

# BMJ Open Hospital-based acute care in the last 30 days of life among patients with chronic disease that received early, late or no specialist palliative care: a retrospective cohort study of eight chronic disease 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 (chronic obstructive pulmonary disease (COPD)), (6) liver disease, (7) neurodegenerative disease and (8) renovascular 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 hospitalisation, any intensive care unit (ICU) admission, or death in hospital. Relative risk (RR) and risk difference (RD) 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 with those with no PC exposure (RR 0.69, 95% CI 0.66 to 0.71; RD 0.16, 95% CI 0.15 to 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 to 0.33) and renal disease-specific analyses (RR 0.60, 95% CI 0.43 to 0.84; RD 0.22, 95% CI 0.11 to 0.34), but a ~25% risk reduction was observed for each of heart disease, COPD, neurodegenerative 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 programme operating in institutions and 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 (eg, family physician) is not included.
- Caution is needed when generalising results to other jurisdictions, particularly those that do not have a well-developed specialist palliative care programme.

## 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 WHO defines PC as ‘an approach that improves the quality of life (QoL) 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 patients with terminal cancer, 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 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 (chronic obstructive pulmonary disease (COPD)), advanced liver disease, neurodegenerative diseases and renovascular 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, for example, 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 patients with cancer,<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 most common 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

This study was set in the Calgary Zone (CZ) of Alberta Health Services (AHS). CZ encompasses the city of Calgary and surrounding semirural areas (88% urban, 12% rural). It contains ~1.6 million people, or ~38% of Alberta, Canada’s population.<sup>23</sup> AHS is the provincial health authority tasked with delivering publicly funded universal healthcare to the population, including access to PC in institutional and community settings. The specialist PC service in CZ is a longstanding (~20 years), mature, integrated programme which includes PC consult teams (institutional, community-based and cancer pain and symptom clinic), a tertiary PC unit, palliative home care (PHC) (available within Calgary city limits only), and hospices (institutional and community-based).<sup>24</sup> All services provided by and activities performed by the CZ specialist PC programme/providers are captured in operational databases (Sunrise Clinical Manager, Palliative Care Database (PallID), PARIS, and Pathways Continuing Care Application Data, see online supplemental table 1) managed by AHS, which are used to manage workflows, admission, consultation and discharge. The criteria for PC referral in Alberta are like most PC programmes with a focus on symptoms, advance care planning, and general support for patients, caregivers and providers.

### Cohort description

This was an administrative data-based retrospective cohort study of CZ decedents who died between 1 January 2007 and 31 December 2016. Regional, provincial, and national healthcare databases were used to identify palliative, community and acute care service use before death. A list of the databases accessed (including the specialist PC databases), and the information extracted from each, is available (see online supplemental table 1). Patients 18 years or older and deceased from a PC-amenable condition, including: (1) malignant cancer, (2) heart disease and heart failure (abbreviated ‘heart disease/failure’), (3) dementia, vascular dementia, Alzheimer’s disease, senility (abbreviated ‘dementia’), (4) haemorrhagic, ischaemic and unspecified stroke (abbreviated ‘stroke’), (5) COPD and respiratory failure (abbreviated ‘COPD’), (6) liver disease, (7) neurodegenerative diseases and (8) renovascular disease and renal failure (abbreviated ‘renal disease/failure’), were included.<sup>10 11</sup> These conditions were identified based on International Classification of Diseases 10th Revision (ICD-10) codes for underlying cause of death as recorded on the death certificate (see online supplemental table 2 for the ICD-10 codes used).<sup>10 11</sup> Administrative data were linked, aggregated and deidentified by the data analytics service within AHS.

### 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.

The results of this study will be disseminated to the academic community through presentation of the findings at relevant national and international meetings (eg, the annual International Congress on Palliative Care, European Association for Palliative Care, and Canadian Hospice Palliative Care Conference); presenting the findings at local rounds (Tom Baker Cancer Centre, Cumming School of Medicine), and disseminating the results to networks of researchers associated with primary care, palliative care, and health services research (including the O’Brien Institute for Public Health). Strategies to disseminate the findings to healthcare organisations and policy-makers include presenting the study findings to policy makers at the local, provincial (eg, Alberta Health Services, Alberta Health, Covenant Health, Cancer Control Alberta), and national levels.

### 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 ED visit, (3) two or more hospital admissions, (4) 15 or more days of hospitalisation, 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 categorised 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 (ie,  $\geq 8$  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 categorised 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),  $\geq 91$  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,  $\geq 3$ ), estimated household income based on postal code (categories: US\$0–71,680 (reference), US\$71 765–90 112, US\$90 197–108 032, US\$108 083–128 384, US\$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),  $\geq 1$ ), and admissions to long-term care before death (categories: 0 (reference),  $\geq 1$ ). For rurality, decedents were assigned an urban or rural designation using a 7-level categorisation 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  $\sim 20\%$  of the population was in each group.

Household income quintile was then assigned based on decedents last known residence postal code. Categorisation 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

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, general home care use, and days spent in hospital before death. All analyses were performed in R V.4.0.0. The general model formula used was:  $\text{glm}(\text{O} \sim \text{E} + \text{covariates}, \text{family} = \text{Poisson}(\text{link} = \text{log}))$ , where ‘O’ is the outcome, one of the indicators of hospital-based acute care in the last 30 days of life (with the levels ‘no’ (reference), ‘yes’), and where ‘E’ is the exposure of interest, specialist PC use (with the levels ‘no’ specialist PC use (reference) vs 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 in the main analysis, and in secondary analyses late specialist PC (reference) vs early specialist PC). Covariates adjusted for are as listed in the ‘covariates’ section. Robust standard errors were estimated using the covariance matrix of model parameters, obtained using the *vcovHC* function implemented in the R package *sandwich*.<sup>34</sup> A separate Poisson regression model was run for each of the six outcomes listed in the ‘Outcome’ section. RRs are reported with 95% CIs based on robust standard errors.

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

#### Absolute RD

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

## RESULTS

### Characteristics of decedents

A total of 47169 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; renovascular disease/failure 1%. Fifty-one per cent of decedents were women, with women making up a larger percentage of the dementia category (65%) and a smaller percentage of the liver disease category (39%) (online supplemental table 3). Patients with liver disease were on average much younger at death; patients with dementia 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 (eg, 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) (online supplemental table 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 per cent of decedents had a long-term care admission prior to death; however, this varied considerably by disease category. Patients with dementia were most likely to be admitted to long-term care (61%); patients with cancer and liver disease 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-PHC visits. Over 60% of the cohort spent 0 days in hospital 90–365 days before death, 15% spent between 1 and 10 days, and 24% spent between 11 and 275 days in hospital for this period (table 1). The COPD, liver disease and renovascular disease/failure groups were more likely to have more days in hospital 90 to 365 days before death (online supplemental table 3).

### Specialist PC exposure prior to death

Overall, 49% of decedents received one or more specialist PC service prior to death (table 1). Patients with cancer were most exposed (86%); patients with heart disease least exposed (20%). For the other chronic disease categories, the proportion of PC exposed decedents was: neurodegenerative disease, 48%; renovascular 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 to 2016, we observed a significant increase in the proportion of decedents exposed to specialist PC, overall, and independently for each disease category except renovascular disease (online supplemental table 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), neurodegenerative 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) (online supplemental table 5). The biggest changes occurred for COPD (+14%, 7% to 20% from 2007 to 2016). Finally, patients first encountered specialist PC primarily through PC consult team visits (81%), followed by PHC (15%) (table 1).

### 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 per cent of decedents spent  $>14$  days in hospital in last 30 days of life. Fewer than 10% of patients experience the remaining indicators of hospital-based acute care:  $>1$  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% of decedents experienced one or more indicators of hospital-based acute care. The average number of positive indicators per patient was 1.8 (of 5). Patients with liver disease were notable in being much more likely to experience hospital-based acute care in the last 30 days of life (78% of all liver patients); a greater proportion died in hospital (76%) and used the ICU (26%). Patients with dementia 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  $>1$  hospitalisation (+0.5%) and  $>1$  ED visit (+0.8%) in the last 30 days of life (online supplemental table 6). Combining these indicators in the aggregate hospital-based acute care indicator, changes over time were not significant.

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

	Specialist PC prior to death, n (row %)					
	Overall (n=47 169), n (col %)	No (n=23 931 (51))	Yes (n=23 238 (49))	Yes, by timing categories*		
				Early (≥90 before death), n=7736 (33)	Late (≥8 but <90 days before death), n=11 373 (49)	Very late (<8 days before death), n=4129 (18)
<b>Chronic disease causing death</b>						
Cancer	18 263 (39)	2 469 (14)	15 794 (86)	5 743 (36)	8 401 (53)	1 650 (10)
Heart disease/failure	15 206 (32)	12 165 (80)	3 041 (20)	803 (26)	1 257 (41)	981 (32)
Dementia	5 010 (11)	3 912 (78)	1 098 (22)	321 (29)	457 (42)	320 (29)
Stroke	3 108 (7)	2 166 (70)	942 (30)	121 (13)	353 (37)	468 (50)
COPD	2 905 (6)	1 787 (62)	1 118 (38)	426 (38)	350 (31)	342 (31)
Liver disease	1 044 (2)	583 (56)	461 (44)	60 (13)	218 (47)	183 (40)
Neurodegenerative disease	1 015 (2)	523 (52)	492 (48)	191 (39)	202 (41)	99 (20)
Renovascular disease/failure	618 (1)	326 (53)	292 (47)	71 (24)	135 (46)	86 (29)
<b>Sex</b>						
Female	23 865 (51)	12 025 (50)	11 840 (50)	4 137 (35)	5 647 (48)	2 056 (17)
Male	23 304 (49)	11 906 (51)	11 398 (49)	3 599 (32)	5 726 (50)	2 073 (18)
<b>Age at death</b>						
<61	6 749 (14)	2 672 (40)	4 077 (60)	1 699 (42)	1 914 (47)	464 (11)
61–70	7 066 (15)	2 806 (40)	4 260 (60)	1 591 (37)	2 110 (50)	559 (13)
71–80	10 449 (22)	4 658 (45)	5 791 (55)	1 838 (32)	2 988 (52)	965 (17)
81–90	15 355 (33)	8 573 (56)	6 782 (44)	1 957 (29)	3 294 (49)	1 531 (23)
≥91	7 550 (16)	5 222 (69)	2 328 (31)	651 (28)	1 067 (46)	610 (26)
<b>Rurality</b>						
Urban	41 664 (88)	20 352 (49)	21 312 (51)	7 171 (34)	10 353 (49)	3 788 (18)
Rural	5 505 (12)	3 579 (65)	1 926 (35)	565 (29)	1 020 (53)	341 (18)
<b>Household income quintile</b>						
Q1	13 211 (28)	7 603 (58)	5 608 (42)	1 821 (32)	2 738 (49)	1 049 (19)
Q2	10 972 (23)	5 371 (49)	5 601 (51)	1 868 (33)	2 776 (50)	957 (17)
Q3	8 896 (19)	4 324 (49)	4 572 (51)	1 493 (33)	2 253 (49)	826 (18)
Q4	6 614 (14)	3 099 (47)	3 515 (53)	1 125 (32)	1 734 (49)	656 (19)
Q5	7 476 (16)	3 534 (47)	3 942 (53)	1 429 (36)	1 872 (47)	641 (16)
<b>CCI score</b>						
0	32 666 (69)	16 787 (51)	15 879 (49)	5 720 (36)	7 857 (49)	2 302 (14)
1 (score 1–2)	9 399 (20)	4 512 (48)	4 887 (52)	1 336 (27)	2 392 (49)	1 159 (24)
2 (score ≥3)	5 104 (11)	2 632 (52)	2 472 (48)	680 (28)	1 124 (45)	668 (27)
<b>Year of death</b>						
2007–2008	8 771 (19)	5 043 (57)	3 728 (43)	1 204 (32)	1 916 (51)	608 (16)
2009–2010	9 032 (19)	4 795 (53)	4 237 (47)	1 347 (32)	2 193 (52)	697 (16)
2011–2012	9 195 (19)	4 490 (49)	4 705 (51)	1 600 (34)	2 259 (48)	846 (18)
2013–2014	9 731 (21)	4 673 (48)	5 058 (52)	1 663 (33)	2 425 (48)	970 (19)
2015–2016	10 440 (22)	4 930 (47)	5 510 (53)	1 922 (35)	2 580 (47)	1 008 (18)
<b>Community care use†</b>						
LTC admission, yes	8 747 (19)	6 419 (73)	2 328 (27)	1 120 (48)	709 (30)	499 (21)
Home care visit, yes	32 265 (68)	13 171 (41)	19 094 (59)	7 184 (38)	9 152 (48)	2 758 (14)
Non-palliative home care only	25 943 (55)	13 171 (51)	12 782 (49)	3 968 (31)	6 195 (48)	2 619 (20)

Continued

Table 1 Continued

	Specialist PC prior to death, n (row %)					
	Overall (n=47 169), n (col %)	No (n=23 931 (51))	Yes (n=23 238 (49))	Yes, by timing categories*		
				Early (≥90 before death), n=7736 (33)	Late (≥8 but <90 days before death), n=11 373 (49)	Very late (<8 days before death), n=4129 (18)
Hospitals days 90–365 days before death						
0 days	28 562 (61)	16 717 (59)	11 845 (41)	2504 (21)	6747 (57)	2594 (22)
1–10 days	7255 (15)	2724 (38)	4531 (62)	1640 (36)	2230 (49)	661 (15)
11–275 days	11 352 (24)	4490 (40)	6862 (60)	3592 (52)	2396 (35)	874 (13)
Initiating specialist PC service						
Consult team	18 915 (40)	–	18 915 (81)§	5472 (29)	9443 (50)	4000 (21)
Inpatient	13 402 (71)	–	13 402 (71)‡	3204 (59)‡	6882 (73)‡	3316 (83)‡
Community	5355 (28)	–	5355 (28)‡	2232 (41)‡	2491 (26)‡	632 (16)‡
Emergency department	158 (1)	–	158 (1)‡	36 (1)‡	70 (1)‡	52 (1)‡
TPCU	116 (<1)	–	116 (0)§	32 (28)	72 (62)	12 (10)
Pain and symptom clinic	638 (1)	–	638 (3)§	469 (74)	163 (26)	6 (1)
Palliative home care	3568 (8)	–	3569 (15)§	1763 (49)	1695 (47)	111 (3)

\*Row percentages shown are calculated of those who received specialist PC, unless otherwise indicated.

‡Evaluated at any time prior to death.

‡Column percentage are shown, calculated of those who received a consult team visit within specialist PC strata.

§Column percentage are shown, calculated of those who received any specialist PC.

CCI, Charlson Comorbidity Index; COPD, chronic obstructive pulmonary disease; LTC, long-term care; PC, palliative care; Q, quintile; TPCU, tertiary PC unit.

### 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 with those with no specialist PC (RR 0.69; 95% CI 0.66 to 0.71; RD 0.16; 95% CI 0.15 to

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 with no specialist PC exposure, late specialist PC exposure was associated

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					
	>1 ED visit	>1 hospital admission	Any ICU admission	>14 days in hospital	Death in an acute care hospital or bed	Indicators aggregated
All decedents	4224 (9)	3861 (8)	3073 (7)	9903 (21)	19 679 (42)	22 712 (48)
Cause of death						
Cancer	1960 (11)	2007 (11)	607 (3)	4645 (25)	7416 (41)	9281 (51)
Heart disease, failure	1162 (8)	927 (6)	1533 (10)	2418 (16)	6337 (42)	6904 (45)
Dementia, senility	143 (3)	126 (3)	16 (0)	673 (13)	1020 (20)	1259 (25)
Stroke	339 (11)	227 (7)	312 (10)	644 (21)	1846 (59)	1958 (63)
COPD	323 (11)	298 (10)	247 (9)	707 (24)	1590 (55)	1724 (59)
Liver disease	168 (16)	180 (17)	271 (26)	448 (43)	792 (76)	811 (78)
Neurodegenerative diseases	57 (6)	46 (5)	42 (4)	180 (18)	367 (36)	425 (42)
Renovascular disease, failure	72 (12)	50 (8)	45 (7)	188 (30)	311 (50)	350 (57)

COPD, chronic obstructive pulmonary disease; ED, emergency department; ICU, intensive care unit.

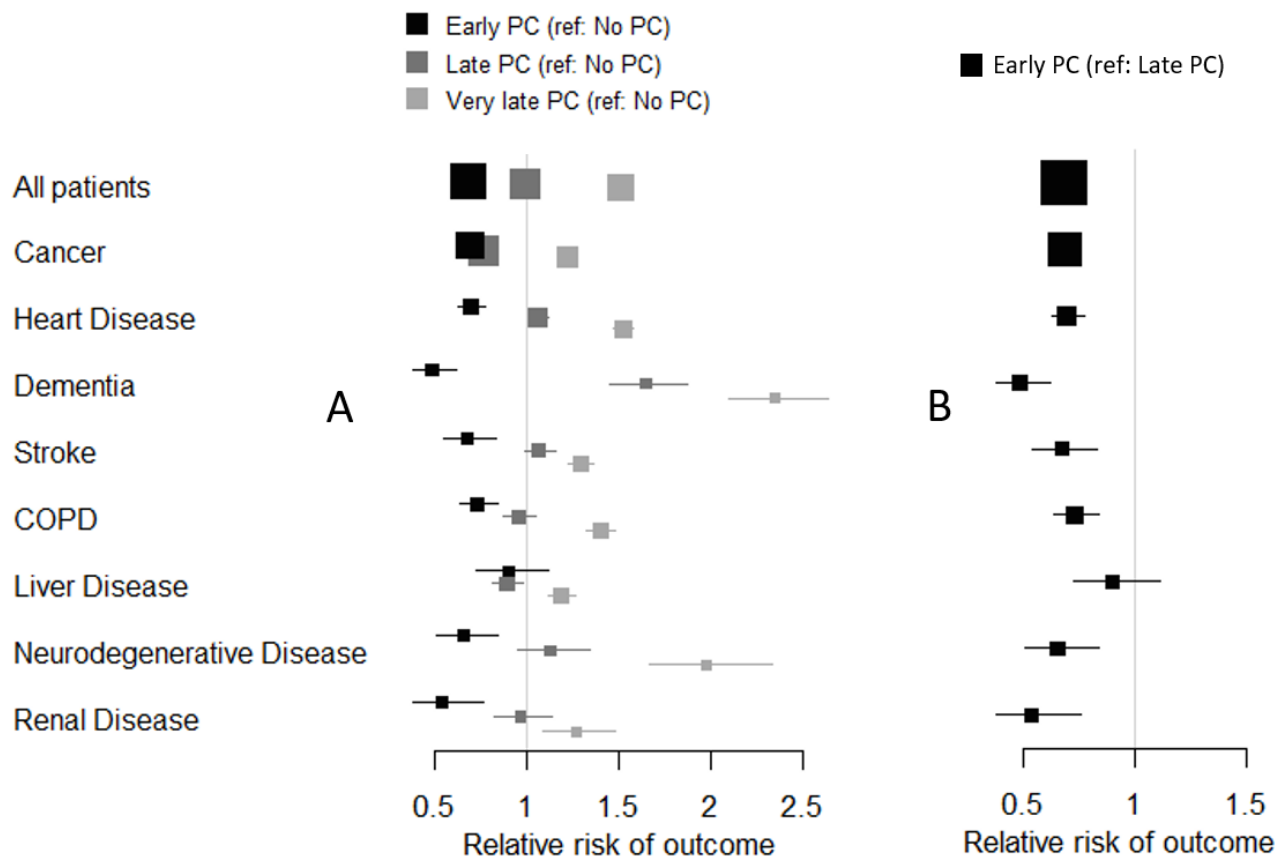
**Table 3** Relatives risks and risk differences indicating the association between specialist palliative care (PC) use and indicators of hospital-based acute care in the last 30 days of life for all decedents

	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 hospital	Aggregate hospital care indicator
All decedents (n=47 169)	Reference	Reference	Reference	Reference	Reference	Reference
No specialist PC	Reference	Reference	Reference	Reference	Reference	Reference
Early specialist PC (≥90 before death)	RR (95% CI); p 0.96 (0.95 to 0.97); p<0.001	0.98 (0.98 to 0.99); p<0.001	0.91 (0.90 to 0.91); p<0.001	1.01 (1.00 to 1.02); p=0.004	0.84 (0.84 to 0.85); p<0.001	0.69 (0.66 to 0.71); p<0.001
Late specialist PC (≥8 but <90 days before death)	Absolute RD (95% CI); p 0.04 (0.04 to 0.05); p<0.001	0.02 (0.01 to 0.02); p<0.001	0.10 (0.10 to 0.11); p<0.001	0.02 (0.01 to 0.03); p=0.003	0.23 (0.22 to 0.25); p<0.001	0.16 (0.15 to 0.17); p<0.001
Very late specialist PC (<8 days before death)	RR (95% CI); p 0.98 (0.97 to 0.99); p<0.001	1.04 (1.03 to 1.05); p<0.001	0.90 (0.90 to 0.91); p<0.001	1.16 (1.15 to 1.17); p<0.001	0.88 (0.87 to 0.89); p<0.001	0.99 (0.96 to 1.01); p=0.26
	Absolute RD (95% CI); p 0.02 (0.01 to 0.03); p<0.001	0.04 (0.04 to 0.05); p<0.001	0.11 (0.10 to 0.12); p<0.001	0.19 (0.17 to 0.20); p<0.001	0.19 (0.17 to 0.20); p<0.001	0.01 (0.00 to 0.02); p=0.067
	RR (95% CI); p 1.05 (1.04 to 1.06); p<0.001	1.05 (1.04 to 1.06); p<0.001	0.96 (0.95 to 0.97); p<0.001	1.12 (1.10 to 1.13); p<0.001	1.13 (1.12 to 1.14); p<0.001	1.51 (1.48 to 1.54); p<0.001
	Absolute RD (95% CI); p 0.05 (0.04 to 0.07); p<0.001	0.05 (0.04 to 0.06); p<0.001	0.04 (0.03 to 0.05); p<0.001	0.13 (0.12 to 0.15); p<0.001	0.21 (0.19 to 0.22); p<0.001	0.28 (0.26 to 0.29); p<0.001

RRs and RDs are adjusted for underlying chronic disease causing death, sex, age at death, year of death, rurality, income, Charlson Comorbidity Index 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 one aggregate indicator of hospital-based acute care, for RR and RD (total of 12 models). ED, emergency department; ICU, intensive care unit; RD, risk difference; RR, relative risk.

### Any indicator of hospital-based acute care in the last 30 days of life (aggregate indicator)



**Figure 1** The relative risk (RR) of experiencing any indicator of hospital-based acute care in the last 30 days of life given specialist palliative care (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 with no specialist PC. In (B), early specialist ( $\geq 90$  days before death) is compared with late specialist PC ( $\geq 8$  but  $< 90$  days before death), separating the effect of exposure and timing. Results from eight disease specific and one all decedent model are shown in panels (A) and (B) ( $9 \times 2$  total). Exact values of estimates plotted are provided in online supplemental tables 7 and 9). RRs are adjusted for sex, age at death, year of death, rurality, income, Charlson Comorbidity Index score, long-term care admission, general home care use, and days spent in hospital 90–365 days before death. RRs for the all decedent model are also adjusted for chronic disease group. Plots were constructed using the R package forestplot V.1.10. COPD, chronic obstructive pulmonary disease; EOL, end-of-life.

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 with 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.

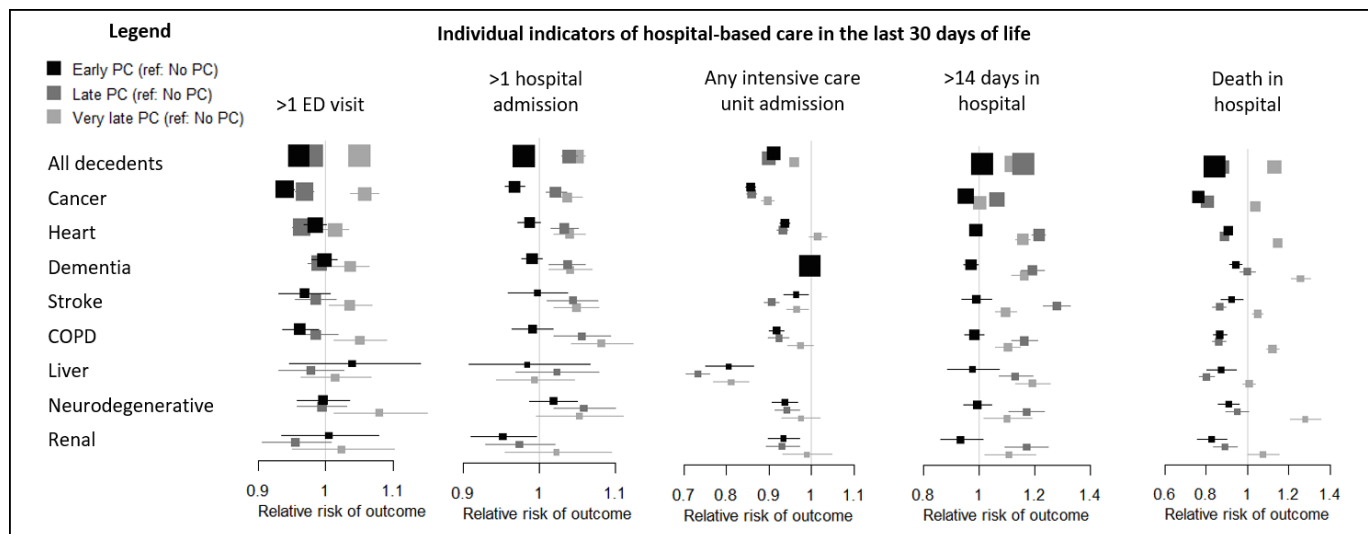
In a secondary analysis examining only patients that received specialist PC, where early specialist PC was compared with late specialist PC (figure 1, online supplemental table 7), RR and RD estimates were found to be similar to main models where early specialist PC was compared with no specialist PC. For example, those exposed to early specialist PC (vs 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 to 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 with those who had no PC exposure (figure 1, online supplemental table 8). The effect was strongest in cancer (RR 0.53, 95% CI 0.50 to 0.55; RD 0.31, 95% CI 0.29 to 0.33) and renal disease (RR 0.60, 95% CI 0.43 to 0.84; RD 0.22, 95% CI 0.11 to 0.34) decedents, but a  $\sim 25\%$  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





**Figure 2** The relative risk (RR) of experiencing individual indicator of hospital-based acute care in the last 30 days of life given specialist palliative care (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 with no specialist PC. Results from eight disease-specific and one all decedent model are shown for each indicator ( $8 \times 5$  total). Exact values of estimates plotted are provided in table 3 and online supplemental table 8. RRs are adjusted for sex, age at death, year of death, rurality, income, Charlson Comorbidity Index score, long-term care admission, general home care use, and days spent in hospital 90–365 days before death. RRs for the all decedent model are also adjusted for chronic disease group. Plots were constructed using the R package forestplot V.1.10. COPD, chronic obstructive pulmonary disease; EOL, end-of-life.

of any hospital-based acute care for patients with cancer (RR 0.76, 95% CI 0.74 to 0.79) and liver disease (RR 0.89, 95% CI 0.81 to 0.98), but increased risk for patients with dementia (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 and online supplemental table 9), RR estimates were found to be similar to main models where early specialist PC was compared with 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 47169 chronic disease decedents in Calgary, Alberta, Canada from 2007 to 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 with those with no specialist PC exposure, or when compared with those with late specialist PC. Four of five outcome indicators showed this relationship (table 3). And, this association was independently observed in all disease groups except for dementia (the latter was not significant). The association between late PC exposure (vs no exposure) was inconsistent across disease groups and outcomes. For most disease categories, late PC exposure was associated with decreased risk of death in hospital and ICU admission, but increased risk of  $>1$  hospital admission and  $>14$  days in hospital in the last month of life. We hypothesise this result is explained by patients whose first exposure to specialist PC occurs in the last month of life (but  $>7$  days), likely triggered by a hospital admission in the last month life. Specialist PC would be highly correlated with hospital admission (ie, increase risk) for these patients. Importantly however, late specialist PC was still associated with reduced risk of ICU admission and death in hospital for these patients. Finally, very late PC (vs no exposure) was consistently associated with increased risk of hospital-based acute care indicators (all except ICU admission) across all disease groups. Specialist PC initiated this late would not be expected to reduce healthcare resources use in the last 30 days of life, nor provide sufficient time to organise the healthcare resources needed to enable death at home. These patients likely only receive specialist PC because they were in hospital in the last 7 days of life, explaining the observed increase in risk.



### Comparison with other studies

Many studies have reported on the relationship between PC exposure and hospital-based acute care near the EOL in patients with cancer,<sup>15–21</sup> consistently finding that PC exposure reduces risk of hospital-based care near the EOL. Fewer studies have focused on patients without cancer, and results have been limited to the disease categories examined (heart failure,<sup>36–39</sup> dementia,<sup>40–41</sup> end-stage renal disease (ESRD),<sup>42–43</sup> and end-stage liver disease<sup>44</sup>). In these prior studies, PC exposure has not been consistently associated with indicators of healthcare resource use (often not significant). However, a recent well-powered study of seven chronic disease, looking at the impact of physician-delivered PC on hospital-based acute care, found results similar to ours.<sup>22</sup> Indeed, Quinn *et al* found that PC exposure (any vs none) was associated with reduced rates of ED visits, hospital and ICU admissions, and death in hospital for cancer, COPD, ESRD, stroke and cirrhosis (liver) decedents.<sup>22</sup> Our study add to these results by showing the association of PC timing on these outcomes. We show that early PC exposure, over late, is associated with reductions in risk of hospital-based acute care in the last 30 days of life. These studies are notably different in how PC is measured. Quinn *et al* defined PC exposure as newly initiated (in last 6 months of life but excluding the last 7 days), physician delivered, and based on billing data.<sup>22</sup> Here, PC is defined as any specialist PC service (physician or nursing consultants, PHC, hospice) at any time (after diagnosis of underlying cause of death), based on data from specialist PC operational databases. Yet, the overall results are similar, with additional clarity now on the association of early versus late PC timing. Similar to our study, Rosenwax *et al*<sup>45</sup> observed increased PC exposure over time for patients without cancer chronic disease in Australia,<sup>45</sup> as did a recent study of Ontario decedents (2004–2014).<sup>46</sup> In both, as in our study, the biggest increases occur for patients with liver disease and COPD.

### Strengths and limitations

While this study was large and population based, it had several important limitations. First, the outcome indicators used in this study were developed and validated based on patients with cancer use of healthcare resources.<sup>47</sup> Indicators specific to non-cancer chronic diseases are not well developed or validated. As a result, the outcomes examined may not be as appropriate for measuring quality of EOL care for the non-cancer chronic diseases categories. Patient and provider preferences for EOL care may differ by chronic disease condition and require further exploration to interpret the associations reported here. Development of disease-specific quality of EOL care indicators would help ensure the right outcomes (those that matter to patients) are used in future research. As it is, not all hospital-based acute care in the last 30 days of life is inappropriate, and we do not mean to imply that healthcare interventions should solely focus on reducing such care. Some hospital-based interventions at the EOL are likely

appropriate and in line with patient and caregiver preferences. Unfortunately, data on patient preferences are not available in our healthcare administrative data and is beyond the scope of this study.

Second, unlike prior studies based on billing claims data,<sup>18–19–22</sup> here we only evaluated care provided by *specialist* PC providers (as recorded in institutional specialist PC databases). As the latter databases are used to manage all day-to-day specialist PC team-patient activities (eg, consultation, admission), there should be very little misclassification in terms of who received *specialist* PC (and when); however, this has not been formally measured and reported on. Importantly, there is no specialist PC provision outside of this in our jurisdiction. Our PC data sources (listed in online supplemental table 1) and study approach are anticipated to result in under-reporting of PC exposure, specifically as it relates to PC provided by non-specialist PC providers (eg, generalist physicians). However, our data sources and approach confer high confidence that all *specialist* PC services received by patients are accurately captured, across all care settings (ie, home, hospital, and hospice).

Finally, this study examined only specialist PC provided to patients living in a primarily urban region (12% rural population), in one province, in a high-income country. Caution is needed when generalising to other jurisdictions. In regions that do not have a well-developed specialist PC programme (a programme that is itself a result of the population being studied), patient's PC needs must be met by non-specialist providers or go unmet. The PC delivered by these providers (or alternative programmes) may differ in their effect on the hospital-based outcomes examined here. Even in jurisdiction with well-developed PC programmes, patient preferences for care may differ by population (influenced, for example, by social and cultural factors), and could affect the choice to receive PC and other acute care interventions. We note that our results are largely consistent with those of a recent well-powered study of patients with chronic disease in Ontario, Canada.<sup>22</sup>

### Implications for clinicians and policy-makers

More work is needed to address differences in PC access observed here and elsewhere.<sup>45–46</sup> Further, more work is needed to ensure earlier timing of first PC exposure. We know PC benefits patients without cancer chronic disease through QoL improvements.<sup>48–50</sup> Our current result shows that PC is also associated with reducing risk of hospital-based acute care in the last 30 days of life across most chronic disease categories. Sufficient follow-up time is necessary for the benefits of specialist PC to be realised; hence, the call for earlier PC, however, late PC is still better than none in terms of reducing death in hospital and ICU admissions. Given finite healthcare resources, chronic disease groups with lower PC exposure and more likely to experience hospital-based acute care in the last 30 days of life, could be prioritised for focused efforts to improve access. For example, 78% of liver disease and

59% of COPD decedents experience hospital-based acute care in the last 30 days of life, but only 44% (6% early) and 38% (15% early), respectively, receive specialist PC. Patients dying from these conditions still lag far behind patients with cancer both in terms of PC access and timing.

### 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 early initiation of advance care planning discussions, cannot be overstated. An ongoing challenge is knowing precisely when and who to refer to specialist PC to best leverage these providers expertise,<sup>51</sup> recognising that in many places this is a scarce resource. This is true particularly for patients without cancer chronic diseases 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 patients<sup>52</sup> with and without cancer.<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 that the right outcomes are focused on by all providers.

Within specialist PC, questions remain on the role that location and model of delivery play in improving patient QoL and optimising healthcare resource use near the EOL.<sup>52</sup> For example, how do the different specialist PC services (eg, PHC, 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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**Contributors** ME, AS, PC and AF contributed to the study concept and design. PC, AF, KB, T-MP and LS were responsible for acquisition of data. ME, AF, KB, PC and AS were responsible for data processing and interpretation of the data. ME performed all statistical analyses and drafted the manuscript. AS, PC, AF, KB, T-MP and LS contributed to the critical revision of the manuscript for important intellectual content. AS obtained funding and is the guarantor. The corresponding author attests that all listed authors meet the authorship criteria and that no other authors meeting the criteria have been omitted.

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**Data availability statement** Data are available upon reasonable request. The data set from this study is held securely in coded form at the University of Calgary. While the conditions of our ethics approval prohibit making the data set publicly available, access to anonymised summary level (aggregate data) may be granted (conditional on permission from data custodian: Alberta Health Services) upon request by emailing [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca). The full data set creation plan and underlying analytic code are available upon request by emailing [ayn.sinnarajah@ahs.ca](mailto:ayn.sinnarajah@ahs.ca), understanding that the programmes may rely on coding templates or macros that are unique Alberta Health Services and this study.

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