

# Palliative care delivery across health sectors: A population-level observational study

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## Abstract

**Background:** Little population-level information exists about the delivery of palliative care across multiple health sectors, important in providing a complete picture of current care and gaps in care.

**Aim:** Provide a population perspective on end-of-life palliative care delivery across health sectors.

**Design:** Retrospective population-level cohort study, describing palliative care in the last year of life using linked health administrative databases.

**Setting/participants:** All decedents in Ontario, Canada, from 1 April 2010 to 31 March 2012 ( $n = 177,817$ ).

**Results:** Across all health sectors, about half (51.9%) of all decedents received at least one record of palliative care in the last year of life. Being female, middle-aged, living in wealthier and urban neighborhoods, having cancer, and less multi-morbidity were all associated with higher odds of palliative care receipt. Among 92,276 decedents receiving palliative care, 84.9% received care in acute care hospitals. Among recipients, 35 mean days of palliative care were delivered. About half (49.1%) of all palliative care days were delivered in the last 2 months of life, and half (50.1%) had palliative care initiated in this period. Only about one-fifth of all decedents (19.3%) received end-of-life care through publicly funded home care. Less than 10% of decedents had a record of a palliative care home visit from a physician.

**Conclusion:** We describe methods to capture palliative care using administrative data. Despite an estimate of overall reach (51.9%) that is higher than previous estimates, we have shown that palliative care is infrequently delivered particularly in community settings and to non-cancer patients and occurs close to death.

## Keywords

Palliative care, palliative medicine, end-of-life care, cancer, home care services, house calls

### What is already known about the topic?

- The reach of palliative care across all healthcare sectors—including acute care, outpatient clinics, and home care—has never been directly observed at a population level in Canada or elsewhere.
- Furthermore, the intensity and timing of palliative care are rarely described at a population level.

### What this paper adds?

- Across all health sectors, about half (51.9%) of all decedents received at least one record of palliative care in the last year of life, with the majority receiving care in acute care.

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- We show, at a population-level, that cancer patients are more likely (odds ratio: 2.46; 95% confidence interval: 2.40–2.52) to receive palliative care, while those with congestive heart failure and dementia are less likely to receive such care.
- *Late delivery and initiation.* Half (49.1%) of all palliative care days were delivered in the last 2 months prior to death, and half (50.1%) had palliative care initiated in these last 2 months.
- *Little care in the community.* Less than 1 in 5 received palliative home care and less than 1 in 10 received a palliative physician home visit.

#### Implications for practice, theory, or policy

- Linked routinely collected data can be used to examine the provision of palliative care in the population.
- Overall reach of palliative care across sectors is higher than previous sector-based estimates.
- However, palliative care, particularly in community settings and among non-cancer patients, remains infrequently delivered and occurs close to death.

## Introduction

The aging baby boomer cohort effect<sup>1</sup> along with an increasing life expectancy<sup>2</sup> is leading to an increasingly aged population in many jurisdictions and an impending growing need for palliative care.<sup>3</sup> Palliative care aims to provide relief of physical symptoms and supportive care for patients and their caregivers during the dying process. It is delivered by multiple providers, including physicians, nurses, and other healthcare practitioners, often in team-based approach. A Cochrane review found that home palliative services for adults with advanced illness are associated with positive outcomes, particularly decreased symptom burden and increased odds of a home death.<sup>4</sup>

Significant efforts are currently underway to understand and improve palliative and end-of-life care across Canada—the setting of this study—and elsewhere. This includes initiatives undertaken by government,<sup>5,6</sup> by coalitions,<sup>7,8</sup> and led by professional bodies of healthcare practitioners.<sup>9,10</sup> Palliative care is provided in various care settings, including acute care and other hospital settings, long-term care facilities (i.e. nursing homes), hospices, and in people's homes. However, palliative care in the Canadian context, not unlike other jurisdictions, has been described as a patchwork of uncoordinated services, delivered unsystematically and varying depending on the services available at the region, care facility, and provider levels.<sup>3,7,11</sup> Despite this sentiment, there is little population- and system-wide data to describe the provision of palliative care across health sectors.<sup>7</sup> These data are needed to highlight the true population reach of palliative care and identify areas where care can be improved and potentially better integrated.

We sought to explore, at a population level, the pervasiveness of palliative care delivery near the end of life. Most previous studies have examined, in isolation, single sectors such as palliative home care,<sup>4</sup> outpatient physician care,<sup>12–14</sup> and hospital-based palliative care.<sup>15–17</sup> A recent study from England estimated the proportion of the population in high-income countries needing palliative care (69%–82%); yet,

this study could not find a direct estimate of the actual proportion in the United Kingdom or elsewhere that receive such care.<sup>18</sup> No previous study, to our knowledge, has examined the coverage of palliative care across the convergence of all major sectors combined, delivered by various healthcare disciplines, in and out of the context of palliative care specialist teams. We fill this gap using a series of population-level, health administrative databases linked at the individual level to capture palliative care provision across health sectors. This includes care provided by all physician specialties across all settings and publicly funded home care provided in the home by nurses, personal support workers, and other allied health professionals. Our objective was to illuminate patterns of care delivery (e.g. intensity, initiation) and potential gaps in care in the population.

## Methods

We conducted an observational, retrospective cohort study examining palliative care provision to decedents in their last year of life. We captured all deaths in a 2-year period, from 1 April 2010 to 31 March 2012 (fiscal year (FY) 2010/2011 to 2011/2012) in Ontario, a Canadian province with more than 13 million people. Using encrypted health card numbers as unique identifiers, records of healthcare use were linked across various administrative databases held at the Institute for Clinical and Evaluative Sciences (ICES). Ethics approval was obtained from the Sunnybrook Health Sciences Centre Research Ethics Board in Toronto, Canada, and from the Ottawa Hospital Research Institute Ethics Board in Ottawa, Canada.

### Data sources and definitions

Deaths were identified using the Ontario Registered Persons Database (RPDB). The RPDB contains information on all persons who are registered for the purposes of

Ontario health insurance coverage and was also used to obtain patient age, sex, and postal code. The databases and codes used to identify palliative care across sectors are outlined in Appendix 1; more details of these databases can be found elsewhere.<sup>19</sup> The decedents' socioeconomic status was measured using their neighborhood income 1 year prior to death. Following well-established methods, both neighborhood income and rurality were captured by linking to Statistics Canada census data using postal codes.<sup>20</sup> The presence of chronic conditions at death was captured using previously developed—and in some cases validated—chronic disease databases at ICES.<sup>21</sup> A total of 16 chronic diseases were examined (congestive heart failure, osteoporosis, diabetes, hypertension, chronic obstructive pulmonary disease, arrhythmias, osteoarthritis, rheumatoid arthritis, cancer, depression, renal disease, stroke, coronary artery disease, asthma, previous heart attack, and dementia) and the total number of diseases identified was totaled for each individual.

### Measurement of Outcomes

All records of healthcare use paid for by the provincial Ministry of Health and Long-Term Care (MOHLTC) in the last year of life were retrieved. Our main outcome was whether a decedent had at least one record of palliative care in each of the health sectors examined and in all sectors combined (Appendix 1). A main source of palliative care records was from physician billings across all specialties and includes—but is not limited to—claims from palliative care specialists. Physician claims for palliative care consults were captured and designated according to where care was delivered: outpatient clinic, home, hospital inpatient, long-term care, or complex continuing care. We examined palliative care delivered in the *community* by physicians—in the outpatient and home setting—and through publicly funded home care. For the home setting, physician weekly case management fees, telephone consults, and codes specific to palliative care home visits were also captured. Publicly funded palliative home care—delivered by nurses, personal support workers, and other allied healthcare workers—was captured if a client received an end-of-life designation by the home care program, or if services were delivered in a hospice or palliative care unit. An end-of-life designation—typically reserved for those who are deemed to have less than 6 months to life—is associated with a significant increase in services offered, with a palliative care philosophy.

We also examined palliative care delivered in *institutions*; namely, in acute care hospitals (both emergency room visits and admissions), in complex continuing care facilities, and in long-term care homes. In addition to physician billing codes, consultation to a palliative care team—typically consisting of multi-disciplinary palliative care specialists—and the corresponding services were

captured in the emergency room and in inpatient services. In long-term care and complex continuing care, we also captured hospice care delivered. Details on the codes we used to capture palliative care are outlined in Appendix 1.

### Intensity and initiation of palliative care

The number of days that palliative care was delivered was observed for each sector. For acute care admissions, we totaled the number of days for admission that had palliative care as the most responsible reason for admission and conservatively counted 1 day if palliative care was only a contributing reason. For all other sectors, we counted the days on which palliative care services were recorded.

For individual and all decedents, we observed the total number of palliative care days delivered (i.e. intensity) in each of the 12 months in the last year prior to death. We also examined for each decedent when palliative care was first observed in the last year of life (i.e. initiation). For care intensity, we sorted individuals into quintiles of total unique days of care received. For initiation time, we sorted individuals into quintiles of days prior to death when palliative care was initiated. Decedents can be in different quintiles within the initiation and intensity attributes. For each quintile, we then calculated the mean number of days among individuals within each quintile.

### Statistical analysis

We examined differences in the characteristics (sex, age-group, neighborhood income quintile, rurality, and chronic conditions) of those who received palliative care versus those who did not and used chi-squared tests to determine statistical significance. We then conducted a logistic regression to examine the associations of these characteristics with the outcome of receipt of palliative care in the last year of life. To represent sentinel chronic diseases of the different non-sudden trajectories of dying, we included cancer (terminal illness), congestive heart failure (organ failure), and dementia (frailty) in the multivariable model.<sup>22</sup> We included only three of the individual chronic conditions to minimize co-linearity introduced with the total number of chronic conditions. All statistical tests were two-tailed and *p* values were used to determine statistical significance. We used SAS 9.3 (SAS Institute Inc., Cary, NC, USA) for all analyses.

### Results

We captured 177,817 deaths in the 2 years of follow-up, 51.9% of whom were observed to have at least one palliative care claim in their last year of death in any of the sectors examined. About half (49.1%) of all palliative care days were delivered in the last 2 months of life, and half (50.1%) had palliative care initiated in this period.

**Table 1.** Characteristics of decedent cohort, comparing those who received at least 1 palliative service in the last year of life with those who did not.

Characteristic	No. (%) of decedents				p value	
	Palliative Care n = 92,276		No Palliative Care n = 85,541			All n = 177,817
Female	47,187	(51.1%)	42,553	(49.7%)	89,740	<0.005
Male	45,089	(48.9%)	42,988	(50.3%)	88,077	<0.005
Age, yr						
<19	337	(0.4%)	2,414	(2.8%)	2,751	<0.005
19–44	1,568	(1.7%)	3,948	(4.6%)	5,516	<0.005
45–54	4,497	(4.9%)	4,962	(5.8%)	9,459	<0.005
55–64	10,469	(11.3%)	8,036	(9.4%)	18,505	<0.005
65–74	16,731	(18.1%)	11,364	(13.3%)	28,095	<0.005
75–84	27,636	(29.9%)	21,372	(25.0%)	49,008	<0.005
85–94	26,157	(28.3%)	26,789	(31.3%)	52,946	0.006
95+	4,881	(5.3%)	6,656	(7.8%)	11,537	<0.005
Neighborhood Income						
Quintile 1 (Q1)	20,484	(22.3%)	20,226	(24.4%)	40,710	0.201
Q2	19,450	(21.2%)	17,270	(20.8%)	36,720	<0.005
Q3	17,593	(19.2%)	16,110	(19.4%)	33,703	<0.005
Q4	17,449	(19.0%)	15,423	(18.6%)	32,872	<0.005
Q5 (Highest)	16,734	(18.2%)	14,033	(16.9%)	30,767	<0.005
Rurality						
Urban	79,538	(86.4%)	70,183	(84.0%)	149,721	<0.005
Rural	12,527	(13.6%)	13,371	(16.0%)	25,898	<0.005
Chronic Diseases*						
Congestive Heart Failure	17,873	(10.1%)	19,603	(11.0%)	37,476	<0.005
Diabetes	26,942	(15.2%)	26,339	(14.8%)	53,281	0.009
COPD	16,979	(9.5%)	15,609	(8.8%)	32,588	<0.005
Cancer	28,596	(16.1%)	12,658	(7.1%)	41,254	<0.005
Renal	9,668	(5.4%)	9,301	(5.2%)	18,969	0.008
Stroke	7,404	(4.2%)	8,454	(4.8%)	15,858	<0.005
Coronary Artery Disease	25,121	(14.1%)	24,540	(13.8%)	49,661	0.009
Dementia	13,699	(7.7%)	20,302	(11.4%)	34,001	<0.005
No. Chronic Diseases*						
0	7,086	(7.7%)	9,658	(11.3%)	16,744	<0.005
1	11,696	(12.7%)	9,834	(11.5%)	21,530	<0.005
2	16,615	(18.0%)	13,646	(16.0%)	30,261	<0.005
3	17,459	(18.9%)	14,771	(17.3%)	32,230	<0.005
4	14,913	(16.2%)	13,281	(15.5%)	28,194	<0.005
5	10,835	(11.7%)	10,449	(12.2%)	21,284	0.008
6+	13,672	(14.8%)	13,902	(16.3%)	27,574	0.166

COPD: chronic obstructive pulmonary disease.

\*We examined 16 chronic diseases using previous healthcare claims. Please see text for more details.

### Factors associated with palliative care receipt

Those receiving palliative care tended to have higher representation in the middle age groups, from 55 to 85 years (Table 1). Those receiving palliative care tended to slightly live in wealthier neighborhoods and in urban areas ( $p < 0.005$ ). They are more likely to have cancer (16.1% vs 7.1%,  $p < 0.005$ ) and less likely to have dementia (7.7% vs 11.4%,  $p < 0.005$ ). The multivariate model presented in Table 2 showed that males, after adjustment, were less

likely to receive palliative care (odds ratio (OR): 0.83; 95% confidence interval (CI): 0.82–0.85), as were those living in rural regions (OR: 0.80; 95% CI: 0.78–0.83). Those with cancer (cf. those who did not) had more than double the odds of receiving palliative care (OR: 2.46; 95% CI: 2.40–2.52); conversely, those with congestive heart failure (OR: 0.88; 95% CI: 0.86–0.91) and dementia (OR: 0.60; 95% CI: 0.59–0.62) were less likely to receive palliative care. Increasing multi-morbidity was generally associated with decreasing likelihood of palliative care receipt.

**Table 2.** Multivariate logistic-regression examining factors associated with receipt of palliative care in the last year of life among 177,817 decedents.

Characteristic	All (n= 177,817)	Odds ratio (95% CI)	p value
<b>Sex</b>			
Female	89,740	1.00	
Male	88,077	0.83 (0.82–0.85)	<0.0001
<b>Age (years)</b>			
19	2751	1.00	
19–44	5516	1.18 (1.00–1.40)	0.0488
45–54	9459	2.66 (2.26–3.12)	<0.0001
55–64	18,505	3.91 (3.34–4.58)	<0.0001
65–74	28,095	4.51 (3.85–5.28)	<0.0001
75–84	49,008	4.30 (3.68–5.04)	<0.0001
85–94	52,946	3.56 (3.04–4.17)	<0.0001
95+	11,537	2.87 (2.44–3.37)	<0.0001
<b>Neighborhood income</b>			
Quintile 1 (Q1)	40,710	1.00	
Q2	36,720	1.08 (1.05–1.12)	<0.0001
Q3	33,703	1.06 (1.02–1.09)	0.0005
Q4	32,872	1.08 (1.05–1.12)	<0.0001
Q5 (highest)	30,767	1.12 (1.08–1.15)	<0.0001
<b>Rurality</b>			
Urban	149,721	1.00	
Rural	25,898	0.80 (0.78–0.83)	<0.0001
<b>Chronic diseases</b>			
Congestive heart failure	37,476	0.88 (0.86–0.91)	<0.0001
No congestive heart failure.	140,341	1.00	
Cancer	41,254	2.46 (2.40–2.52)	<0.0001
No cancer.	136,563	1.00	
Dementia	34,001	0.60 (0.59–0.62)	<0.0001
No dementia.	143,816	1.00	
<b>No. of chronic diseases</b>			
0	16,744	1.00	
1	21,530	1.06 (1.01–1.11)	0.0121
2	30,261	0.97 (0.93–1.01)	0.1851
3	32,230	0.91 (0.87–0.95)	<0.0001
4	28,194	0.86 (0.82–0.90)	<0.0001
5	21,284	0.81 (0.77–0.85)	<0.0001
6+	27,574	0.78 (0.74–0.82)	<0.0001

CI: confidence interval.

### Palliative care across health sectors

Of the 92,276 decedents receiving palliative care, a large proportion were identified in acute care hospitals and through outpatient physician claims (84.9% and 63.9%, respectively) (Table 3). Only about one-fifth of all decedents (34,311 of 177,817, or 19.3%)—and 32.4% of the 105,869 receiving home care in their last year of life (data not shown)—received a designation of end of life or palliative from publicly funded home care. Less than 10% of all decedents had a record of a palliative care home visit from a physician in their last year of life; more than half of these visits occurred in the month prior to death (data not shown).

### Intensity and initiation of palliative care

Among palliative care decedents, an average of 39.6 days of palliative care was delivered in the last year of life across sectors; removing days of overlap between sectors, an average of 35.2 days of unique days in the last year of life had at least one palliative care claim (Table 4). There was a large difference in the intensity of palliative care delivered among palliative care decedents in the highest and lowest quintiles (1.8 mean days versus 112.8 days) (Table 4).

The total number of palliative care days across all sectors more than doubled from the 12th month prior to death (69,618 days) to the 7th month prior to death (156,867

**Table 3.** Delivery of palliative care across healthcare sectors.

Sector	No. (%) of palliative care decedents		No. (%) of palliative care days delivered		Mean palliative care days among users
	<i>n</i> = 92,276 (100%)		<i>n</i> = 3,649,594 (100%)		
Community palliative care					
Any outpatient physician claim	58,981	(63.9%)	623,007	(17.1%)	10.6
Home-based physician care	16,959	(18.4%)	82,244	(2.3%)	4.8
Home care	34,311	(37.2%)	1,613,043	(44.2%)	47.0
Institutional palliative care					
Long-term care	892	(1.0%)	4069	(0.1%)	4.6
Complex continuing care	6009	(6.5%)	41,248	(1.1%)	6.9
Hospital inpatient	78,344	(84.9%)	1,367,866	(37.5%)	17.5
Emergency room	283	(0.3%)	361	(0.0%)	1.3

**Table 4.** Initiation and intensity of palliative care across all health sectors.

	Initiation Mean days prior to death (range)	Intensity Mean no. of palliative care days delivered (range)
Quintiles of decedents <sup>a</sup>		
Q1: latest initiation/lowest intensity	3.7 (0–9)	1.8 (1–2)
Q2	18.1 (10–32)	6.1 (3–10)
Q3	59.2 (33–98)	17.9 (11–26)
Q4	159.9 (99–235)	39.3 (27–56)
Q5: earliest initiation/highest intensity	314.5 (236–360)	112.8 (57–360)
All ( <i>n</i> = 92,276)	111.1 (0–360)	35.2 (1–360)

<sup>a</sup>Decedents were sorted into two sets of quintiles based on time of initiation and intensity of care delivered (i.e. decedents can be in different quintiles within the initiation and intensity columns).

days), then almost tripled in the 3rd month (410,655 days), and finally more than tripled in the last month of life (1,251,618 days) (Figure 1). There were more palliative care days delivered in community-based settings (outpatient physician visits, home care, long-term care) than in hospital-based settings (hospital inpatient care, complex continuing care, and emergency room visits), with the exception of the last month prior to death.

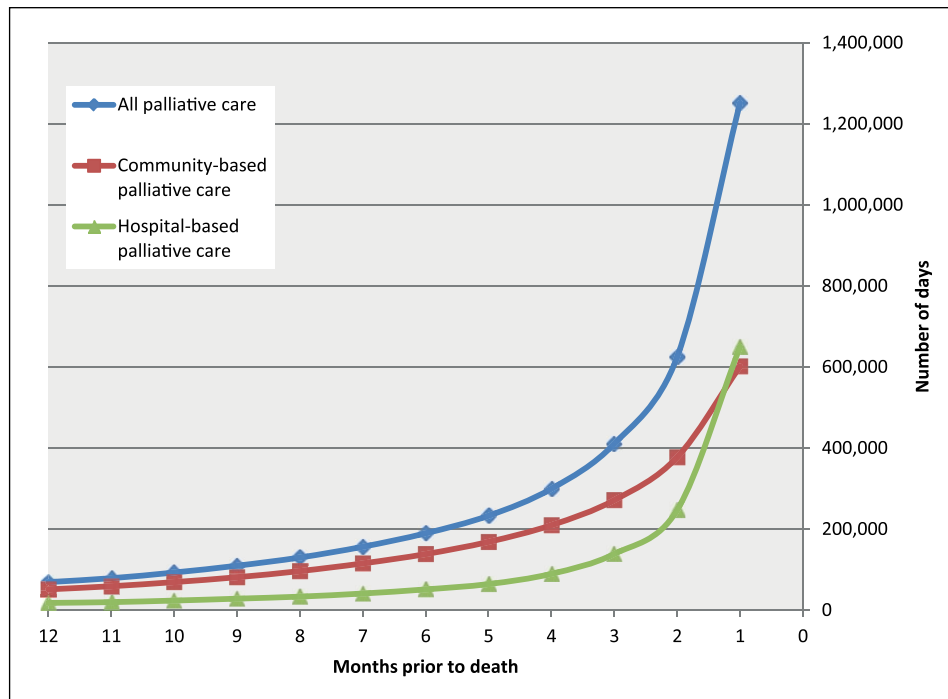
Examining the palliative care cohort in their last 12 months of life, 35,824 (38.8%) had their *first* palliative care claim in the last month prior to death, and 11,093 (12.0%) had their first palliative care claim in the second last month (data not shown). There was a large difference in the mean days prior to death that palliative care was initiated among the latest and earliest quintiles (3.7 versus 314.5 days) (Table 4).

## Discussion

We examined the provision of palliative care at the end-of-life—delivered both by specialist and non-specialist healthcare practitioners—using population-based administrative databases across a wide range of health sectors. We observed that one in two in their last year of life will be recorded to have at least one palliative care encounter;

this is higher than the often quoted 15%–30% population estimate for end-of-life hospice palliative care in Canada.<sup>23,24</sup> We observed that being female, middle-aged, having *less* multi-morbidity, and living in urban and higher income neighborhoods were associated with palliative care receipt. Further work needs to be done to unpack the narratives behind these associations, but differences are likely somewhat attributable to issues of access and perceived futility of curative care. We also confirm across health sectors the often-held belief that cancer patients are more likely to receive palliative care than those on the organ failure (e.g. congestive heart failure) and frailty (e.g. dementia) trajectories.<sup>25–27</sup>

Elsewhere, Murtagh et al.<sup>18</sup> estimated the number of people in England receiving palliative care to be between 100,000 and 242,000 (20%–49%), depending on the hypothetical levels of overlap across three healthcare sectors. Overall, it is expected that about 69%–82% of those dying in high-income countries will need palliative care.<sup>18</sup> At a population-level, we are not aware of any other estimates of cross-sectoral palliative care reach—in Canada or elsewhere—that is taken from direct observation. Ontario has a single payer system, with mainly public *funding* for the sectors examined and a mix of private (e.g. most physician care) and public (e.g. most hospital care) *delivery* of



**Figure 1.** Number of days of palliative care delivered by month prior to death for: all sectors, community-based palliative care (outpatient physician visits, home care, long-term care), and hospital-based palliative care (inpatient care in hospital, complex continuing care, and emergency room visits).

services; these results are potentially generalizable to other jurisdictions with similar health systems (e.g. England, Norway, and Australia).<sup>28</sup> Given that access and use of health services generally decline without coverage,<sup>29</sup> we anticipate palliative care reach to be *generally* lower in countries with lower levels of universal coverage (e.g. developing nations), whether it be from a single or multi-payer insurance. Conversely, we expect palliative care reach to be higher in areas in countries that devote more social and health resources to end-of-life care (e.g. The Netherlands).<sup>30</sup>

Many receiving palliative care received only a few encounters; one in four received two or less encounters. Additionally, half of encounters occurred *and* were initiated in the 2 months prior to death, contrary to World Health Organization's definition of palliative care, to be delivered early in the course of a disease.<sup>31</sup> Overall, we observed large variation in the intensity and time of initiation of palliative care. Of the palliative care observed, a large proportion was delivered through home care and outpatient physician visits; however, a large number of palliative care days are also delivered in acute care hospitals, especially in the last month prior to death. Furthermore, we have shown that overall, only a small proportion of the decedent population will ever receive end-of-life care in their home through palliative home care, and even less from physician home visits. Our findings are consistent with the small number of population-based studies that

show that only a small proportion of the population will receive palliative care in their home at the end of life.<sup>32,33</sup> It is also consistent with a recent study that compared end-of-life care for cancer patients across seven developed countries, showing that Canada—along with Belgium, England, Germany, and Norway—was more hospital centric than The Netherlands or the United States.<sup>28</sup>

### Limitations and strengths

Our estimate does not include services paid out-of-pocket and palliative care delivered that is not recorded as such in the databases. We also recognize that the underreporting of palliative care is a limitation in all population-level administrative data. Yet, such data currently offer the only direct window into palliative care in the population. The observed low level of palliative home visits by physicians, for example, is likely *partly* due from underuse of palliative care billing codes; a physician home visit is captured when a palliative care travel code is used, or when any travel code is used along with a palliative care diagnosis. However, when we examined home visits for any reason in the last year of life—using well-known general travel codes that are linked to monetary compensation—we still observed that less than one in five (19.1%) of decedents will receive a visit in the last year of life for any reason (data not shown). Similarly, care that is palliative in nature is likely being delivered at the end of life for a significant proportion of

long-term care residents (the majority of long-term care residents in Ontario die in a long-term care facility), but is not coded as being palliative in nature. Our study offers the first look at the health administrative codes that can be used in the Canadian context—future work can elucidate the magnitude of miscoding and underreporting across different jurisdictions.

Additionally, we examined the penetration of palliative care among all decedents, including those who die suddenly of external and other unexpected causes. Many of these individuals likely did not receive palliative care because of the acute nature of death. Only 6.5% of Canadian deaths in 2011 were due to external causes;<sup>34</sup> it is difficult to estimate the proportion in the population dying unexpectedly, with one previous study in the United Kingdom putting an estimate of 25%.<sup>35</sup> Partly offsetting our underestimation of the reach of palliative care is our lack of data (aside from physician services) for hospice palliative care; about 2500 of Ontarians die yearly in hospices, or about 3% of all deaths.

The major strength of this study is the inclusion of a large set of health sectors, linked at the individual level, for a large population-based cohort of decedents. This allows direct observation of palliative care provision in the *entire population* for the major healthcare sectors, largely generalizable to other Canadian provinces and other high-income countries with publicly funded health care. This information provides feedback to the healthcare system on its provision of palliative care across different settings and by proximity to death.

## Conclusion

We have demonstrated the feasibility and challenges of capturing meaningful palliative care across health sectors using linked administrative data. Similar studies on palliative and/or end-of-life care could be conducted in jurisdictions with population-level data linked across health sectors (e.g. in many other Canadian provinces, the United Kingdom, Australia, and Scandinavian countries).<sup>28</sup> Such work enables a variety of future work including those that monitor quality of care, examine the supporting factors that improve access to palliative care, evaluate the effect of palliative care on outcomes, and evaluate the effect of interventions to improve access and outcomes. Sector-specific data are most meaningful when they describe well-defined palliative care services, such as palliative physician home visits and a palliative home care program.

Health care at the end of life in many populations, including in Canada, predominantly occurs in acute care institutions.<sup>28,32,33</sup> Our findings show that palliative care follows this pattern. This is in stark contrast to the finding that the majority of the population prefer to die at home, with four-fifths not changing preference as their illness progressed.<sup>36</sup> We have also shown that there is large variation

in the intensity and timing of care, with many receiving little care, and a significant proportion of care initiated and delivered close to death.

Augmenting palliative home care programs and increasing palliative care delivered by physicians in both outpatient and home settings require addressing a complex web of barriers. This likely includes improving training, ensuring adequate remuneration, improving the use of prognostic tools, and, for physicians, providing protected time for home visits. Palliative care also needs to focus on targeting patient populations less likely to receive care, including those without cancer. Both palliative home care and physician home visits have been shown to improve outcomes at the end of life.<sup>4</sup> Ontario and other jurisdictions can continue its efforts to support aging and dying in appropriate places of care by improving the reach of palliative care to the dying.

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## Author contribution

P.T. was the lead author; the other authors were involved with all stages in the conceptualizing and editing of this article. This includes design and conception or analysis and interpretation of the data, drafting or revising for intellectual content, and final approval of the version submitted for publication. All authors act as guarantors and affirm that the article is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained. All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

## Data sharing

Using encrypted health card numbers as unique identifiers, records of healthcare use and costs were linked across various administrative databases. No written consent was obtained; all data were encrypted using health card numbers as unique identifiers. Thus, all records used were de-identified and anonymized. All data were housed and analyzed at ICES, a prescribed entity for the purposes of section 45 Ontario's Personal Health Information Privacy Act.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethics

This study has been approved by the research ethics board at the ICES, at Sunnybrook Health Sciences Centre in Toronto, ON, Canada, and by the research ethics board at the Ottawa Hospital Research Institute at Ottawa, ON, Canada.



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## Submission declaration

Work described has not been published previously. It is not under consideration for publication elsewhere. This publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and, if accepted, it will not be published elsewhere including electronically in the same form, in English or in any other language, without the written consent of the copyright-holder. We have followed the STROBE checklist for observational, cross-sectional studies.

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## Appendix I

### Codes used to identify the provision of palliative care

1. *Outpatient physician billings for palliative care*. Provision of services by physicians as captured in the Ontario Health Insurance Plan (OHIP) database through the following codes:
  - A945: Special palliative care consultation in clinic, office, home; minimum 50 min
  - K023: Palliative care support in half hour increments; may be used to add time for longer consultations following a code for A945, or for any PC support visit. Exclude if patient is in hospital, long-term care (LTC), complex continuing care (CCC), or rehabilitation
  - G512: Weekly care case management from palliative primary care management (Monday–Sunday)
  - G511: Telephone services to patient receiving PC at home (max. 2/week)
  - B966: Travel premium for palliative care (billed with B998/B996)
  - B998: Home visit for palliative care between 07:00 and 24:00
  - B997: Home visit for palliative care between 24:00 and 07:00
  - K700: Palliative care outpatient case conference
2. Home-based physician home visits for palliative care, using the following subset of outpatient physician care from OHIP:
  - Travel codes B966, B997, B998 and telephone consult code G511
3. Hospital admissions:
  - (a) Data source: Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD):
    - ICD-10 Code: Z51.5 and ICD-9 Code: V66.7: Any diagnosis of “palliative” as the main or contributing reason for admission
    - PATSERV=58: main patient service of “palliative care” was responsible for care
    - PRVSERV[1-8] or INSERV[1-20]=00121: “palliative medicine” was a provider who provided service, or an intervention service code of palliative medicine was provided.
  - (b) Data source: OHIP billing codes for inpatient physician services:
    - C945: Special palliative care consult (minimum 50 min); K023 may be used to add time for longer consultations following a code for C945, or may be billed alone
    - C882: Family medicine palliative care, non-emergency (routine) hospital inpatient service
    - C982: Specialist palliative care, non-emergency (routine) hospital inpatient service
    - E083: Subsequent visit and palliative care visit by the most responsible physician premium; following C982 or C882 or C122, C123, C124, C142, C143
    - K023: Palliative care support in half hour increments, if patient was in hospital during date of claim

4. Emergency room visits using the National Ambulatory Care Reporting System (NACRS):
  - PRVSERV [1-10]=00121: Provider service code of palliative medicine
  - CONSULTSERV1 to CONSULTSERV3=00121: Consult service of palliative medicine was called
5. Home Care:
  - (a) Data source: Resident Assessment Instrument—Contact Assessment (RAI-CA):
    - B2c=1: Referral to initiate/continue palliative care
    - B4=12: Expected place of stay during service of Hospice facility or Palliative Care Unit
  - (b) Data source: RAI-Home Care:
    - P2S=1 or 2: Hospice care was provided with complete or partial adherence
    - CC3f goals of care=palliative care
  - (c) Data source: Home Care Database (HCD):
    - SRC\_admission=95: Service recipient code (i.e. classification) of end of life on admission
    - Service\_RPC=95: Service care goal of end of life; patient provided service under end-of-life designation
    - Residence\_type=2000: Staying in hospice or palliative care unit while receiving service
    - SRC\_discharge=95: Service recipient code of end of life on discharge
6. Long-term care (LTC) facilities
  - (a) Data source: OHIP billing codes:
    - K023: Palliative care support in half hour increments if delivered in LTC
    - W872: Family physician palliative care subsequent visit
    - W972: Specialist physician palliative care subsequent visit
  - (b) Data source: Continuing Care Reporting System (CCRS):
    - CCRS\_P1AO=1: Received hospice care in last 14 days
7. Complex Continuing Care (CCC)
  - (a) Data source: OHIP billing codes:
    - K023: Palliative care support in half hour increments if delivered in CCC
    - W882: Family physician palliative care subsequent visit
    - CCRS\_P1AO=1: Received hospice care in last 14 days