiction. Our PC data sources (listed in **eTable 1**) and  
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3 study approach are anticipated to result in underreporting of PC exposure, specifically as it relates to  
4 PC provided by non-specialist PC providers (e.g., generalist physicians). However, our data sources and  
5 approach confer high confidence that all *specialist* PC services received by patients are accurately  
6 captured, across all care settings (i.e., home, hospital, and hospice).  
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10 Finally, this study examined only specialist PC provided to patients living in a primarily urban  
11 region (12% rural population), in one province, in a high-income country. Caution is needed when  
12 generalizing to other jurisdictions. In regions that do not have a well-developed specialist PC program  
13 (a program that is itself a result of the population being studied), patient's PC needs must be met by  
14 non-specialist providers or go unmet. The PC delivered by these providers (or alternative programs)  
15 may differ in their effect on the hospital-based outcomes examined here. Even in jurisdiction with well-  
16 developed PC programs, patient preferences for care may differ by population (influenced, for  
17 example, by social and cultural factors), and could affect the choice to receive PC and other acute care  
18 interventions. We note that our results are largely consistent with those of a recent well-powered  
19 study of chronic disease patients in Ontario, Canada.<sup>22</sup>  
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### 30 **Implications for clinicians and policymakers**

31 More work is needed to address differences in PC access observed here and elsewhere.<sup>45 46</sup> Further,  
32 more work is needed to ensure earlier timing of first PC exposure. We know PC benefits non-cancer  
33 chronic disease patients through QoL improvements<sup>48-50</sup>. Our current result shows that PC is also  
34 associated with reducing risk of hospital-based acute care in the last 30 days of life across most chronic  
35 disease categories. Sufficient follow-up time is necessary for the benefits of specialist PC to be realized,  
36 hence the call for earlier PC, however, late PC is still better than none in terms of reducing death in  
37 hospital and ICU admissions. Given finite healthcare resources, chronic disease groups with lower PC  
38 exposure and more likely to experience hospital-based acute care in the last 30 days of life, could be  
39 prioritized for focussed efforts to improve access. For example, 78% of liver disease and 59% of COPD  
40 decedents experience hospital-based acute care in the last 30 days of life, but only 44% (6% early) and  
41 38% (15% early), respectively, receive specialist PC. Patients dying from these conditions still lag far  
42 behind cancer patients both in terms of PC access and timing.  
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### Unanswered questions and future work

The reality for many jurisdictions is very limited access to, or a continuing lack of, specialist PC providers. Given this, the importance of disease-specific specialists and primary care physicians in providing PC, particularly early PC, and initiation of important advance care planning discussions, can not be overstated. An ongoing challenge in knowing precisely when and who to refer to specialist PC to best leverage these providers expertise,<sup>51</sup> recognizing that in many places this is a scarce resource. This is true particularly for non-cancer chronic diseases patients where the disease trajectory is less predictable, and can be much longer.<sup>4 51</sup> Addressing this challenge is important as evidence shows that the addition of PC benefits outcomes for cancer<sup>52</sup> and non-cancer patients.<sup>53-55</sup> Future work examining differing patient needs and preferences by chronic disease is needed, and could inform referral to specialist PC services, which in turn would impact timing of PC referrals. Development of disease-specific quality of EOL care indicators would help ensure the right outcomes are focussed on by all providers.

Within specialist PC, questions remain on the role location and model of delivery play in improving patient QoL and optimizing healthcare resource use near the EOL.<sup>52</sup> For example, how do the different specialist PC services (e.g. palliative home care, palliative consult team) compare in their impact on QoL and EOL resource use outcomes, and does it differ by chronic disease (underlying cause of death). At the level of individual specialist PC services, is there a difference in timing for each? For many patients, specialist PC is a complex, multifaceted intervention, and determining what aspect of the care have the greatest impact on outcomes could help in determining how to deliver the highest quality and highest value EOL care.

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3 **Contributor and guarantor information:** ME, AS, PC, AF contributed to the study concept and design.  
4 PC, AF, KB, T-MP, LS were responsible for acquisition of data. ME, AF, KB, PC, AS were responsible for  
5 data processing and interpretation of the data. ME performed all statistical analyses and drafted the  
6 manuscript. AS, PC, AF, KB, T-MP, LS contributed to the critical revision of the manuscript for important  
7 intellectual content. AS obtained funding and is the guarantor. The corresponding author attests that  
8 all listed authors meet the authorship criteria and that no other authors meeting the criteria have been  
9 omitted.  
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23 **Competing Interests:** All authors have completed the ICMJE uniform disclosure form at  
24 [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare: support from a research grant AS received from the  
25 MSI Foundation to perform this work; no financial relationships with any organizations that might have  
26 an interest in the submitted work in the previous three years; no other relationships or activities that  
27 could appear to have influenced the submitted work.  
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34 **Ethical Approval:** Ethics approval was granted by the University of Calgary Human Research Ethics  
35 Cancer Committee (17-0445).  
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40 **Data Sharing:** The dataset from this study is held securely in coded form at the University of Calgary.  
41 While the conditions of our ethics approval prohibit making the dataset publicly available, access to  
42 anonymized summary-level (aggregate data) may be granted upon request by emailing  
43 [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca). The full dataset creation plan and underlying analytic code are available from  
44 upon request by emailing [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca), understanding that the programmes may rely on  
45 coding templates or macros that are unique AHS and this study.  
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3 The corresponding author (AS) affirms that the manuscript is an honest, accurate, and transparent  
4 account of the study being reported; that no important aspects of the study have been omitted; and  
5 that any discrepancies from the study as planned (and, if relevant, registered) have been explained.  
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### 10 **Dissemination to participants and related patient and public communities:**

11 The results of this study will be disseminated to the academic community through presentation of the  
12 findings at relevant national and international meetings (eg, the annual International Congress on  
13 Palliative Care, European Association for Palliative Care, and Canadian Hospice Palliative Care  
14 Conference); presenting the findings at local rounds (Tom Baker Cancer Centre, Cumming School of  
15 Medicine), and disseminating the results to networks of researchers associated with primary care,  
16 palliative care, and health services research (including the O'Brien Institute for Public Health).

17 Strategies to disseminate the findings to healthcare organisations and policy makers include presenting  
18 the study findings to policy makers at the local, provincial (eg, Alberta Health Services, Alberta Health,  
19 Covenant Health, Cancer Control Alberta), and national levels.  
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30 Figure 1: The relative risk (RR) of experiencing any indicator of hospital-based acute care in the last 30  
31 days of life given specialist PC exposure and timing status. In A) early specialist ( $\geq 90$  days before death),  
32 late specialist PC ( $\geq 8$  but  $< 90$  days before death), and very late specialist PC ( $< 8$  days before death), are  
33 compared to no specialist PC. In B) early specialist ( $\geq 90$  days before death) is compared to late  
34 specialist PC ( $\geq 8$  but  $< 90$  days before death), separating the effect of exposure and timing. Results from  
35 eight disease-specific and 1 all decedent model are shown in panels A and B (9x2 total). Exact values of  
36 estimates plotted are provided in eTables 7 and 9). RRs are adjusted for sex, age at death, year of  
37 death, rurality, income, CCI score, long-term care admission, general home care use, and days spent in  
38 hospital 90-365 days before death. RR's for the all decedent model are also adjusted for chronic  
39 disease group. Plots were constructing using the R package forestplot v1.10. Abbreviations used: COPD  
40 chronic obstructive pulmonary disease, PC palliative care, EOL end-of-life.  
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45 Figure 2: The relative risk (RR) of experiencing individual indicator of hospital-based acute care in the  
46 last 30 days of life given specialist PC exposure. Early specialist ( $\geq 90$  days before death), late specialist  
47 PC ( $\geq 8$  but  $< 90$  days before death), and very late specialist PC ( $< 8$  days before death), are compared to  
48 no specialist PC. Results from eight disease-specific and 1 all decedent model are shown for each  
49 indicator (8x5 total). Exact values of estimates plotted are provided in Table 3 and eTable 8). RRs are  
50 adjusted for sex, age at death, year of death, rurality, income, CCI score, long-term care admission,  
51 general home care use, and days spent in hospital 90-365 days before death. RR's for the all decedent  
52 model are also adjusted for chronic disease group. Plots were constructing using the R package  
53 forestplot v1.10. Abbreviations used: COPD chronic obstructive pulmonary disease, PC palliative care,  
54 EOL end-of-life.  
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## TABLES

**Table 1:** Summary characteristics of decedents at the time of death.

	Overall (N=47,169), n (col %)	Specialist PC prior to death, n (row %)				
		No (n=23,931)	Yes (n= 23,238)	Yes, by timing categories <sup>a</sup>		
				Early (≥90 before death), n=7,736	Late (≥8 but <90 days before death), n=11,373	Very late (<8 days before death), n=4,129
<b>Chronic disease causing death</b>						
Cancer	18263 (39)	2469 (14)	15794 (86)	5743 (36)	8401 (53)	1650 (10)
Heart disease/failure	15206 (32)	12165 (80)	3041 (20)	803 (26)	1257 (41)	981 (32)
Dementia	5010 (11)	3912 (78)	1098 (22)	321 (29)	457 (42)	320 (29)
Stroke	3108 (7)	2166 (70)	942 (30)	121 (13)	353 (37)	468 (50)
COPD	2905 (6)	1787 (62)	1118 (38)	426 (38)	350 (31)	342 (31)
Liver disease	1044 (2)	583 (56)	461 (44)	60 (13)	218 (47)	183 (40)
Neuro-degenerative disease	1015 (2)	523 (52)	492 (48)	191 (39)	202 (41)	99 (20)
Reno-vascular disease/failure	618 (1)	326 (53)	292 (47)	71 (24)	135 (46)	86 (29)
<b>Sex</b>						
Female	23865 (51)	12025 (50)	11840 (50)	4137 (35)	5647 (48)	2056 (17)
Male	23304 (49)	11906 (51)	11398 (49)	3599 (32)	5726 (50)	2073 (18)
<b>Age at death</b>						
< 61	6749 (14)	2672 (40)	4077 (60)	1699 (42)	1914 (47)	464 (11)
61-70	7066 (15)	2806 (40)	4260 (60)	1591 (37)	2110 (50)	559 (13)
71-80	10449 (22)	4658 (45)	5791 (55)	1838 (32)	2988 (52)	965 (17)
81-90	15355 (33)	8573 (56)	6782 (44)	1957 (29)	3294 (49)	1531 (23)
≥91	7550 (16)	5222 (69)	2328 (31)	651 (28)	1067 (46)	610 (26)
<b>Rurality</b>						
Urban	41664 (88)	20352 (49)	21312 (51)	7171 (34)	10353 (49)	3788 (18)
Rural	5505 (12)	3579 (65)	1926 (35)	565 (29)	1020 (53)	341 (18)
<b>Household income quintile</b>						
Q1	13211 (28)	7603 (58)	5608 (42)	1821 (32)	2738 (49)	1049 (19)
Q2	10972 (23)	5371 (49)	5601 (51)	1868 (33)	2776 (50)	957 (17)

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2	Q3	8896 (19)	4324 (49)	4572 (51)	1493 (33)	2253 (49)	826 (18)
3	Q4	6614 (14)	3099 (47)	3515 (53)	1125 (32)	1734 (49)	656 (19)
4	Q5	7476 (16)	3534 (47)	3942 (53)	1429 (36)	1872 (47)	641 (16)
5	<b>CCI score</b>						
6	0	32666 (69)	16787 (51)	15879 (49)	5720 (36)	7857 (49)	2302 (14)
7	1 (score 1-2)	9399 (20)	4512 (48)	4887 (52)	1336 (27)	2392 (49)	1159 (24)
8	2 (score ≥3)	5104 (11)	2632 (52)	2472 (48)	680 (28)	1124 (45)	668 (27)
9	<b>Year of death</b>						
10	2007-2008	8771 (19)	5043 (57)	3728 (43)	1204 (32)	1916 (51)	608 (16)
11	2009-2010	9032 (19)	4795 (53)	4237 (47)	1347 (32)	2193 (52)	697 (16)
12	2011-2012	9195 (19)	4490 (49)	4705 (51)	1600 (34)	2259 (48)	846 (18)
13	2013-2014	9731 (21)	4673 (48)	5058 (52)	1663 (33)	2425 (48)	970 (19)
14	2015-2016	10440 (22)	4930 (47)	5510 (53)	1922 (35)	2580 (47)	1008 (18)
15	<b>Community care use<sup>b</sup></b>						
16	LTC admission, yes	8747 (19)	6419 (73)	2328 (27)	1120 (48)	709 (30)	499 (21)
17	Home care visit, yes	32265 (68)	13171 (41)	19094 (59)	7184 (38)	9152 (48)	2758 (14)
18	Non-palliative home care only	25943 (55)	13171 (51)	12782 (49)	3968 (31)	6195 (48)	2619 (20)
19	<b>Hospital days 90-365 days before death</b>						
20	0 days	28562 (61)	16717 (59)	11845 (41)	2504 (21)	6747 (57)	2594 (22)
21	1-10 days	7255 (15)	2724 (38)	4531 (62)	1640 (36)	2230 (49)	661 (15)
22	11-275 days	11352 (24)	4490 (40)	6862 (60)	3592 (52)	2396 (35)	874 (13)
23	<b>Initiating specialist PC service</b>						
24	Consult team	18915 (40)	--	18915 (81) <sup>d</sup>	5472 (29)	9443 (50)	4000 (21)
25	Inpatient	13402 (71)	--	13402 (71) <sup>c</sup>	3204 (59) <sup>c</sup>	6882 (73) <sup>c</sup>	3316 (83) <sup>c</sup>
26	Community	5355 (28)	--	5355 (28) <sup>c</sup>	2232 (41) <sup>c</sup>	2491 (26) <sup>c</sup>	632 (16) <sup>c</sup>
27	Emergency department	158 (1)	--	158 (1) <sup>c</sup>	36 (1) <sup>c</sup>	70 (1) <sup>c</sup>	52 (1) <sup>c</sup>
28	TPCU	116 (<1)	--	116 (0) <sup>d</sup>	32 (28)	72 (62)	12 (10)
29	Pain and symptom clinic	638 (1)	--	638 (3) <sup>d</sup>	469 (74)	163 (26)	6 (1)
30	Palliative home care	3568 (8)	--	3569 (15) <sup>d</sup>	1763 (49)	1695 (47)	111 (3)

PC palliative care, COPD chronic lower respiratory disease, Q quintile, CCI Charlson Comorbidity Index, LTC long term care, TPCU tertiary PC unit.

<sup>a</sup>Row percentages shown are calculated of those who received specialist PC, unless otherwise indicated.

<sup>b</sup>Evaluated at any time prior to death.

<sup>c</sup>Column percentage are shown, calculated of those who received a consult team visit within specialist PC strata.

<sup>d</sup>Column percentage are shown, calculated of those who received any specialist PC.

**Table 2:** Hospital-based acute care use in the last 30-days of life.

	Hospital-based acute care in the last 30 days of life				Death in an acute care hospital or bed	Indicators aggregated
	> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital		
<b>All decedents</b>	4224 (9)	3861 (8)	3073 (7)	9903 (21)	19679 (42)	22712 (48)
<b>Cause of death</b>						
Cancer	1960 (11)	2007 (11)	607 (3)	4645 (25)	7416 (11)	9281 (51)
Heart disease, failure	1162 (8)	927 (6)	1533 (10)	2418 (16)	6337 (12)	6904 (45)
Dementia, senility	143 (3)	126 (3)	16 (0)	673 (13)	1020 (10)	1259 (25)
Stroke	339 (11)	227 (7)	312 (10)	644 (21)	1846 (19)	1958 (63)
COPD	323 (11)	298 (10)	247 (9)	707 (24)	1590 (15)	1724 (59)
Liver disease	168 (16)	180 (17)	271 (26)	448 (43)	792 (15)	811 (78)
Neuro-degenerative diseases	57 (6)	46 (5)	42 (4)	180 (18)	367 (16)	425 (42)
Reno-vascular disease, failure	72 (12)	50 (8)	45 (7)	188 (30)	311 (10)	350 (57)

*COPD* chronic lower respiratory disease, *EOL* end-of-life, *ED* emergency department, *ICU* intensive care unit.

**Table 3:** Relatives risks and risk differences indicating the association between specialist PC use and indicators of hospital-based acute care in the last 30 days of life for all decedents.

		Indicators of hospital-based acute care in the last 30 days of life					
		> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital	Death in an acute care	Aggregate hospital care indicator
<b>All decedents (n=47,169)</b>							
<b>No specialist PC</b>	<i>reference</i>	<i>reference</i>	<i>reference</i>	<i>reference</i>	<i>reference</i>	<i>reference</i>	<i>reference</i>
<b>Early specialist PC (≥90 before death)</b>	RR (95% CI); p	0.96 (0.95-0.97); p<0.001	0.98 (0.98-0.99); p<0.001	0.91 (0.90-0.91); p<0.001	1.01 (1.00-1.02); p=0.004	0.84 (0.84-0.85); p<0.001	0.69 (0.66-0.71); p<0.001
	Absolute RD (95% CI); p	0.04 (0.04-0.05); p<0.001	0.02 (0.01-0.02); p<0.001	0.10 (0.10-0.11); p<0.001	0.02 (0.01-0.03); p=0.003	0.23 (0.22-0.25); p<0.001	0.16 (0.15-0.17); p<0.001
<b>Late specialist PC (≥8 but &lt;90 days before death)</b>	RR (95% CI); p	0.98 (0.97-0.99); p<0.001	1.04 (1.03-1.05); p<0.001	0.90 (0.90-0.91); p<0.001	1.16 (1.15-1.17); p<0.001	0.88 (0.87-0.89); p<0.001	0.99 (0.96-1.01); p=0.26
	Absolute RD (95% CI); p	0.02 (0.01-0.03); p<0.001	0.04 (0.04-0.05); p<0.001	0.11 (0.10-0.12); p<0.001	0.19 (0.17-0.20); p<0.001	0.19 (0.17-0.20); p<0.001	0.01 (0.00-0.02); p=0.067
<b>Very late specialist PC (&lt;8 days before death)</b>	RR (95% CI); p	1.05 (1.04-1.06); p<0.001	1.05 (1.04-1.06); p<0.001	0.96 (0.95-0.97); p<0.001	1.12 (1.10-1.13); p<0.001	1.13 (1.12-1.14); p<0.001	1.51 (1.48-1.54); p<0.001
	Absolute RD (95% CI); p	0.05 (0.04-0.07); p<0.001	0.05 (0.04-0.06); p<0.001	0.04 (0.03-0.05); p<0.001	0.13 (0.12-0.15); p<0.001	0.21 (0.19-0.22); p<0.001	0.28 (0.26-0.29); p<0.001

PC palliative care, RR relative risk, RD risk difference, CI confidence interval, ED emergency department, ICU intensive care unit.

R Rs and RDs are adjusted for underlying chronic disease causing death, sex, age at death, year of death, rurality, income, CCI score, long-term care admission, general home care use, and days spent in hospital 90-365 days before death.

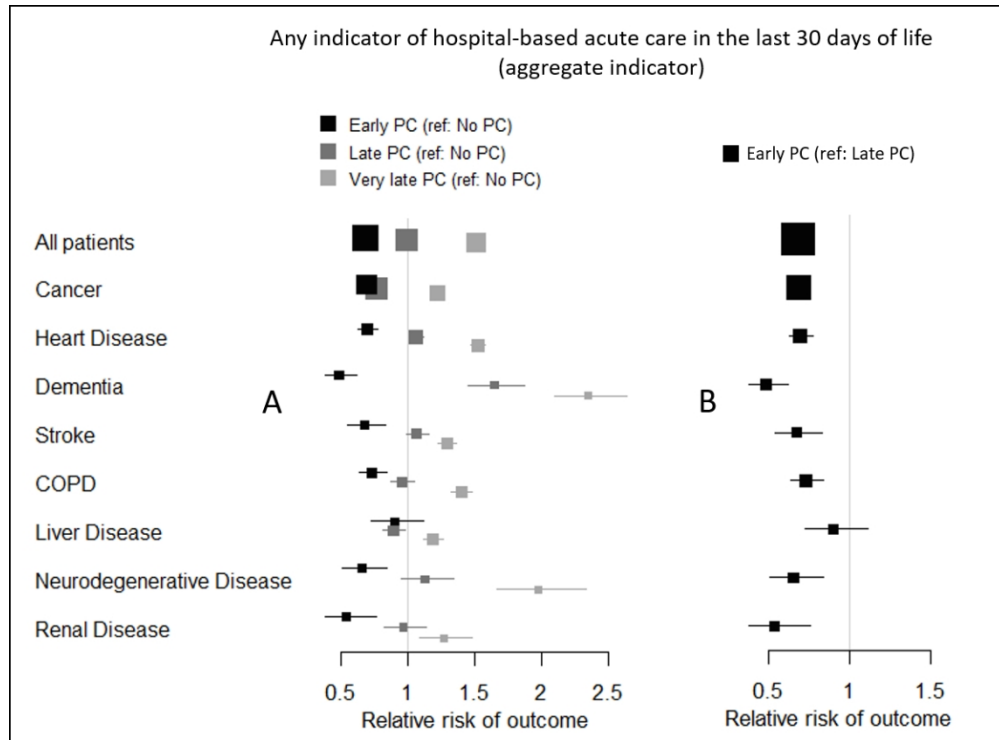
Separate models were run for each of the 5 individual and 1 aggregate indicator of hospital-based acute care, for RR and RD (total of 12 models).

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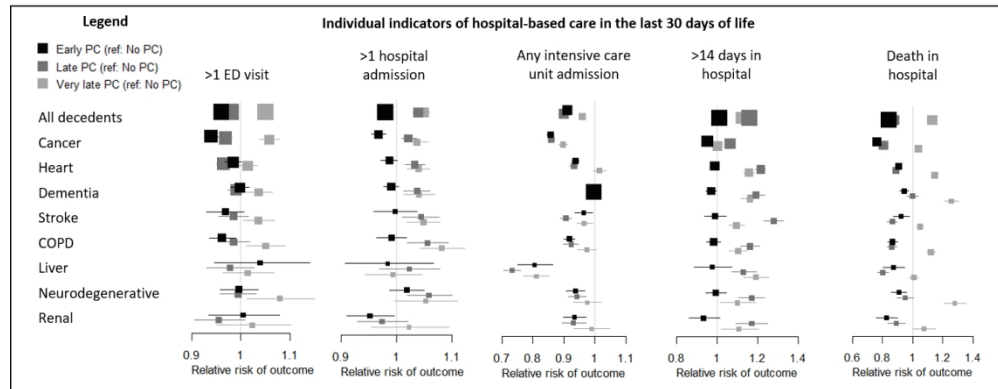
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The relative risk (RR) of experiencing any indicator of hospital-based acute care in the last 30 days of life given specialist PC exposure and timing status. In A) early specialist ( $\geq 90$  days before death), late specialist PC ( $\geq 8$  but  $< 90$  days before death), and very late specialist PC ( $< 8$  days before death), are compared to no specialist PC. In B) early specialist ( $\geq 90$  days before death) is compared to late specialist PC ( $\geq 8$  but  $< 90$  days before death), separating the effect of exposure and timing. Results from eight disease-specific and 1 all decedent model are shown in panels A and B (9x2 total). Exact values of estimates plotted are provided in eTables 7 and 9). RRs are adjusted for sex, age at death, year of death, rurality, income, CCI score, long-term care admission, general home care use, and days spent in hospital 90-365 days before death. RR's for the all decedent model are also adjusted for chronic disease group. Plots were constructed using the R package forestplot v1.10. Abbreviations used: COPD chronic obstructive pulmonary disease, PC palliative care, EOL end-of-life.





The relative risk (RR) of experiencing individual indicator of hospital-based acute care in the last 30 days of life given specialist PC exposure. Early specialist ( $\geq 90$  days before death), late specialist PC ( $\geq 8$  but  $< 90$  days before death), and very late specialist PC ( $< 8$  days before death), are compared to no specialist PC. Results from eight disease-specific and 1 all decedent model are shown for each indicator (8x5 total). Exact values of estimates plotted are provided in Table 3 and eTable 8). RRs are adjusted for sex, age at death, year of death, rurality, income, CCI score, long-term care admission, general home care use, and days spent in hospital 90-365 days before death. RR's for the all decedent model are also adjusted for chronic disease group. Plots were constructing using the R package forestplot v1.10. Abbreviations used: COPD chronic obstructive pulmonary disease, PC palliative care, EOL end-of-life.

## ELECTRONIC SUPPLEMENTARY MATERIAL

**eTable 1:** Data sources for each variable in the study

Variables	Database-level	Database Name
<b>Specialist PC</b>		
Receipt of PC consult team visit (institutional, community-based)	Regional, CZ, AHS	Sunrise Clinical Manager & Pathways Continuing Care Application Data
Receipt of palliative home care visit	Regional, CZ, AHS	PARIS
Admission to a tertiary PC unit	Regional, CZ, AHS	Sunrise Clinical Manager
Admission to a PC hospice bed	Regional, CZ, AHS	Sunrise Clinical Manager & Pathways Continuing Care Application Data
Use of PC pain and symptom clinic (cancer patients only)	Regional, CZ, AHS	Alberta Cancer Registry: ARIA
<b>Hospital-based acute care at the end-of-life</b>		
Death in an acute care hospital or bed (including ED)	National, CIHI	Discharge Abstract Database & National Ambulatory Care Reporting System (DAD & NACRS)
Emergency department visits in the last 30 days of life	National, CIHI	NACRS
Hospital admissions in the last 30 days of life	National, CIHI	DAD
Days of hospitalization in the last 30 days of life	National, CIHI	DAD
Intensive care unit (ICU) admissions in the last 30 days of life	National, CIHI	DAD
<b>Covariates</b>		
Long term care use (based on admission date)	Regional, CZ, AHS	Ambulatory Continuing Care Information System
General home care use (based on start date)	Regional, CZ, AHS	PARIS
Sex	Provincial, AH	Longitudinal Demographic Profile (LDP)
Rurality (urban versus rural)	Provincial, AH	LDP
Age at death, in 5 year groups (for anonymity purposes)	Provincial, AH	LDP
Median neighbourhood income quintiles based on postal code	National, Provincial, AH	Census 2016 & LDP (for most recent postal code)
Year of death	Provincial, AH	Vital Statistics
Underlying cause of death	Provincial, AH	Vital Statistics
Days spent in hospital 90-365 days before death	National, CIHI	DAD

CIHI Canadian Institute for Health Information, CZ Calgary Zone, AHS Alberta Health Services, AH Alberta Health, PC palliative care

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**eTable 2:** ICD-10 codes used to assign chronic disease categories.

Conditions included	ICD-10 Codes
All deaths from malignant neoplasms	C00-C97
Heart disease and heart failure	I00-I52 (excluding I12/I13-renal)
Dementia, vascular dementia, Alzheimer’s disease, senility	F01, F03, G30, R54
Haemorrhagic, ischaemic and unspecified stroke	I60-I69
Chronic lower respiratory disease, respiratory failure	J40-J47 & J96
Liver Disease	K70-K77
Neurodegenerative	G10, G20, G35, G122, G90.3, G23.1
Reno-vascular disease, renal failure	I12, I13, N17, N18, N28

**eTable 3:** Summary characteristics of decedents at the time of death by underlying cause of death

	Cancer (N=18,263, n (col %))	Heart disease/ failure (N=15,206), n (col %)	Dementia, (N=5,010), n (col %)	Stroke (N=3,108), n (col %)	COPD (N=2,905), n (col %)	Liver disease (N=1,044), n (col %)	Neuro- degenerative diseases (N=1,015), n (col %)	Reno- vascular disease/ failure (N=618), n (col %)
<b>Sex</b>								
Female	8813 (48)	7250 (48)	3275 (65)	1848 (59)	1476 (51)	407 (39)	469 (46)	327 (53)
Male	9450 (52)	7956 (52)	1735 (35)	1260 (41)	1429 (49)	637 (61)	546 (54)	291 (47)
<b>Age at death (years)</b>								
< 61	3969 (22)	1635 (11)	16 (0)	256 (8)	151 (5)	512 (49)	176 (17)	34 (6)
61-70	4052 (22)	1829 (12)	95 (2)	213 (7)	376 (13)	269 (26)	185 (18)	47 (8)
71-80	4843 (27)	3021 (20)	566 (11)	603 (19)	861 (30)	162 (16)	275 (27)	118 (19)
81-90	4382 (24)	5424 (36)	2435 (49)	1306 (42)	1134 (39)	87 (8)	307 (30)	280 (45)
≥91	1017 (6)	3297 (22)	1898 (38)	730 (23)	383 (13)	14 (1)	72 (7)	139 (22)
<b>Rurality</b>								
Urban	16164 (89)	13401 (88)	4505 (90)	2710 (87)	2532 (87)	898 (86)	897 (88)	557 (90)
Rural	2099 (11)	1805 (12)	505 (10)	398 (13)	373 (13)	146 (14)	118 (12)	61 (10)
<b>Household income quintile</b>								
Q1 - Lowest	4560 (25)	4656 (31)	1335 (27)	919 (30)	968 (33)	355 (34)	246 (24)	172 (28)
Q2	4504 (25)	3462 (23)	1003 (20)	701 (23)	698 (24)	265 (25)	185 (18)	154 (25)
Q3	3455 (19)	2875 (19)	947 (19)	594 (19)	524 (18)	178 (17)	207 (20)	116 (19)
Q4	2698 (15)	2005 (13)	757 (15)	428 (14)	353 (12)	132 (13)	160 (16)	81 (13)
Q5 - Highest	3046 (17)	2208 (15)	968 (19)	466 (15)	362 (12)	114 (11)	217 (21)	95 (15)
<b>CCI score</b>								
0	14088 (77)	8881 (58)	4264 (85)	2068 (67)	1703 (59)	644 (62)	767 (76)	251 (41)
1 (score 1-2)	3186 (17)	3435 (23)	591 (12)	721 (23)	764 (26)	293 (28)	194 (19)	215 (35)
2 (score ≥3)	989 (5)	2890 (19)	155 (3)	319 (10)	438 (15)	107 (10)	54 (5)	152 (25)
<b>Year of death</b>								
2007-2008	3464 (19)	2892 (19)	722 (14)	649 (21)	562 (19)	192 (18)	170 (17)	120 (19)

2009-2010	3588 (20)	2975 (20)	850 (17)	642 (21)	508 (17)	181 (17)	169 (17)	119 (19)
2011-2012	3556 (19)	3016 (20)	950 (19)	610 (20)	565 (19)	200 (19)	199 (20)	99 (16)
2013-2014	3697 (20)	3135 (21)	1172 (23)	578 (19)	586 (20)	224 (21)	215 (21)	124 (20)
2015-2016	3958 (22)	3188 (21)	1316 (26)	629 (20)	684 (24)	247 (24)	262 (26)	156 (25)
<b>Community-care use<sup>a</sup></b>								
LTC admission, yes	3068 (17)	2789 (18)	806 (16)	797 (26)	650 (22)	427 (41)	152 (15)	58 (9)
Home care visit, yes	14410 (79)	8688 (57)	3557 (71)	2152 (69)	1692 (58)	795 (76)	493 (49)	478 (77)
Non-palliative home care only	8455 (46)	8511 (56)	3543 (71)	2073 (67)	1668 (57)	789 (76)	474 (47)	440 (71)
<b>Hospital days 90-365 days before death</b>								
0 days	9568 (52)	1521 (66)	3690 (74)	2200 (71)	10105 (52)	542 (52)	646 (64)	290 (47)
1-10 days	3795 (21)	432 (12)	358 (7)	346 (11)	1898 (15)	178 (17)	141 (14)	107 (17)
11-275 days	4900 (27)	952 (21)	962 (19)	562 (18)	3203 (33)	324 (31)	228 (22)	221 (36)
<b>Initiating specialist PC service<sup>c</sup></b>								
Consult team	11636 (74)	2948 (97)	1092 (99)	928 (99)	1087 (97)	449 (97)	491 (100)	284 (97)
Inpatient <sup>b</sup>	8036 (69)	2195 (74)	738 (68)	830 (89)	765 (70)	376 (84)	259 (53)	203 (71)
Community <sup>b</sup>	3482 (30)	739 (25)	344 (32)	93 (10)	317 (29)	73 (16)	228 (46)	79 (28)
ED <sup>b</sup>	118 (1)	14 (0)	10 (1)	5 (1)	5 (0)	0 (0)	4 (1)	2 (1)
TPCU	113 (1)	3 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Pain and symptom clinic	637 (4)	0 (0)	0 (0)	1 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Palliative home care	3408 (22)	90 (3)	6 (1)	13 (1)	31 (3)	12 (3)	1 (0)	8 (3)

PC palliative care, COPD chronic lower respiratory disease, Q quintile, CCI Charlson Comorbidity Index, LTC long term care, TPCU tertiary PC unit.

<sup>a</sup> Evaluated at any time prior to death.

<sup>b</sup> Percentages are calculated of those who received a PC consult team visit, within chronic disease strata.

<sup>c</sup> Percentages are calculated of those who received specialist PC (early, late, or very late), unless otherwise indicated.

**eTable 4:** The proportion of decedents exposed to specialist palliative care (at any time) by year.

Year	Overall	Cancer	Heart disease/ failure	COPD	Dementia	Stroke	Liver disease	Neuro-degenerative diseases	Reno-vascular disease/ failure
2007	41.6	80.9	11.7	21.7	10.3	19.1	26.1	34.6	48.1
2008	43.4	83.9	13.4	24.3	13.2	21.3	26.0	32.6	45.6
2009	46.1	85.1	14.7	30.4	17.9	26.4	44.8	57.8	42.1
2010	47.7	85.3	17.0	33.9	18.9	30.0	36.5	41.9	41.9
2011	50.1	88.3	20.4	40.1	25.2	29.7	39.2	61.0	37.3
2012	52.3	87.8	21.7	42.9	27.0	40.1	45.6	51.5	56.3
2013	51.0	87.8	23.6	43.2	20.7	34.4	51.8	54.3	49.2
2014	52.9	89.5	25.2	47.5	25.7	34.8	51.8	43.6	44.3
2015	53.5	88.1	25.5	49.6	27.1	35.7	48.4	56.4	48.6
2016	52.1	87.4	25.3	45.7	23.7	32.9	62.0	47.4	56.0
% $\Delta^a$	<b>+10.3</b>	<b>+5.3</b>	<b>+12.8</b>	<b>+24.5</b>	<b>+13.5</b>	<b>+14.2</b>	<b>+29</b>	<b>+17.6</b>	<b>+5.9</b>

<sup>a</sup> Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear increase in the proportion of decedents with any specialist PC exposure prior to death (Chi-squared Test for Trend in Proportions was  $p < 0.05$ ).

**eTable 5:** The proportion of decedents exposed to specialist palliative care early (≥90 days before death) by year.

	Overall	Cancer	Heart disease, failure	Dementia, senility	Stroke	COPD	Liver disease	Neuro-degenerative diseases	Renal disease/failure
2007	13.1	29.0	1.7	0.9	0.9	7.1	2.2	7.4	7.7
2008	14.4	30.6	3.4	2.5	3.3	6.5	1.0	14.6	2.9
2009	14.1	29.4	3.4	3.0	2.7	7.4	3.1	18.1	1.3
2010	15.7	29.9	4.3	4.0	4.8	15.5	4.7	24.4	1.5
2011	17.6	34.1	5.9	7.4	3.1	15.2	7.2	20.0	1.8
2012	17.2	32.1	5.5	7.7	3.5	15.7	5.8	23.2	1.8
2013	16.5	31.5	6.1	5.1	5.1	16.9	7.9	21.0	1.4
2014	17.7	32.3	7.1	8.4	5.3	17.3	9.1	16.4	1.8
2015	18.1	31.6	7.1	10.5	4.9	22.1	5.6	26.4	1.9
2016	18.7	33.7	7.7	8.7	5.6	19.7	9.1	15.8	1.1
%Δ <sup>a</sup>	<b>4.7</b>	<b>2.8</b>	<b>4.8</b>	<b>7.8</b>	<b>3.1</b>	<b>14.2</b>	<b>5.7</b>	9.1	1.8

<sup>a</sup> Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear increase in the proportion of decedents with any specialist PC exposure prior to death (Chi-squared Test for Trend in Proportions was p<0.05).

**eTable 6:** The proportion of the decedents with hospital-based acute care in the last 30 days of life

Hospital-based acute care in the last 30 days of life						
Year	> 1 ED visit in last 30 days of life	> 1 hospital admission in last 30 days of life	> 14 days in hospital in last 30 days of life	Any ICU/SCU admission in last 30 days of life	Death in an acute care hospital or bed	Aggregate hospital care indicator
2007	8.2	7.8	21.8	7.8	44.1	49.3
2008	9.0	6.7	21.5	7.0	41.8	48.2
2009	8.3	6.7	19.8	7.2	41.6	48.0
2010	8.5	7.7	21.0	6.1	41.1	46.5
2011	8.3	9.1	21.9	6.0	40.0	47.4
2012	8.8	9.1	21.3	6.6	41.6	48.9
2013	9.3	9.6	21.8	6.5	44.6	50.1
2014	9.9	9.6	22.0	6.0	42.7	49.5
2015	9.6	8.4	20.6	6.0	40.1	47.5
2016	9.3	7.2	18.6	6.2	39.9	46.3
% $\Delta^a$	<b>+0.8</b>	<b>+0.5</b>	<b>-2.0</b>	<b>-1.3</b>	<b>-2.9</b>	-1.8

<sup>a</sup> Percent change in the proportion of decedents in 2007/2008 versus 2015/2016.

Bold indicates that as year increased, there was a linear change (increase or decrease) in the proportion of decedents who experienced the acute care use indicator indicated (Chi-squared Test for Trend in Proportions was  $p < 0.05$ ). ED emergency department, ICU intensive care unit.



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**eTable 7:** Relatives risks and risk differences indicating the association between specialist PC timing (early versus late) and hospital-based care in the last 30 days of life for all decedents.

		Indicators of hospital-based acute care in the last 30 days of life					Aggregate hospital care indicator
		> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital	Death in an acute care	
Decedents that received late-early specialist PC (n=19,109)							
<b>Late specialist PC (≥8 but &lt;90 days before death)</b>		reference	reference	reference	reference	reference	reference
<b>Early specialist PC (≥90 before death)</b>	RR (95% CI); p	0.97 (0.97-0.98); p<0.001	0.95 (0.94-0.95); p<0.001	0.99 (0.98-0.99); p<0.001	0.87 (0.87-0.88); p<0.001	0.95 (0.94-0.96); p<0.001	0.68 (0.66-0.70); p<0.001
	RD (95% CI); p	0.03 (0.02-0.04); p<0.001	0.06 (0.05-0.07); p<0.001	0.01 (0.00-0.01); p<0.001	0.17 (0.16-0.18); p<0.001	0.07 (0.06-0.08); p<0.001	0.16 (0.15-0.18); p<0.001

PC palliative care, RR relative risk, RD risk difference, CI confidence interval, ED emergency department, ICU intensive care unit.

RRs and RDs are adjusted for underlying chronic disease causing death, sex, age at death, year of death, rurality, income, CCI score, long-term care admission, general home care use, and days spent in hospital 90-365 days before death.

Separate models were run for each of the 5 individual and 1 aggregate indicator of hospital-based acute care, for RR and RD (total of 12 models).

**eTable 8:** The association between specialist PC timing (late, early, versus none) and hospital-based care in the last 30 days of life for eight chronic-condition specific analyses.

		Indicators of hospital-based acute care in the last 30 days of life					Aggregate hospital care indicator
		> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital	Death in an acute care	
<b>Cancer decedents only model, n=18,263</b>							
	None	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p 0.94 (0.93-0.95); p<0.001	0.97 (0.96-0.98); p<0.001	0.86 (0.85-0.87); p<0.001	0.95 (0.94-0.97); p<0.001	0.76 (0.75-0.77); p<0.001	0.53 (0.5-0.55); p<0.001
	Late	RR (95% CI); p 0.97 (0.96-0.98); p<0.001	1.02 (1.01-1.04); p<0.001	0.86 (0.85-0.87); p<0.001	1.06 (1.05-1.08); p<0.001	0.81 (0.79-0.82); p<0.001	0.76 (0.74-0.79); p<0.001
	Very Late	RR (95% CI); p 1.06 (1.04-1.08); p<0.001	1.04 (1.02-1.06); p<0.001	0.90 (0.88-0.91); p<0.001	1.00 (0.98-1.02); p=0.89	1.04 (1.02-1.05); p<0.001	1.21 (1.17-1.26); p<0.001
<b>Heart disease/failure decedents only model, n=15,206</b>							
	None	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p 0.98 (0.97-1); p=0.062	0.99 (0.97-1); p=0.092	0.94 (0.93-0.95); p=0	0.99 (0.97-1.01); p=0.293	0.91 (0.88-0.93); p<0.001	0.77 (0.7-0.85); p<0.001
	Late	RR (95% CI); p 0.96 (0.95-0.98); p<0.001	1.03 (1.02-1.05); p<0.001	0.93 (0.92-0.94); p<0.001	1.22 (1.19-1.24); p<0.001	0.89 (0.87-0.91); p<0.001	1.06 (1.01-1.11); p=0.03
	Very Late	RR (95% CI); p 1.01 (0.99-1.03); p=0.152	1.04 (1.02-1.06); p<0.001	1.02 (0.99-1.04); p=0.142	1.16 (1.13-1.19); p<0.001	1.15 (1.13-1.17); p<0.001	1.52 (1.46-1.58); p<0.001
<b>Dementia decedents only model, n=5,010</b>							
	None	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p 1 (0.98-1.02); p=0.828	0.99 (0.98-1); p=0.161	1 (0.99-1); p<0.001	0.97 (0.94-1); p=0.043	0.94 (0.91-0.98); p<0.001	0.85 (0.68-1.06); p=0.15
	Late	RR (95% CI); p 0.99 (0.97-1.01); p=0.207	1.04 (1.01-1.06); p=0.002	1 (0.99-1.01); p=0.723	1.19 (1.15-1.24); p<0.001	1 (0.97-1.04); p=0.998	1.65 (1.45-1.87); p<0.001
	Very Late	RR (95% CI); p 1.04 (1.01-1.06); p=0.013	1.04 (1.01-1.07); p=0.004	0.99 (0.99-1); p=0.001	1.16 (1.12-1.21); p<0.001	1.26 (1.1-1.3); p<0.001	2.35 (2.1-2.63); p<0.001
<b>Stroke decedents only model, n=3,108</b>							
	None	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p 0.97 (0.93-1.01); p=0.108	1 (0.96-1.04); p=0.91	0.96 (0.94-0.99); p=0.016	0.99 (0.94-1.04); p=0.713	0.93 (0.87-0.98); p=0.007	0.76 (0.63-0.93); p=0.006

1								
2	Late	RR (95% CI); p	0.99 (0.96-1.02); p=0.341	1.04 (1.01-1.08); p=0.008	0.91 (0.89-0.92); p<0.001	1.28 (1.23-1.33); p<0.001	0.86 (0.83-0.9); p<0.001	1.06 (0.98-1.15); p=0.124
3								
4	Very Late	RR (95% CI); p	1.04 (1-1.07); p=0.023	1.05 (1.02-1.08); p=0.001	0.97 (0.94-0.99); p=0.01	1.1 (1.06-1.14); p<0.001	1.05 (1.02-1.08); p<0.001	1.29 (1.22-1.36); p<0.001
5								
6	COPD decedents only model, n=2,905							
7	None		reference	reference	reference	reference	reference	reference
8								
9	Early	RR (95% CI); p	0.96 (0.94-0.99); p=0.006	0.99 (0.96-1.02); p=0.489	0.92 (0.9-0.94); p<0.001	0.98 (0.95-1.02); p=0.36	0.87 (0.84-0.9); p<0.001	0.73 (0.65-0.82); p<0.001
10								
11	Late	RR (95% CI); p	0.99 (0.95-1.02); p=0.368	1.06 (1.02-1.09); p=0.003	0.92 (0.9-0.95); p<0.001	1.16 (1.12-1.21); p<0.001	0.86 (0.83-0.9); p<0.001	0.95 (0.87-1.04); p=0.302
12								
13	Very Late	RR (95% CI); p	1.05 (1.01-1.09); p=0.01	1.08 (1.04-1.12); p<0.001	0.97 (0.94-1); p=0.092	1.1 (1.06-1.15); p<0.001	1.12 (1.09-1.15); p<0.001	1.4 (1.32-1.48); p<0.001
14								
15	Liver disease decedents only model, n=1,044							
16	None		reference	reference	reference	reference	reference	reference
17								
18	Early	RR (95% CI); p	1.04 (0.95-1.14); p=0.425	0.98 (0.91-1.07); p=0.701	0.81 (0.75-0.86); p<0.001	0.98 (0.89-1.08); p=0.623	0.87 (0.8-0.95); p=0.001	0.81 (0.66-0.99); p=0.036
19								
20	Late	RR (95% CI); p	0.98 (0.93-1.03); p=0.365	1.02 (0.97-1.08); p=0.411	0.73 (0.7-0.76); p<0.001	1.13 (1.07-1.19); p<0.001	0.8 (0.77-0.84); p<0.001	0.89 (0.81-0.98); p=0.014
21								
22	Very Late	RR (95% CI); p	1.01 (0.96-1.07); p=0.589	0.99 (0.94-1.05); p=0.815	0.81 (0.77-0.85); p<0.001	1.19 (1.13-1.26); p<0.001	1.01 (0.98-1.04); p=0.6	1.19 (1.12-1.26); p<0.001
23								
24	Neuro-degenerative disease decedents only model, n=1,105							
25	None		reference	reference	reference	reference	reference	reference
26								
27	Early	RR (95% CI); p	1 (0.96-1.04); p=0.837	1.02 (0.99-1.05); p=0.229	0.94 (0.91-0.97); p<0.001	0.99 (0.94-1.05); p=0.807	0.91 (0.86-0.96); p=0.001	0.73 (0.58-0.92); p=0.008
28								
29	Late	RR (95% CI); p	0.99 (0.96-1.03); p=0.75	1.06 (1.02-1.1); p=0.003	0.94 (0.92-0.97); p<0.001	1.17 (1.11-1.24); p<0.001	0.95 (0.9-1.01); p=0.008	1.12 (0.95-1.34); p=0.181
30								
31	Very Late	RR (95% CI); p	1.08 (1.01-1.15); p=0.02	1.05 (1-1.11); p=0.063	0.97 (0.93-1.02); p=0.275	1.1 (1.02-1.19); p=0.016	1.28 (1.21-1.36); p<0.001	1.97 (1.67-2.33); p<0.001
32								
33	Reno-vascular disease/failure decedents only model, n=618							
34	None		reference	reference	reference	reference	reference	reference
35								
36	Early	RR (95% CI); p	1 (0.94-1.08); p=0.905	0.95 (0.91-1); p=0.031	0.93 (0.9-0.97); p=0.001	0.93 (0.86-1.01); p=0.098	0.83 (0.76-0.9); p<0.001	0.6 (0.43-0.84); p=0.003
37								
38	Late	RR (95% CI); p	0.96 (0.91-1.01); p=0.095	0.97 (0.93-1.02); p=0.278	0.93 (0.89-0.97); p=0.001	1.17 (1.1-1.25); p<0.001	0.89 (0.83-0.95); p=0.001	0.96 (0.82-1.13); p=0.649
39								
40	Very Late	RR (95% CI); p	1.02 (0.95-1.1); p=0.547	1.02 (0.96-1.1); p=0.516	0.99 (0.93-1.05); p=0.727	1.11 (1.02-1.2); p=0.014	1.07 (1.15); p=0.044	1.27 (1.08-1.48); p=0.003
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1  
2 *PC* palliative care, *RR* relative risk, *CI* confidence interval, *COPD* chronic lower respiratory disease, *ED* emergency department, *ICU* intensive  
3 care unit

4 Early specialist *PC* exposure was defined as  $\geq 90$  before death, late as  $\geq 8$  but  $< 90$  days before death, and very late as  $\geq 4$  days before death.

5 *RRs* are adjusted for sex, age at death, year of death, rurality, income, *CCI* score, long-term care admission, general home care use, and days  
6 spent in hospital 90-365 days before death.

7  
8 Separate models were run for each of the 5 individual and 1 aggregate indicator of hospital-based acute care, for each chronic disease group  
9 (total of  $6 \times 8 = 48$  models).

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**eTable 9:** The association between specialist PC timing (early versus late) and hospital-based care in the last 30 days of life for eight chronic-condition specific analyses.

		Indicators of hospital-based acute care in the last 30 days of life					Aggregate hospital care indicator
		> 1 ED visit	> 1 hospital admission	Any ICU admission	> 14 days in hospital	Death in acute care	
<b>Cancer decedents only model, n=2,060</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	0.97 (0.96-0.97); p=0	0.95 (0.94-0.95); p=0	0.99 (0.99-1); p=0	0.9 (0.88-0.91); p=0	0.94 (0.92-0.95); p=0
							0.69 (0.66-0.72); p=0
<b>Heart disease/failure decedents only model, n=14,144</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	1.01 (0.99-1.03); p=0.26	0.95 (0.93-0.97); p=0	0.97 (0.96-0.99); p=0	0.82 (0.8-0.85); p=0	0.99 (0.98-1.02); p=0.403
							0.69 (0.63-0.77); p=0
<b>Dementia decedents only model, n=776</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	1.01 (0.98-1.04); p=0.455	0.96 (0.93-0.98); p=0.003	1 (0.99-1); p=0.103	0.81 (0.77-0.85); p=0	0.92 (0.89-0.96); p=0.001
							0.48 (0.38-0.62); p=0
<b>Stroke decedents only model, n=474</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	0.96 (0.91-1.01); p=0.089	0.97 (0.91-1.02); p=0.256	1.03 (0.99-1.07); p=0.099	0.8 (0.74-0.85); p=0	1.05 (0.99-1.12); p=0.025
							0.67 (0.54-0.83); p=0
<b>COPD decedents only model, n=2,905</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	0.97 (0.93-1.01); p=0.112	0.93 (0.89-0.97); p=0.001	0.98 (0.96-1); p=0.102	0.83 (0.79-0.87); p=0	0.98 (0.96-1.03); p=0.002
							0.73 (0.63-0.84); p=0
<b>Liver disease decedents only model, n=278</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	1.06 (0.96-1.16); p=0.254	0.96 (0.88-1.04); p=0.327	1.09 (1.02-1.16); p=0.013	0.85 (0.77-0.94); p=0.002	1.07 (0.99-1.17); p=0.008
							0.9 (0.72-1.11); p=0.332
<b>Neuro-degenerative disease decedents only model, n=393</b>							
	Late	reference	reference	reference	reference	reference	reference
	Early	RR (95% CI); p	1 (0.96-1.04); p=0.945	1 (0.97-1.02); p=0.713	0.65 (0.51-0.84); p=0.001	0.94 (0.88-1.01); p=0.087	0.88 (0.83-0.93); p=0.007
							0.96 (0.92-1); p=0.055
<b>Reno-vascular disease/failure decedents only model, n=206</b>							

1			reference	reference	reference	reference	reference	reference
2	Late		1.03 (0.96-1.1);	0.96 (0.91-	0.98 (0.94-	0.76 (0.7-0.84);	0.9 (0.82-0.99);	0.54 (0.38-
3	Early	RR (95% CI); p	p=0.476	1.01); p=0.112	1.02); p=0.308	p=0	p=0.031	0.76); p=0

RR relative risk, CI confidence interval, COPD chronic lower respiratory disease, ED emergency department, ICU intensive care unit  
 Early specialist PC exposure was defined as ≥90 before death, late as ≥8 but <90 days before death (reference group)  
 RRs are adjusted for sex, age at death, year of death, rurality, income, CCI score, long-term care admission, general home care use, and  
 days spent in hospital 90-365 days before death.  
 Separate models were run for each of the 5 individual and 1 aggregate indicator of hospital-based acute care, for each chronic disease  
 group (total of 6\*8=48 models).

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