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Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.

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Abstract: 280 words

Objectives: To examine the disparity in access to palliative care between different disease trajectories.

Design: A retrospective population-based decedent cohort study using linked administrative health data sets

Setting: Ontario, Canada

Participants: Ontario decedents between April 1, 2010 and December 31, 2012. Patients were categorized into disease trajectories: terminal illness (e.g. cancer), organ failure (e.g. chronic heart failure), frailty (e.g. dementia), sudden death, or other.

Interventions: Receipt of palliative care services in institutional and community settings, derived from a validated list of palliative care codes from multiple administrate databases.

Outcome measures: Receiving any palliative care services in the last year of life (yes/no), intensity (total days), and time of initiation of palliative care, in hospital and community sectors. Multivariable analysis examined the association between disease trajectory and the receipt of palliative care in the last year of life.

Results: We identified 235,159 decedents in Ontario. In the last year of life, 88% of terminal illness, 44% of organ failure, and 32% of frailty decedents accessed at least one palliative care service. Most care was provided during an inpatient hospitalization. Terminal illness decedents received twice as many palliative care days (mean of 49 days), which were initiated about four times earlier (107 days before death) compared to organ failure and frailty decedents. Multivariate analysis showed that terminal illness was associated with a 17 times increase in likelihood to receive palliative care than frailty.

Conclusions: Decedents with terminal illness disease trajectory are far more likely to receive any palliative care, with increased intensity, and earlier before death than those dying of organ failure or frailty. These large disparities exist despite recent increased evidence on how to improve palliative care interventions for non-cancer diseases.

Strengths and Limitations of this study

- This study examines palliative care access disparity across a comprehensive list of services in multiple settings as well as by disease trajectory

- This is a large population-based study, within a universal health system where patients have access to both institutional and community palliative care but disparities exist
- This work provides a baseline for improvement of equitable access to palliative care for patients in all trajectories
- Using administrative health data to capture use of palliative care is limited by under-coding of care delivered, particularly in the community setting
- We are unable to account for the quality of care, privately obtained care, or patients' end-of-life care preferences and how those differ between trajectory

Introduction

With the population aging and living longer with more comorbidities, health systems are focused on providing quality end-of-life care through improved palliative care services.[1,2] Earlier availability of palliative care to terminal patients has been shown to improve quality of life, reduce late-life health services utilization, and even extend survival.[3,4,5] However, palliative care is often not delivered or initiated very late in the dying trajectory. Research shows that dying trajectories differ greatly by disease.[6,7,8] The main three trajectories are: 1) terminal illness, typical of cancer (high-function followed by acute decline); 2) organ failure, typical of heart and lung disease (medium-high function, intermittent acute exacerbations and partial recovery); and 3) frailty, typical of dementia (low function, and prolonged, gradual dwindling).

Evidence shows that palliative care is more often provided to cancer versus non-cancer patients[9,10,11,12] because of the 'predictability' of decline[8,13,14], availability of cancer prognostic tools[15,16,17], and the history of hospice care and cancer. However, little has been done to describe access patterns amongst differing disease trajectories on a population level.

This study focuses on patients in Ontario, Canada who, through a universal health care system, have the potential to access both community and institutional palliative care. Ontario is the largest province in Canada, and has the highest number of deaths.[18] Previous studies have shown that a little over half of patients in Ontario received palliative care in their last year of life[19], though it did not examine variations by disease trajectory. This study examines how disease trajectory is associated with access to palliative care services in both hospital and community sectors. We also examine time to initiation and intensity of palliative care at end-of-life. We hypothesize that the terminal illness trajectory will receive more access, early initiation, and more intensity of palliative care services than other disease trajectories. Identifying any variations by dying trajectory will allow for more disease-specific strategies for quality improvement initiatives.

Methods:

We conducted a retrospective cohort study of Ontario decedents who died between April 1, 2010 and December 31, 2012. We used linked administrative health databases, held at the Institute for Clinical Evaluative Sciences, to identify palliative care services used across multiple health sectors in the 12 months before death. We used a previously derived list of palliative care codes from multiple administrate databases.[19,20] The databases included: Physician claims database, which captured palliative care services billed by physicians; Home Care Database and the interRAI databases captured publicly-funded home care services, such as nursing or personal support care, with palliative care intent; Discharge Abstract Database and the National Ambulatory Care Reporting System captured hospitalizations and emergency department visits, respectively, where palliative care was the main reason for admission or consulted; and Continuing Care Reporting System captured palliative care provided in long-term care and complex continuing care settings. We also linked with the Vital Statistics database (Office of the Register General – Deaths database) for date of death, sex, age and postal code; and Statistics Canada Census data for income quintile and rurality via postal codes.[21]

We further categorized decedents by the major trajectories of functional decline at end of life, defined by main cause of death as per prior research,[7,8,22] which have also been validated in Canada.[23,24] Using ICD-10 codes from the death certificate (see Appendix I), decedents were classified into these trajectories: terminal illness (e.g. cancer), organ failure (e.g. chronic heart failure), frailty (e.g. Alzheimers), sudden death (e.g. accident), and other. (See Table 1 for top 5 ICD diagnoses codes for each trajectory)

Outcomes of interest

The primary outcome of interest was whether a decedent received palliative care at least once in the last 12 months of life. We further categorized palliative care services delivered in an institutional (i.e. hospital inpatient, complex continuing care, long-term care, and ED) and community settings (i.e. outpatient care, home care, and home-based physician billing). We also examined timing to initiation of palliative care, defined as first instance of any palliative

care service captured in the last year of life. If a decedent had the first palliative care service outside of the window, initiation was represented as 365 days. We also examined intensity of palliative care by totaling the number of days palliative care was delivered, categorized by service. In an acute hospital setting, palliative care days were counted for the entire duration of stay when the patient was admitted as palliative and the most responsible diagnosis for the hospital stay was also palliative, the main service provider was palliative, or palliative care was consulted. For all remaining palliative acute hospital encounters only a single day of the hospitalization was counted.

Statistical Analysis

Descriptive mean and median statistics describe the usage patterns of decedents as well as the trajectory of care in the last year of life. Multivariate logistic regression was used to predict the likelihood of any use of palliative care. A negative binomial regression was used to predict the number of days of palliative care that a decedent would receive in the last year of life. Covariates included in the models include: sex, age, income quintile, rurality[21,25] and Charlson comorbidity score.[26] Ethics approval for this study was received from the Ottawa Hospital Research Institute Ethics Board in Ottawa, Canada.

Results

During the study period, we identified 235,159 decedents, who used a total of 4,497,685 days of palliative care services in the last year of life (mean 19.1 days per decedent). Our cohort was categorized into end-of-life trajectories: 32% as terminal illness, 31% organ failure 31%, 29% frailty, 5% other, and 3% as sudden death. (Table 2) Decedent characteristics were similar across all the trajectories, with the exception of frailty which had more older females and sudden death which had younger decedents with fewer comorbidities. Males and females were equally represented and the 80% were aged 65 years or older. 79% of the cohort had 3 or more comorbidities, where hypertension was the most prevalent, followed by osteoarthritis, cancer, diabetes, and congestive heart failure. Remaining results will focus on the three major disease trajectories: terminal illness, organ failure, and frailty.

Palliative Care Usage

Among the full cohort, 54% received at least one palliative care service in the last year of life. Palliative care from an institutional and community setting was mainly delivered by hospital inpatient services (46% of overall cohort) and community outpatient services (25%) respectively. Palliative care physician home visits were delivered to 6% of the overall decedent cohort. However, there was wide variation in use of palliative care across end-of-life trajectories. (Table 3) Across all settings, 88% of those in the terminal illness trajectory received palliative care, compared to 44% of the organ failure trajectory, and 32% in the frailty trajectory. Within particular settings, the terminal illness trajectory had nearly twice as many decedents receiving palliative care services in the hospital inpatient setting (76%) than the other trajectories. Many terminal illness decedents received outpatient palliative care (53%) and end-of-life homecare services (47%), which was four and eight times more respectively, than in the other two trajectories. Palliative care physician home visits were delivered to 15% of terminal illness decedents, compared to 3% of organ failure decedents and 2% of frailty decedents.

Intensity of palliative care

Among users of palliative care in any setting, terminal illness has the highest mean number of palliative care days, ranging from 17 in an institution and 32 in the community, compared to 12 and 11 for organ failure, and 11 and 10 for frailty trajectories. In all trajectories, about half of all palliative care days used occurred in the last two months of life, with a two-fold increase in the last month of life. (Figure 1) For example, decedents in the terminal illness trajectory averaged eight palliative care days in the second to last month before death, which increased to 13 days in the final month of life.

Initiation of palliative care

Decedents in the terminal illness trajectory had palliative care initiated a median of 107 days before death, more than four times earlier than organ failure (median 22 days) and frailty

(median 24 days). In terms of intensity terminal illness trajectory had palliative care on 37% of days after initiation versus 25% and 23% in organ failure and frailty decedents. (Table 3)

Multivariable analyses of odds of using any palliative care services

When examining the odds of using any palliative care services in the last year of life, decedents with a terminal illness trajectory have an odds ratio of 17.0 (OR 95% CI: 17.03, 17.09) when compared to those with a frailty trajectory (controlling for sex, age, income quintile, rurality, and number of comorbidities. (Table 4) Decedents in the organ failure trajectory are nearly twice (OR 1.7, 95% CI: 1.68-1.72) as likely to use any palliative care compared to frailty trajectory.

Multivariable analyses of number of palliative care days received

Negative binomial regression analysis shows that decedents in the terminal illness trajectory receive seven times more days of palliative care (IRR: 6.94, 95% CI: 6.91, 6.97) in the last year of life than decedents with a frailty trajectory. Increasing comorbidity was associated with higher number of days of palliative care received in the last year of life.

Discussion:

Our population-based analysis of decedents in Ontario, Canada shows that while nearly half of decedents receive at least 1 palliative care service, there are large disparities based on dying trajectory. 88% of those dying in the terminal illness trajectory (predominantly cancer deaths) received palliative care services, compared to organ failure (44%) or frailty trajectories (32%). The terminal illness group also received twice as many palliative care services, and four times earlier than the other two trajectories, after controlling for multiple covariates. In spite of the fact that most patients express a wish to receive care and die at home,[27,28,29]most palliative care was delivered in an inpatient hospital setting across all trajectories.

There has been a large body of international literature describing the bias of palliative care for cancer patients.[6,13,19,30,31,32,33] For instance, comparing to the European Union, non-cancer patients in Northern England were 11 times less likely to be referred to palliative care

teams than cancer patients.[31] In a Swiss hospital's palliative care consult team, non-cancer patients took longer to be referred than cancer patients, and had less days on palliative care service before death.[30] Our study advances prior work because it examines disparities in a population-based study, within a universal health system, and includes a comprehensive list of palliative care services across multiple settings. Of note, Ontario does not require an eligibility criteria of less than six months to live to receive palliative care services, like in the USA's Medicare hospice benefit (over age 65). Comparing the two systems, in our overall cohort, 53% received at least 1 palliative care service, whereas in the US Medicare hospice benefit in 2015, 46% received at least 1 day in hospice.[34] The hospice benefit served 28% cancer patients, whereas among those receiving palliative care in our cohort 53% had terminal illness. The average length of stay for all patients enrolled in hospice was 70 days in the US compared to 59 days in Ontario, Canada. The vast majority of the Ontario palliative care services were delivered in hospital in-patient units, compared to at home or nursing facilities in the US. The differences likely reflect the benefit's interdisciplinary visiting hospice service that delivers care to patient's homes, a comprehensive service which does not exist in Canada.

The disparities in access to palliative care for those dying of frailty and organ failure compared to a cancer illness is striking considering the growing body of evidence of efficacious palliative care interventions for non-cancer diseases[35,36,37,38] and the international attention on guidelines to improve palliative care for non-cancer diagnoses.[39] Improving access to non-cancer diagnosis will need to include overcoming the stigma of palliative care's association with imminent death and medical failure.[40,41] Moreover, our data highlights a large opportunity for improved access: very few people receive community-based palliative care, especially homecare services and physician home-visits for non-cancer disease trajectories.

Limitations of using administrative health data to capture the use of palliative care include the under-coding of palliative care delivered, particularly in the community,[19] since elements of palliative care may be provided but not billed. We cannot describe the quality of care or include any privately obtained care. We also were unable to account for patients' preferences for treatment and how those may differ by disease trajectory. We hypothesize that palliative care in the community, particularly end-of-life home care services and physician home

visits, are high-quality palliative care since they have been shown to be associated with fewer hospitalizations at the end of life.[42] Unlike the extensive hospice system in UK or USA, Ontario, Canada only has about 25 residential hospice facilities, each with a dozen beds, where 1-3% of decedents die each year. Thus we cannot directly compare hospice-specific services. However, when hospice care is provided, it occurs after initiation of palliative home care services—which is included in our study.

In conclusion, our study quantifies a large disparity in access to palliative care for those dying from organ failure and frailty trajectories. Decedents with a terminal illness trajectory, exemplified by a cancer diagnosis, are significantly more likely to receive palliative care services than the other dying trajectories; they receive more services (intensity) both in hospital and community, and these services are initiated earlier in the dying trajectory. Even still, all trajectories could benefit from increased access to palliative care services, particularly palliative home care services and physician home visits. This work provides a baseline for improvement of equitable access to palliative care for patients across all trajectories.

Author Contributions: H.S. and P.T. conceptualized the study and R.P performed the data abstraction, and analysis. All authors contributed to interpretation and critical analysis of results. E.O and H.S. drafted the first manuscript and all authors were responsible for contributing to the critical content and review of the manuscript. 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 this study as planned have been explained. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

Data Sharing: Using encrypted health card numbers as unique identifies, 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 analyses at ICES, a prescribed entity for the purposes of section 45 of Ontario's Personal Health Information Privacy Act

Declaration of conflicting interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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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Tables and Figures:

Figure 1. Average monthly palliative care days used by trajectory

Table 1: Top 5 causes of death by disease trajectory

	Terminal Illness	Organ Failure	Frailty	Sudden Death	Other
1	Bronchus and Lung Cancer; N=17,883 (23.6%)	Other chronic obstructive pulmonary disease; N=8,944 (12.4%)	Chronic ischaemic heart disease; N=19,424 (28.8%)	Intentional self-harm by hanging, strangulation and suffocation; N=1,047 (13.4%)	Other septicaemia; N=2,735 (23.2%)
2	Colon cancer; N=5,597 (7.4%)	Stroke, not specified as haemorrhage or infarction; N=7,233 (10.0%)	Acute myocardial infarction; N=13,249 (19.6%)	Accidental poisoning by and exposure to narcotics and hallucinogens; N=714 (9.1%)	Unspecified fall; N=2,329 (19.8%)
3	Breast Cancer; N=5,250 (6.9%)	Unspecified diabetes mellitus; N=4,937 (6.8%)	Unspecified dementia; N=12,025 (17.8%)	Accidental poisoning by and exposure to other unspecified drugs, medicaments and biological substances; N=394 (5.0%)	Other fall on same level; N=1,737 (14.7%)
4	Pancreatic Cancer; N=4,140 (5.5%)	Heart failure; N=3,308 (4.6%)	Alzheimer's disease; N=5,761 (8.5%)	Exposure to unspecified factor; N=347 (4.4%)	Other ill-defined and unspecified causes of mortality; N=891 (7.6%)
5	Prostate Cancer; N=3,816 (5.0%)	Other interstitial pulmonary diseases; N=2,289 (3.2%)	Pneumonia, organism unspecified; N=4,851 (7.2%)	Motor- or nonmotor-vehicle accident; N=335 (4.3%)	Fall on and from stairs and steps; N=541 (4.6%)

Table 2. Cohort Demographics by End-of-Life Disease Trajectory

	Terminal Illness		Organ Failure		Frailty		Other		Sudden Death		Overall	
	N	%	N	%	N	%	N	%	N	%	N	%
Total cohort	75,657	32	72,363	31	67,513	29	11,784	5	7,842	3	235,159	100
Sex												
Male	39,125	52	34,371	48	30,703	45	5,295	45	4,987	64	114,481	49
Female	36,532	48	37,992	53	36,810	55	6,489	55	2,855	36	120,678	51
Age												
<19	172	<1	691	1	47	<1	827	7	435	6	217	1
19-44	1,886	2	1,601	2	479	1	332	3	2,636	34	6,934	3
45-54	5,454	7	3,247	4	1,738	3	442	4	1,547	20	1,242	5
55-64	12,311	16	6,631	9	4,193	6	730	6	1,090	14	24,955	11
65-74	18,042	24	10,885	15	7,472	11	1,229	10	676	9	38,304	16
75-84	22,790	30	21,447	30	18,990	28	2,959	25	780	10	66,966	28
85-94	13,730	18	23,514	32	27,641	41	4,257	36	592	8	69,734	30
95+	1,272	2	4,347	6	6,953	10	1,008	9	86	1	1,366	6
Income*												
Lowest	16,014	21	17,288	24	15,637	23	2,545	22	2,008	26	53,492	23
Low	15,931	21	15,344	21	13,634	20	2,317	20	1,626	21	48,852	21
Middle	14,698	19	13,727	19	13,059	19	2,086	18	1,474	19	45,044	19
High	14,621	19	13,074	18	12,884	19	2,063	18	1,358	17	44,000	19
Highest	13,996	19	12,136	17	11,850	18	1,967	17	1,258	16	41,207	18
Urban*												
Urban	64,302	85	61,171	85	57,853	86	9,752	83	6,564	84	199,642	85
Rural	1,123	15	1,074	15	9,558	14	1,286	11	1,211	15	34,027	14
Number of Chronic Diseases												
0	348	<1	2,049	3	1,649	2	1,166	10	1,791	23	7,003	3
1	6,496	9	3,732	5	3,674	5	672	6	1,891	24	16,465	7
2	11,388	15	6,463	9	7,144	11	1,150	10	1,358	17	27,503	12
3	14,846	20	9,543	13	9,710	14	1,559	13	1,022	13	36,680	16
4	14,238	19	11,296	16	11,059	16	1,815	15	674	9	39,082	17
5	11,260	15	11,772	16	10,730	16	1,740	15	457	6	35,959	15
6+	17,081	23	27,508	38	23,547	35	3,682	31	649	8	72,467	31

*Does not equal 100%: a small number of records are missing this information

Table 3. Use (≥1 encounters) of palliative care by end of life trajectory and sector in the last year of life

Sector and Setting of Palliative Care	End of life trajectory: TERMINAL ILLNESS (N=75,657)	ORGAN FAILURE (N=72,363)	FRAILTY (N=67,513)	OVERALL* (N=235,159)
ANY PALLIATIVE CARE IN ANY SETTING	88.0%	44.4%	32.4%	53.6%
PALLIATIVE CARE IN AN INSTITUTIONAL CARE SETTING				
Any Institutional Care	76.4%	39.9%	26.1%	46.5%
Hospital Inpatient	75.6%	39.4%	25.2%	45.9%
Complex Continuing Care	6.0%	1.4%	1.1%	2.7%
Long-term Care	0.4%	0.4%	0.9%	0.5%
Emergency Room	0.2%	<0.1%	<0.1%	0.1%
PALLIATIVE CARE IN A COMMUNITY CARE SETTING				
Any Community Care	68.6%	17.2%	15.1%	32.4%
Outpatient	52.7%	12.4%	11.9%	24.8%
Home Care	46.8%	6.0%	3.4%	18.0%
Physician Home Visits	14.8%	2.5%	1.9%	6.2%
AMONG USERS of PALLIATIVE CARE				
Mean days of Institutional Care	16.54	12.02	10.71	14.10
Mean days of Community Care	32.08	10.74	9.68	21.59
INITIATION AND INTENSITY				
Median number of days before death to palliative care initiation (IQR)	107 (33, 246)	22 (6, 124)	24 (6, 132)	59 (13, 200)
Proportion of days following initiation in which palliative care was used (IQR)	37% (0.18,0.67)	25% (0.1, 0.7)	23% (0.1,0.64)	33% (0.14,0.67)

*Overall includes the sudden death (3%) and other (5%) trajectories which account for 8% of the total cohort. These are not individually shown here

Table 4. Predictive models for the use of palliative care

Exposure	Use of Palliative Care (Yes/No)‡		Number of Palliative Care days*	
	Odds ratio (95% CI)		Incident Rate Ratio (95% CI)	
Trajectory				
Terminal Illness	17.06	(17.03, 17.09)	6.94	(6.91, 6.97)
Organ Failure	1.70	(1.68, 1.72)	1.56	(1.54, 1.58)
Frailty	REF.		REF.	
Other	1.60	(1.56, 1.64)	0.97	(0.93, 1.01)
Sudden Death	0.35	(0.27, 0.43)	0.22	(0.16, 0.28)
Sex				
Female	1.06	(1.04, 1.08)	1.08	(1.06, 1.10)
Male	REF.		REF.	
Age				
<19	0.72	(0.64, 0.80)	0.78	(0.72, 0.84)
19-45	0.89	(0.84, 0.94)	0.98	(0.93, 1.03)
45-54	REF.		REF.	
55-64	1.08	(1.04, 1.12)	0.97	(0.93, 1.01)
65-74	1.17	(1.13, 1.21)	0.95	(0.92, 0.98)
75-84	1.16	(1.12, 1.20)	0.90	(0.86, 0.94)
85-94	1.00	(0.84, 1.16)	1.67	(1.55, 1.79)
>=95	1.10	(1.05, 1.15)	0.91	(0.86, 0.96)
Income Quintiles				
Q1	REF.		REF.	
Q2	1.05	(1.02, 1.08)	1.09	(1.06, 1.12)
Q3	1.01	(0.98, 1.04)	1.08	(1.05, 1.11)
Q4	1.07	(1.04, 1.10)	1.10	(1.07, 1.13)
Q5	1.09	(1.06, 1.12)	1.19	(1.16, 1.22)
Rurality				
Rural	REF.		REF.	
Urban	1.28	(1.25, 1.31)	1.23	(1.2, 1.26)
Number of Comorbidites				
0	REF.		REF.	
1	3.27	(3.18, 3.36)	2.82	(2.75, 2.89)
2	3.74	(3.65, 3.83)	3.13	(3.06, 3.20)
3	4.12	(4.03, 4.21)	3.43	(3.36, 3.50)
4	4.53	(4.44, 4.62)	3.69	(3.62, 3.76)
5	4.75	(4.66, 4.84)	3.97	(3.90, 4.04)
≥6	5.40	(5.31, 5.49)	4.83	(4.76, 4.90)

‡ Multivariable logistic regression was used to determine odds ratio

* Negative binomial regression was used to determine incident rate ratio

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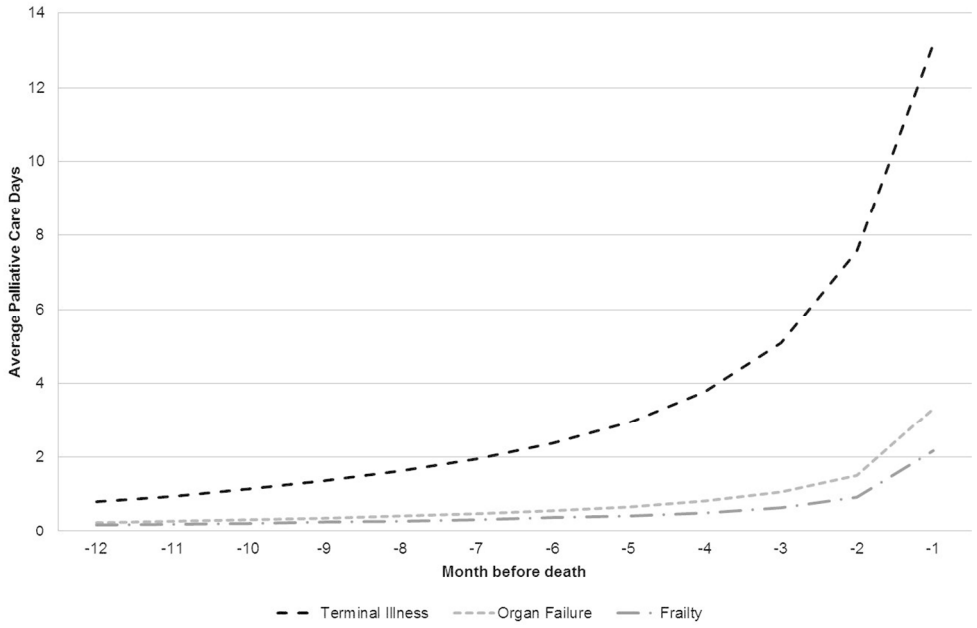

Figure 1. Average monthly palliative care days used by trajectory

228x145mm (150 x 150 DPI)

Appendix I: ICD-10-CA Codes used for Trajectory Group Assignment

Trajectory Group	Underlying Cause of Death Code (ICD10CA)
Sudden Death	R95, R96, W03, W2 – W9, W11 - W17, X, V, Y0 - Y2, Y30 - Y36
Frailty	A02 - A04, A08, A09, A37, A48, A49, B01, B02, B37, B95, B96, E4, E5, E60 - E64, E86, E87, E97, F00 - F03, G20 - G26^, G30 - G32, G35 - G37, G81, G82, I21, I25.0, I25.3, I25.4, I25.5, I25.6, I25.8, I25.9, I251, I69, J00 - J06, J10 - J16, J18, J20 - J22, J69, J80, K59, L89, M00 - M03, M05 - M09, M11 - M19, M32 - M36, M41 - M43, M45, M46, M80 - M85, M91, M92, N30, R54, R63.3, R63.4
Terminal Illness	B24, C, D1 - D3, D40 - D48, N18
Organ Failure	A15 - A19, A50 - A53, A80, A81, A86 - A89, B15 - B19, B90 - B94, D5 - D70, D71 - D77, D80 - D84, D86, D89, E00 - E07, E10 - E16, E2, E30 - E35, E65 - E68, E70 - E75.0, E75.1, E75.2, E75.3, E75.4, E75.5, E75.6, E76 - E80, E83 - E85, E88, F1, G0, G10 - G13, G40, G41, G45 - G47, G5, G60 - G64, G70 - G73, G80, G90 - G95, H0 - H8, H91 - H95, I01, I05 - I13, I15, I20, I22 - I24, I25.2, I26 - I28, I3, I4, I50 - I52, I60 - I68, I70 - I74, I77 - I79, I8, I95, I97 - I99, J30.0, J30.1, J30.2, J30.3, J30.4, J31.0, J31.1, J31.2, J32 - J38, J40 - J45, J47, J60 - J68, J70, J81, J82, J84 - J86, J90 - J94, J96, J98, J99, K0, K10 - K14, K20 - K23, K25 - K31, K35 - K38, K40 - K46, K50 - K52, K55 - K58, K60.0, K60.1, K60.2, K60.3, K60.4, K60.5, K61.0, K61.1, K61.2, K61.3, K61.4, K62, K63, K65 - K67, K70 - K73, K74.0, K74.1, K74.2, K74.3, K74.4, K74.5, K74.6, K75 - K77, K80 - K83, K85, K86, K90 - K93, L00, L01.0, L01.1, L02 - L05, L08, L10 - L14, L20 - L27, L28.0, L28.1, L28.2, L29, L30, L40 - L45, L50 - L54, L70 - L74, L93.0, L93.1, L93.2, L94, L95.0, L97 - L99, M10, M22 - M25, M30, M31, M47 - M49, M51, M73, M79, M86 - M90, M93, M94, N00 - N08, N10 - N13, N14.0, N14.1, N14.2, N14.3, N14.4, N15 - N17, N19 - N22, N25 - N29, N31 - N33, N34.0, N34.1, N34.2, N34.3, N35 - N37, N39 - N45, N47 - N51, N60 - N64, N70 - N77, N8, N90 - N96, Q00 - Q07, Q10 - Q18, Q20 - Q28, Q3, Q40 - Q45, Q50 - Q56, Q6 - Q9

Appendix I: ICD-10-CA Codes used for Trajectory Group Assignment

Trajectory Group	Underlying Cause of Death Code (ICD10CA)
Other	A00, A01, A05 - A07, A20 - A28, A30 - A36, A38 - A44, A46, A54 - A60, A63 - A71, A74 - A79, A82, A85, A91 - A99, B00, B03 - B09, B25 - B27, B30, B33 - B36, B38, B39, B4 - B7, B80 - B83, B85 - B89, B97, B99, F04 - F07, F09, F20 - F25, F28 - F34, F38 - F45, F48, F50 - F55, F59, F6 - F9, G43, G83, G96 - G99, I00, I02, J17, J39, J95, K91, L55 - L68, L80 - L88, L90 - L92, M20, M21, M40, M50, M53, M54, M60 - M63, M65 - M68, M70 - M72, M75 - M77, M95, M96, M99, N46, N97 - N99, O00 - O08, O10 - O16, O21 - O26, O28 - O36, O40 - O48, O6, O70 - O75, O8, O90 - O92, O95 - O99, P00 - P08, P10 - P15, P2, P35 - P39, P5, P60, P61, P70 - P78, P80 - P83, P90 - P96, R0, R1, R20 - R23, R25 - R29, R3, R4, R50 - R53, R55 - R69, R7, R8, R90 - R94, R98, R99, W00 - W02, W04 - W10, W18, W19, Y4 - Y9

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 – title page
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1 – title page
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any pre-specified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Outcomes – 4 Statistical analysis - 5
Data sources/ measurement	8*	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	4 - 5
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	13 (table footnote)
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	NA NA

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			
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	NA
		(b) Give reasons for non-participation at each stage	
		(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	Table 1 - 12
		(b) Indicate number of participants with missing data for each variable of interest	Table 1 - 12
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	5,6 table 3,4
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	NA
		Cross-sectional study—Report numbers of outcome events or summary measures	NA
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	5-6, Table 3, Table 4
		(*b*) Report category boundaries when continuous variables were categorized	Table 4
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	7
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	8
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	8
Generalisability	21	Discuss the generalisability (external validity) of the study results	7,8
Other information			
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	10

*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.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is 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 Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.

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Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.

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Abstract

Objectives: To examine access to palliative care between different disease trajectories and compare to other countries.

Design: A retrospective population-based decedent cohort study using linked administrative data

Setting: Ontario, Canada

Participants: Ontario decedents between April 1, 2010 and December 31, 2012. Patients were categorized into disease trajectories: terminal illness (e.g. cancer), organ failure (e.g. chronic heart failure), frailty (e.g. dementia), sudden death, or other.

Interventions: Receipt of palliative care services from institutional and community settings, derived from a validated list of palliative care codes from multiple administrate databases.

Outcome measures: Receiving any palliative care services in the last year of life (yes/no), intensity (total days), and time of initiation of palliative care, in hospital and community sectors. Multivariable analysis examined the association between disease trajectory and the receipt of palliative care in the last year of life.

Results: We identified 235,159 decedents in Ontario. In the last year of life, 88% of terminal illness, 44% of organ failure, and 32% of frailty decedents accessed at least one palliative care service. Most care was provided during an inpatient hospitalization. Terminal illness decedents received twice as many palliative care days (mean of 49 days) compared to organ failure and frailty decedents. Terminal illness patients initiated palliative care median of 107 days before death, compared to median of 19 days among those using the US Medicare hospice benefit.

Conclusions: Terminal illness decedents are more likely to receive any palliative care, with increased intensity, and earlier before death than organ failure or frailty decedents. This data serves as a useful comparison for other countries with similar and different health care systems and eligibility criteria.

Strengths and Limitations of this study

- This study examines palliative care access and time to initiation across a comprehensive list of health care services by disease trajectory

- This is a large population-based study, within a universal health system, where patients have access to both institutional and community palliative care
- This work provides a baseline measure of equitable access and time to initiation to palliative care for patients in all trajectories, and can be compared to other countries
- Using administrative health data to capture use of palliative care is limited by under-coding of palliative care delivered, particularly in the community setting
- We are unable to account for the quality of care, privately obtained care, or patients' end-of-life care preferences and how those differ between trajectory

Introduction

With the population aging and living longer with more comorbidities, health systems are focused on providing quality end-of-life care through improved palliative care services.[1,2] Earlier availability of palliative care to terminal patients has been shown to improve quality of life, reduce late-life health services utilization, and even extend survival.[3,4,5] However, palliative care is often not delivered or initiated very late in the dying trajectory. Research shows that dying occurs in three main trajectories: 1) terminal illness, typical of cancer (high-function followed by acute decline); 2) organ failure, typical of heart and lung disease (medium-high function, intermittent acute exacerbations and partial recovery); and 3) frailty, typical of dementia (low function, and prolonged, gradual dwindling).[6,7,8]

Evidence shows that palliative care is more often provided to cancer versus non-cancer patients[9,10,11,12,13,14] because of the 'predictability' of decline[8,15,16] and the history of hospice care for cancer patients. This 'predictability' can sometimes be formalized into health policy, such as in the US Medicare Hospice Benefit, which requires a doctor's certification that death is expected within 6 months and that the patient forego any hospital or curative care. Whereas in other countries, like the UK, Australia, and Canada, the eligibility criteria for palliative care does not require either condition. Given the growing body of literature of the benefits of early palliative care in non-cancer diagnoses,[17,18,19,20] there is a dearth of research describing how access to palliative care, particularly time to initiation before death and intensity and type of service use, differs by disease trajectory, and how that may be influenced by health system and various criteria to access palliative care at a population-level.

This study focuses on patients in Ontario, Canada, who can access palliative care services in community and institutional settings without foregoing curative treatment through its universal health care system. Criteria for palliative care referral in the hospital is at the physician's discretion; whereas in the community, they often use the "surprise question" of not being surprised if the patient died within a year, [21] combined with performance status decline.[22] In short, eligibility in Ontario is not formally standardized, which is unlike the standardized criteria of the Gold Standards Framework, which is widespread in the UK. Ontario is the largest province in Canada, and has the highest number of deaths.[23] Previous studies have shown that

half of patients in Ontario received at least 1 palliative care service in their last year of life,[24] though they did not examine variations by disease trajectory. This study examines how disease trajectory is associated with access to palliative care services in multiple settings, including time of initiation before death and intensity and type of service use. We also compare our data to other countries, namely the US, UK, and Western Australia. Our hypothesis is that compared to the US, Ontarians will initiate palliative care services earlier, across all disease trajectories, and compared to UK and Western Australia, access will be similar across all disease trajectories.

Methods:

We conducted a retrospective cohort study of Ontario decedents who died between April 1, 2010 and December 31, 2012. We used linked administrative health databases, held at the Institute for Clinical Evaluative Sciences, to identify palliative care services used across multiple health sectors in the 12 months before death. We used a previously derived comprehensive list of palliative care billing codes to capture palliative care services provided by physicians, nurses and personal support workers in multiple sectors from multiple administrate databases.[24,25] The databases included: Physician claims database, which captured palliative care services billed by physicians in both community and hospital settings; Home Care Database and the interRAI databases captured publicly-funded home care services, such as nursing or personal support care, with palliative care intent; Discharge Abstract Database and the National Ambulatory Care Reporting System captured hospitalizations and Emergency Department (ED) visits, respectively, where palliative care was the main reason for admission or consulted; and Continuing Care Reporting System captured palliative care provided in long-term care and complex continuing care settings. We also linked with the Vital Statistics database for date of death, sex, age and postal code; and Statistics Canada Census data for income quintile and rurality via postal codes.[26]

We further categorized decedents by the major trajectories of functional decline at end of life, defined by main cause of death as per prior research,[7,8,27] which have also been validated in Canada.[28,29] Using ICD-10 codes from the death certificate as defined previously,[28] decedents were classified into these trajectories: terminal illness (e.g. cancer), organ failure

(e.g. chronic heart failure), frailty (e.g. Alzheimers), sudden death (e.g. accident), and other. (Appendix 1 for main causes of death)

Outcomes of interest

The primary outcome of interest was whether a decedent received palliative care at least once in the last 12 months of life. We further categorized palliative care services delivered in 'Any Institutional Care' setting (i.e. hospital inpatient, complex continuing care (analogous to sub-acute care), long-term care, and ED) and 'Any Community Care' settings (i.e. outpatient care, home care, and home-based physician billing). If both a home care and a physician home visit occur on the same day, they count as a separate home care day and separate physician home visit in sub-category analysis. However, both care events count as a single community care day in 'Any Community Care' so as not to double count for community care that happen on the same day and count more care days than calendar days. The same definition applies to 'Any Institutional Care'. In an acute hospital setting, palliative care days were counted for the entire duration of stay when the most responsible diagnosis for the hospital stay was palliative, palliative medicine was a service provider, or a palliative service was provided. For all remaining palliative acute hospital encounters only a single day of the hospitalization was counted (e.g. patient had a post-admission palliative diagnosis). In the community-based settings of care, a palliative care day must have a record of a palliative care service in billing codes; we did not assume that care following the initiation of a palliative care code had a palliative intent in the community settings.

We also examined timing to initiation of palliative care, defined as first instance of any palliative care service captured in the last year of life. If a decedent had the first palliative care service outside of the window, initiation was represented as 365 days. We also examined intensity of palliative care by totaling the number of days palliative care was delivered, categorized by service type.

Statistical Analysis

Descriptive mean and median statistics describe the usage patterns of decedents as well as the trajectory of care in the last year of life. Multivariate logistic regression was used to predict the likelihood of any use of palliative care. A negative binomial regression was used to predict the number of days of palliative care that a decedent would receive in the last year of life. Covariates included in the models include: sex, age, income quintile, rurality[26,30] and number of chronic conditions. The number of chronic conditions is derived using a combination of validated ICES algorithms that use prior hospital and physician claims records to identify the disease and hospital and physician claims records in the prior two years before death. Ethics approval for this study was received from the Ottawa Hospital Research Institute Ethics Board in Ottawa, Canada.

Results

During the study period, we identified 235,159 decedents, who used a total of 4,497,685 days of palliative care services in the last year of life (mean 19.1 days per decedent). Our cohort was categorized into end-of-life trajectories: 32% as terminal illness, 31% organ failure 31%, 29% frailty, 5% other, and 3% as sudden death. (Table 1) Decedent characteristics were similar across all the trajectories, with the exception of frailty which had more older females and sudden death which had younger decedents with fewer comorbidities. Males and females were equally represented and 80% were aged 65 years or older. 79% of the cohort had 3 or more comorbidities, where hypertension was the most prevalent, followed by osteoarthritis, cancer, diabetes, and congestive heart failure. Remaining results will focus on the three major disease trajectories: terminal illness, organ failure, and frailty.

Palliative Care Access

Among the full cohort, 54% received at least one palliative care service in the last year of life. Palliative care from an institutional and community setting was mainly delivered by hospital inpatient services (46% of overall cohort) and community outpatient services (25%) respectively. Palliative care physician home visits were delivered to 6% of the overall decedent cohort. However, there was wide variation in use of palliative care across end-of-life

trajectories. (Table 2) Across all settings, 88% of those in the terminal illness trajectory received palliative care, compared to 44% of the organ failure trajectory, and 32% in the frailty trajectory. Within particular settings, the terminal illness trajectory had nearly twice as many decedents receiving palliative care services in the hospital inpatient setting (76%) than the other trajectories. Many terminal illness decedents received outpatient palliative care (53%) and end-of-life homecare services (47%), which was four and eight times more respectively, than in the other two trajectories. Palliative care physician home visits were delivered to 15% of terminal illness decedents, compared to 3% of organ failure decedents and 2% of frailty decedents.

Intensity of palliative care

Among users of palliative care in any setting, terminal illness has the highest mean number of palliative care days, ranging from 17 in an institution and 32 in the community, compared to 12 and 11 for organ failure, and 11 and 10 for frailty trajectories. In all trajectories, about half of all palliative care days used occurred in the last two months of life, with a two-fold increase in the last month of life. For example, decedents in the terminal illness trajectory averaged eight palliative care days in the second to last month before death, which increased to 13 days in the final month of life.

Initiation of palliative care

Decedents in the terminal illness trajectory had palliative care initiated a median of 107 days before death, more than four times earlier than organ failure (median 22 days) and frailty (median 24 days). In terms of intensity, the terminal illness trajectory had palliative care on 37% of days after initiation versus 25% and 23% in organ failure and frailty decedents. (Table 3)

Multivariable analyses of odds of using any palliative care services

When examining the odds of using any palliative care services in the last year of life, decedents with a terminal illness trajectory have an odds ratio of 17.0 (OR 95% CI: 17.03, 17.09) when compared to those with a frailty trajectory controlling for sex, age, income quintile,

rurality, and number of comorbidities. (Table 3) Decedents in the organ failure trajectory are nearly twice (OR 1.7, 95% CI: 1.68-1.72) as likely to use any palliative care compared to frailty trajectory.

Multivariable analyses of number of palliative care days received

Negative binomial regression analysis shows that decedents in the terminal illness trajectory receive seven times more days of palliative care (IRR: 6.94, 95% CI: 6.91, 6.97) in the last year of life than decedents with a frailty trajectory. Increasing comorbidity was associated with higher number of days of palliative care received in the last year of life.

Comparison of palliative care access in other countries

In our cohort, among those received any palliative care services, 55% died from terminal illness, 27% from organ failure, and 18% from frailty illness trajectories. Whereas among those who received the Medicare Hospice Benefit in the US, 27% had cancer, 17% had dementia, and 30% had cardiac, circulatory or respiratory failure.[31] (Table 4). Data from Western Australia shows 69% of cancer patients and 14% of non-cancer patients had access to specialist palliative care services (compared to 88% of cancer and 39% non-cancer in Ontario, Canada). In UK, among palliative care in-patient admissions, 88% had cancer.

Length of stay also varies by country. In Ontario, UK, and Western Australia, cancer patients had longer median lengths of stays (range 37-107 days) than other disease trajectories (range 6-43 days). However in the US, the trend is the opposite, with dementia patients having the longest median lengths of stay (56 days), and cancer patients have the shortest (19 days).

Discussion:

Our population-based analysis of decedents in Ontario, Canada shows that while nearly half of decedents receive at least 1 palliative care service, there are large disparities based on dying trajectory. 88% of those dying in the terminal illness trajectory (predominantly cancer deaths) received palliative care services, compared to organ failure (44%) or frailty trajectories (32%). The terminal illness group also received twice as many palliative care services, and four

times earlier than the other two trajectories. In our universal health system that does not require patients to forego curative treatment to receive palliative care, the median time from first palliative care service to death is 107 days for terminal illness, 22 days for organ failure, and 24 days for frailty trajectories.

Our hypotheses were incorrect. While our Canadian data demonstrated terminal illness (predominantly cancer) patients received palliative care much earlier before death than in the US, non-cancer patients in Ontario were identified closer to death than in the US. Importantly, the type of palliative care services offered, the training of providers, and the organization of the delivery system are not equivalent between countries. Nonetheless comparing similar statistics between countries can generate hypotheses on how different eligibility criteria and health systems may explain differences in results. For instance, the in-home visiting hospice services offered in the US includes extensive teams of specialist physicians and nurses, and inter-professional providers, which is more comprehensive and coordinated than the services offered across Ontario, Canada.[32] Indeed our results show the vast majority of palliative care services were delivered in hospital in-patient units, not the home as in the US. Yet the requirement to forego curative treatment to receive hospice care in the US, may be a factor in its relatively late initiation for cancer patients, particularly with advancements in cancer treatment. Conversely, the comprehensive home-based focus of the US hospice benefit may explain the higher proportion of non-cancer patients using it and for longer, compared to Ontario, Canada which does not have widespread access to home-based palliative care teams.

Our data is also interesting compared to UK (universal health system) and Western Australia (mix of public and private health systems), which also have no requirements for an expected death certification or to forego curative treatments. Despite this similarity in eligibility, access to palliative care, utilization by disease trajectories, initiation before death, and intensity and type of service use, differ. The physician ratio is lowest in Ontario, Canada than the other countries. The UK and USA have more physician specialists (75%) to generalists (25%) (all specialties), compared to Western Australia and Ontario, which is half-half. The availability of human resources and their training likely affects palliative care access and the delivery model (i.e. specialist or generalist-driven). For instance, in Ontario, one study showed

that there were only 276 of 9,732 family physicians who had palliative care comprise more than 10% of their billings (40% of the cohort billed no palliative care at all).[33] Indeed receipt of physician home-based visits for palliative care was very low across all disease trajectories in our data. The limited availability of palliative care physician specialists may explain preferential access to terminal illness patients, who may traditionally be easier to identify as needing palliative care. Considering the growing body of evidence of efficacious palliative care interventions for non-cancer diseases[17,18,19,20,34] the marked disparities in access to non-cancer patients ought to be a policy priority, and will likely require overcoming the stigma of imminent death and medical failure as well as education on the benefits of early integration.[35,36]

Limitations of using administrative health data to capture the use of palliative care include the potential under-coding of palliative care delivered, particularly in the community and long-term care.[24] In the community, despite financial incentives to use specialized billing codes for palliative care, physicians may provide care reflecting palliative intent or elements of a palliative approach, but not bill as such. This may include discussions about coping, basic symptom management, etc. In long-term care, palliative care billing codes are uncommon, rather monthly management codes and subsequent visit codes are used.[24,37,38] There are potential issues with reliability and validity when using cause of death data to group decedents into disease trajectories, particularly with the non-terminal illness trajectories. For example, not all stroke recovery follow the trajectory pattern of organ failure. We cannot describe the quality of care or include services provided by volunteers, family members, or private care that is not recorded in the health administrative databases. We also do not have an administrative database for hospice services and cannot account for care provided in a residential hospice. However, only 1-3% of deaths occur in a residential hospice, and the majority of hospice care occurs after initiation of palliative home care services—which is included in our study.

In conclusion, our study quantifies a large disparity in access to palliative care for those dying from organ failure and frailty trajectories. Decedents with a terminal illness trajectory, exemplified by a cancer diagnosis, are significantly more likely to receive palliative care services than the other dying trajectories; they receive more services (intensity) both in hospital and community, and these services are initiated earlier in the dying trajectory. All trajectories could

benefit from increased access to palliative home care services and physician home visits. This data serves as a useful comparison for other countries with similar and different health care systems and eligibility criteria to explore palliative care access across disease trajectories.

Author Contributions: H.S. and P.T. conceptualized the study and R.P performed the data abstraction, and analysis. All authors contributed to interpretation and critical analysis of results. E.O and H.S. drafted the first manuscript and all authors were responsible for contributing to the critical content and review of the manuscript. 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 this study as planned have been explained. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

Data Sharing: Using encrypted health card numbers as unique identifies, 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 analyses at ICES, a prescribed entity for the purposes of section 45 of Ontario's Personal Health Information Privacy Act

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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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Table 1. Cohort Demographics by End-of-Life Disease Trajectory

	Terminal Illness		Organ Failure		Frailty		Other		Sudden Death		Overall	
	N	%	N	%	N	%	N	%	N	%	N	%
Total cohort‡	75,657	32	72,363	31	67,513	29	11,784	5	7,842	3	235,159	100
Sex												
Male	39,125	52	34,371	48	30,703	45	5,295	45	4,987	64	114,481	49
Female	36,532	48	37,992	53	36,810	55	6,489	55	2,855	36	120,678	51
Age												
<19	172	<1	691	1	47	<1	827	7	435	6	217	1
19-44	1,886	2	1,601	2	479	1	332	3	2,636	34	6,934	3
45-54	5,454	7	3,247	4	1,738	3	442	4	1,547	20	1,242	5
55-64	12,311	16	6,631	9	4,193	6	730	6	1,090	14	24,955	11
65-74	18,042	24	10,885	15	7,472	11	1,229	10	676	9	38,304	16
75-84	22,790	30	21,447	30	18,990	28	2,959	25	780	10	66,966	28
85-94	13,730	18	23,514	32	27,641	41	4,257	36	592	8	69,734	30
95+	1,272	2	4,347	6	6,953	10	1,008	9	86	1	1,366	6
Income*												
Lowest	16,014	21	17,288	24	15,637	23	2,545	22	2,008	26	53,492	23
Low	15,931	21	15,344	21	13,634	20	2,317	20	1,626	21	48,852	21
Middle	14,698	19	13,727	19	13,059	19	2,086	18	1,474	19	45,044	19
High	14,621	19	13,074	18	12,884	19	2,063	18	1,358	17	44,000	19
Highest	13,996	19	12,136	17	11,850	18	1,967	17	1,258	16	41,207	18
Urban*												
Urban	64,302	85	61,171	85	57,853	86	9,752	83	6,564	84	199,642	85
Rural	1,123	15	1,074	15	9,558	14	1,286	11	1,211	15	34,027	14
No. of Chronic Diseases												
0	348	<1	2,049	3	1,649	2	1,166	10	1,791	23	7,003	3
1	6,496	9	3,732	5	3,674	5	672	6	1,891	24	16,465	7
2	11,388	15	6,463	9	7,144	11	1,150	10	1,358	17	27,503	12
3	14,846	20	9,543	13	9,710	14	1,559	13	1,022	13	36,680	16
4	14,238	19	11,296	16	11,059	16	1,815	15	674	9	39,082	17
5	11,260	15	11,772	16	10,730	16	1,740	15	457	6	35,959	15
6+	17,081	23	27,508	38	23,547	35	3,682	31	649	8	72,467	31

*Does not equal 100%: a small number of records are missing this information

‡ Percentages of 'Total cohort' row represent the proportion of the whole cohort. All other percentages in each descriptive category are representative of the proportion of patients in each category under each trajectory and are not summative across a whole row.

Table 2. Use (≥1 encounters) of palliative care by end of life trajectory and sector in the last year of life

Sector and Setting of Palliative Care	End of life trajectory: TERMINAL ILLNESS (N=75,657)	ORGAN FAILURE (N=72,363)	FRAILTY (N=67,513)	OVERALL* (N=235,159)
ANY PALLIATIVE CARE IN ANY SETTING	88.0%	44.4%	32.4%	53.6%
PALLIATIVE CARE IN AN INSTITUTIONAL CARE SETTING				
Any Institutional Care†	76.4%	39.9%	26.1%	46.5%
Hospital Inpatient	75.6%	39.4%	25.2%	45.9%
Complex Continuing Care	6.0%	1.4%	1.1%	2.7%
Long-term Care	0.4%	0.4%	0.9%	0.5%
Emergency Room	0.2%	<0.1%	<0.1%	0.1%
PALLIATIVE CARE IN A COMMUNITY CARE SETTING				
Any Community Care†	68.6%	17.2%	15.1%	32.4%
Outpatient	52.7%	12.4%	11.9%	24.8%
Home Care	46.8%	6.0%	3.4%	18.0%
Physician Home Visits	14.8%	2.5%	1.9%	6.2%
AMONG USERS of PALLIATIVE CARE				
Mean days of Institutional Care	16.54	12.02	10.71	14.10
Mean days of Community Care	32.08	10.74	9.68	21.59
INITIATION AND INTENSITY				
Median number of days before death to palliative care initiation (IQR)	107 (33, 246)	22 (6, 124)	24 (6, 132)	59 (13, 200)
Proportion of days following initiation in which palliative care was recorded (IQR)	37% (0.18,0.67)	25% (0.1, 0.7)	23% (0.1,0.64)	33% (0.14,0.67)

*Overall includes the sudden death (3%) and other (5%) trajectories which account for 8% of the total cohort. These are not individually shown here.

†Multiple services received on the same calendar day are counted as a single unit of 'Any community care' or 'Any institutional care'. This avoids double counting palliative care in a single day, and prevents decedents from having more service days than total days.

Table 3. Predictive models for the use of palliative care

Exposure	Use of Palliative Care (Yes/No)‡ Odds ratio (95% CI)		Number of Palliative Care days* Incident Rate Ratio (95% CI)	
Trajectory				
Terminal Illness	17.06	(17.03, 17.09)	6.94	(6.91, 6.97)
Organ Failure	1.70	(1.68, 1.72)	1.56	(1.54, 1.58)
Frailty	REF.		REF.	
Other	1.60	(1.56, 1.64)	0.97	(0.93, 1.01)
Sudden Death	0.35	(0.27, 0.43)	0.22	(0.16, 0.28)
Sex				
Female	1.06	(1.04, 1.08)	1.08	(1.06, 1.10)
Male	REF.		REF.	
Age				
<19	0.72	(0.64, 0.80)	0.78	(0.72, 0.84)
19-45	0.89	(0.84, 0.94)	0.98	(0.93, 1.03)
45-54	REF.		REF.	
55-64	1.08	(1.04, 1.12)	0.97	(0.93, 1.01)
65-74	1.17	(1.13, 1.21)	0.95	(0.92, 0.98)
75-84	1.16	(1.12, 1.20)	0.90	(0.86, 0.94)
85-94	1.00	(0.84, 1.16)	1.67	(1.55, 1.79)
>=95	1.10	(1.05, 1.15)	0.91	(0.86, 0.96)
Income Quintiles				
Q1	REF.		REF.	
Q2	1.05	(1.02, 1.08)	1.09	(1.06, 1.12)
Q3	1.01	(0.98, 1.04)	1.08	(1.05, 1.11)
Q4	1.07	(1.04, 1.10)	1.10	(1.07, 1.13)
Q5	1.09	(1.06, 1.12)	1.19	(1.16, 1.22)
Rurality				
Rural	REF.		REF.	
Urban	1.28	(1.25, 1.31)	1.23	(1.2, 1.26)
No. of Comorbidities				
0	REF.		REF.	
1	3.27	(3.18, 3.36)	2.82	(2.75, 2.89)
2	3.74	(3.65, 3.83)	3.13	(3.06, 3.20)
3	4.12	(4.03, 4.21)	3.43	(3.36, 3.50)
4	4.53	(4.44, 4.62)	3.69	(3.62, 3.76)
5	4.75	(4.66, 4.84)	3.97	(3.90, 4.04)
≥6	5.40	(5.31, 5.49)	4.83	(4.76, 4.90)

‡ Multivariable logistic regression was used to determine odds ratio

* Negative binomial regression was used to determine incident rate ratio

Table 4: Comparison of Palliative Care (PC) access and initiation across countries

	Ontario	UK	USA	Western Australia
Criteria to access Palliative care (PC)	• 94,000 deaths in Ontario 2014/2015 • Universal health care • No restrictions on curative along with PC • No written document required to initiate PC, though often the "surprise question" of expected death of 1 year to 6 months is used to initiate care [39] • provided by general practitioners, specialists and homecare providers	• 548,000 deaths 2015 • Primary care delivered heavily by general practitioners and primary care trusts • Universal Health Insurance Patients may be terminal (expected to die within 12 months, have a life-limiting illness or chronic condition with a trajectory that has a sharp functional decline or extensive acute episodes, or require extended care) • Can mix palliative and curative care[40]	• 2.6 M deaths in 2015 • Hospice benefit includes visiting inter-professional providers in home, residential hospices, hospitals, long-term care, etc. • Available to Medicare patients • Must have signed physician note stating expected death within 6 months • Must waive access to curative treatments in order to access hospice benefit[31]	• 23,852 deaths in Western Australia • Mix of private and government service providers • Use 'normative need' to assess access to PC specialists[41]
Physician ratio	• 2.2 physicians / 1,000 ppl (2015) • 47%/53%: generalists/specialists[42]	• 2.8 physicians / 1,000 ppl (2015) • 29%/71%: generalists/specialists[42]	• 2.5 physicians / 1,000 ppl (2011) • 12%/88%: generalists/specialists[42]	• 3.5 physicians/1,000 ppl (2015) • 45%/47%: generalists/specialists[42]
Percent that get Any service	• 54% of decedents between 2010 and 2012 received at least PC services (from billing claims) in any setting. (Table 2)	• 74% of people who are in need of PC receive either specialist or generalist services • 18% of non-malignant access to PC was for chronic respiratory illness, 11% for heart failure[40]	• 1,381,182 of (2.7 Mill deaths in 2015) • ~50% of patients enrolled in Medicare were enrolled in the hospice program (NHPCO, 2016)	• 46% of decedents received any PC[41]
Cancer and non-cancer access	• 88% of terminal illness, 44% of organ failure, and 32% of frailty decedents (or 39% non-cancer) received any PC services (Table 2) • Among those receiving any PC services, 55% died from terminal illness, 27% from organ failure, and 18% from frailty illness trajectories	• 88% of PC inpatients have cancer Diagnosis • 20% of inpatient referrals are for non-cancer[40]	• Among those who received the Hospice benefit, the principal diagnoses were: 27% cancer, 19% cardiac, 16% dementia, and 10% respiratory[31]	• 69% of cancer patients had access to specialist care • 14% of non-cancer patients had access to specialists[41]
Average Length of Stay in PC	Median days of initiation of service to death: • Terminal illness 107 days • Organ failure 22 days • Frailty 24 days (Table 2)	Median days on service in one large study in one region (Leeds, UK): • 37 days for cancer, • 16 days for non-cancer[43]	Mean / (median) days on service • Cancer: 47 / (19) days • cardiac: 76 / (28) days • dementia: 105 / (56) days • respiratory 69 / (19) days • stroke 77 / (20) days[31]	• Median number of days receiving specialist PC was 30 (cancer), 8 (COPD), and 5 (Alzheimers and heart failure)[41] • Median days PC initiated before death: 62 (cancer), 6 (Alzheimers), and 43 (COPD)[41]
Location of service (community, home, hospital	• 68% of cancer decedents have PC in a community setting • 76% in an acute care setting. • <1% of PC for any trajectory was received in a LTC facility. (Table 2)	• ~ 20% of LTC residents were seen by a PC specialist nurse, 96% were seen by a GP • Poor access in hospitals. Only 21% of hospitals provide face-to-face PC 24x7. • 27% of hospital outpatient PC and 17% of community PC provided to non-malignant disease[40]	• Home 56.0 % • Nursing facility 41.3% • Hospice inpatient facility 1.3% • Acute care hospital 0.5% • other 0.9%[31]	• Organ failure patients (ex. Liver failure) tended to receive care in hospital over community settings. • Motor Neuron and cancer decedents had increased access to community services[41]

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Appendix 1: Top 5 causes of death by disease trajectory

1	Bronchus and Lung Cancer; N=17,883 (23.6%)	Other chronic obstructive pulmonary disease; N=8,944 (12.4%)	Chronic ischaemic heart disease; N=19,424 (28.8%)	Intentional self-harm by hanging, strangulation and suffocation; N=1,047 (13.4%)	Other septicaemia; N=2,735 (23.2%)
2	Colon cancer; N=5,597 (7.4%)	Stroke, not specified as haemorrhage or infarction; N=7,233 (10.0%)	Acute myocardial infarction; N=13,249 (19.6%)	Accidental poisoning by and exposure to narcotics and hallucinogens; N=714 (9.1%)	Unspecified fall; N=2,329 (19.8%)
3	Breast Cancer; N=5,250 (6.9%)	Unspecified diabetes mellitus; N=4,937 (6.8%)	Unspecified dementia; N=12,025 (17.8%)	Accidental poisoning by and exposure to other unspecified drugs, medicaments and biological substances; N=394 (5.0%)	Other fall on same level; N=1,737 (14.7%)
4	Pancreatic Cancer; N=4,140 (5.5%)	Heart failure; N=3,308 (4.6%)	Alzheimer's disease; N=5,761 (8.5%)	Exposure to unspecified factor; N=347 (4.4%)	Other ill-defined and unspecified causes of mortality; N=891 (7.6%)
5	Prostate Cancer; N=3,816 (5.0%)	Other interstitial pulmonary diseases; N=2,289 (3.2%)	Pneumonia, organism unspecified; N=4,851 (7.2%)	Motor- or nonmotor-vehicle accident; N=335 (4.3%)	Fall on and from stairs and steps; N=541 (4.6%)

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 – title page
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1 – title page
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any pre-specified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Outcomes – 4 Statistical analysis - 5
Data sources/ measurement	8*	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	4 - 5
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	13 (table footnote)
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	NA NA

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			
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	NA
		(b) Give reasons for non-participation at each stage	
		(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	Table 1 - 12
		(b) Indicate number of participants with missing data for each variable of interest	Table 1 - 12
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	5,6 table 3,4
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	NA
		Cross-sectional study—Report numbers of outcome events or summary measures	NA
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	5-6, Table 3, Table 4
		(*b*) Report category boundaries when continuous variables were categorized	Table 4
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	7
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	8
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	8
Generalisability	21	Discuss the generalisability (external validity) of the study results	7,8
Other information			
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	10

*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.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is 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 Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.

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Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents.

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Abstract

Objectives: To examine access to palliative care between different disease trajectories and compare to other geographic areas.

Design: A retrospective population-based decedent cohort study using linked administrative data

Setting: Ontario, Canada

Participants: Ontario decedents between April 1, 2010 and December 31, 2012. Patients were categorized into disease trajectories: terminal illness (e.g. cancer), organ failure (e.g. chronic heart failure), frailty (e.g. dementia), sudden death, or other.

Interventions: Receipt of palliative care services from institutional and community settings, derived from a validated list of palliative care codes from multiple administrate databases.

Outcome measures: Receiving any palliative care services in the last year of life (yes/no), intensity (total days), and time of initiation of palliative care, in hospital and community sectors. Multivariable analysis examined the association between disease trajectory and the receipt of palliative care in the last year of life.

Results: We identified 235,159 decedents in Ontario. In the last year of life, 88% of terminal illness, 44% of organ failure, and 32% of frailty decedents accessed at least one palliative care service. Most care was provided during an inpatient hospitalization. Terminal illness decedents received twice as many palliative care days (mean of 49 days) compared to organ failure and frailty decedents. Terminal illness patients initiated palliative care median of 107 days before death, compared to median of 19 days among those using the US Medicare hospice benefit.

Conclusions: Terminal illness decedents are more likely to receive any palliative care, with increased intensity, and earlier before death than organ failure or frailty decedents. This data serves as a useful comparison for other countries with similar and different health care systems and eligibility criteria.

Strengths and Limitations of this study

- This study examines palliative care access and time to initiation across a comprehensive list of health care services by disease trajectory

- This is a large population-based study, within a universal health system, where patients have access to both institutional and community palliative care
- This work provides a measure of access and time to initiation to palliative care for patients in all trajectories, and can be compared to other countries
- Using administrative health data to capture use of palliative care is limited by under-coding of palliative care delivered, particularly in the community setting
- We are unable to account for the quality of care, privately obtained care, or patients' end-of-life care preferences and how those differ between trajectory

Introduction

With the population aging and living longer with more comorbidities, health systems are focused on providing quality end-of-life care through improved palliative care services.[1,2] Earlier availability of palliative care to terminal patients has been shown to improve quality of life, reduce late-life health services utilization, and even extend survival.[3,4,5] However, palliative care is often not delivered or initiated until very late in the dying trajectory. Research shows that dying occurs in three main trajectories: 1) terminal illness, typical of cancer (high-function followed by acute decline); 2) organ failure, typical of heart and lung disease (medium-high function, intermittent acute exacerbations and partial recovery); and 3) frailty, typical of dementia (low function, and prolonged, gradual dwindling).[6,7,8]

Evidence shows that palliative care is more often provided to cancer versus non-cancer patients[9,10,11,12,13,14] because of the 'predictability' of decline[8,15,16] and the history of hospice care for cancer patients. This 'predictability' can sometimes be formalized into health policy, such as in the US Medicare Hospice Benefit, which requires a doctor's certification that death is expected within 6 months and that the patient forego any hospital or curative care. Whereas in other countries, like the UK, Australia, and Canada, the eligibility criteria for palliative care does not require either condition. Given the growing body of literature of the benefits of early palliative care in non-cancer diagnoses,[17,18,19,20] there is a dearth of research describing how access to palliative care, particularly time to initiation before death and intensity and type of service use, differs by disease trajectory, and how that may be influenced by health system and various criteria to access palliative care at a population-level.

This study focuses on patients in Ontario, Canada, who can access palliative care services in community and institutional settings without foregoing curative treatment through its universal insured hospital and physician system.[21] Criteria for palliative care referral in the hospital is at the physician's discretion; whereas in the community, they often use the "surprise question" of not being surprised if the patient died within a year, [22] combined with performance status decline.[23] In short, eligibility in Ontario is not formally standardized, which is unlike the standardized criteria of the Gold Standards Framework, which is widespread in the UK. Ontario is the largest province in Canada, and has the highest number of deaths.[24] Previous

studies have shown that half of patients in Ontario received at least 1 palliative care service in their last year of life,[25] though they did not examine variations by disease trajectory. This study examines how disease trajectory is associated with access to palliative care services in multiple settings, including time of initiation before death and intensity and type of service use. We also compare our data to other geographic areas, namely the US, UK, and Western Australia. Our hypothesis is that compared to the US, Ontarians will initiate palliative care services earlier, across all disease trajectories, and compared to UK and Western Australia, access will be similar across all disease trajectories.

Methods:

We conducted a retrospective cohort study of Ontario decedents who died between April 1, 2010 and December 31, 2012. We used linked administrative health databases, held at the Institute for Clinical Evaluative Sciences, to identify palliative care services used across multiple health sectors in the 12 months before death. We used a previously derived comprehensive list of palliative care billing codes to capture palliative care services provided by physicians, nurses and personal support workers in multiple sectors from multiple administrate databases.[25,26] The databases included: Physician claims database, which captured palliative care services billed by physicians in both community and hospital settings; Home Care Database and the interRAI databases captured publicly-funded home care services, such as nursing or personal support care, with palliative care intent; Discharge Abstract Database and the National Ambulatory Care Reporting System captured hospitalizations and Emergency Department (ED) visits, respectively, where palliative care was the main reason for admission or consulted; and Continuing Care Reporting System captured palliative care provided in long-term care and complex continuing care settings. We also linked with the Vital Statistics database for date of death, sex, age and postal code; and Statistics Canada Census data for income quintile and rurality via postal codes.[27]

We further categorized decedents by the major trajectories of functional decline at end of life, defined by main cause of death as per prior research,[7,8,28] which have also been validated in Canada.[29,30] Using ICD-10 codes from the death certificate as defined previously,[29]

decedents were classified into these trajectories: terminal illness (e.g. cancer), organ failure (e.g. chronic heart failure), frailty (e.g. Alzheimers), sudden death (e.g. accident), and other. (Appendix 1 for main causes of death)

Outcomes of interest

The primary outcome of interest was whether a decedent received palliative care at least once in the last 12 months of life. We further categorized palliative care services delivered in 'Any Institutional Care' setting (i.e. hospital inpatient, complex continuing care (analogous to sub-acute care), long-term care, and ED) and 'Any Community Care' settings (i.e. outpatient care, home care, and home-based physician billing). If both a home care and a physician home visit occur on the same day, they count as a separate home care day and separate physician home visit in sub-category analysis. However, both care events count as a single community care day in 'Any Community Care' so as not to double count for community care that happen on the same day and count more care days than calendar days. The same definition applies to 'Any Institutional Care'. In an acute hospital setting, palliative care days were counted for the entire duration of stay when the most responsible diagnosis for the hospital stay was palliative, palliative medicine was a service provider, or a palliative service was provided. For all remaining palliative acute hospital encounters only a single day of the hospitalization was counted (e.g. patient had a post-admission palliative diagnosis). In the community-based settings of care, a palliative care day must have a record of a palliative care service in billing codes; we did not assume that care following the initiation of a palliative care code had a palliative intent in the community settings.

We also examined timing to initiation of palliative care, defined as first instance of any palliative care service captured in the last year of life. If a decedent had the first palliative care service outside of the window, initiation was represented as 365 days. We also examined intensity of palliative care by totaling the number of days palliative care was delivered, categorized by service type.

Statistical Analysis

Descriptive mean and median statistics describe the usage patterns of decedents as well as the trajectory of care in the last year of life. Multivariate logistic regression was used to predict the likelihood of any use of palliative care. A negative binomial regression was used to predict the number of days of palliative care that a decedent would receive in the last year of life. Covariates included in the models include: sex, age, income quintile, rurality[27,31] and number of chronic conditions. The number of chronic conditions is derived using a combination of validated ICES algorithms that use prior hospital and physician claims records to identify the disease and hospital and physician claims records in the prior two years before death. Ethics approval for this study was received from the Ottawa Hospital Research Institute Ethics Board in Ottawa, Canada.

Results

During the study period, we identified 235,159 decedents, who used a total of 4,497,685 days of palliative care services in the last year of life (mean 19.1 days per decedent). Our cohort was categorized into end-of-life trajectories: 32% as terminal illness, 31% organ failure, 29% frailty, 5% other, and 3% as sudden death. (Table 1) Decedent characteristics were similar across all the trajectories, with the exception of frailty which had more older females and sudden death which had younger decedents with fewer comorbidities. Males and females were equally represented and 80% were aged 65 years or older. 79% of the cohort had 3 or more comorbidities, where hypertension was the most prevalent, followed by osteoarthritis, cancer, diabetes, and congestive heart failure. Remaining results will focus on the three major disease trajectories: terminal illness, organ failure, and frailty.

Palliative Care Access

Among the full cohort, 54% received at least one palliative care service in the last year of life. Palliative care from an institutional and community setting was mainly delivered by hospital inpatient services (46% of overall cohort) and community outpatient services (25%) respectively. Palliative care physician home visits were delivered to 6% of the overall decedent cohort. However, there was wide variation in use of palliative care across end-of-life

trajectories. (Table 2) Across all settings, 88% of those in the terminal illness trajectory received palliative care, compared to 44% of the organ failure trajectory, and 32% in the frailty trajectory. Within particular settings, the terminal illness trajectory had nearly twice as many decedents receiving palliative care services in the hospital inpatient setting (76%) than the other trajectories. Many terminal illness decedents received outpatient palliative care (53%) and end-of-life homecare services (47%), which was four and eight times more respectively, than in the other two trajectories. Palliative care physician home visits were delivered to 15% of terminal illness decedents, compared to 3% of organ failure decedents and 2% of frailty decedents.

Intensity of palliative care

Among users of palliative care in any setting, terminal illness has the highest mean number of palliative care days, ranging from 17 in an institution and 32 in the community, compared to 12 and 11 for organ failure, and 11 and 10 for frailty trajectories. In all trajectories, about half of all palliative care days used occurred in the last two months of life, with a two-fold increase in the last month of life. For example, decedents in the terminal illness trajectory averaged eight palliative care days in the second to last month before death, which increased to 13 days in the final month of life.

Initiation of palliative care

Decedents in the terminal illness trajectory had palliative care initiated a median of 107 days before death, more than four times earlier than organ failure (median 22 days) and frailty (median 24 days). In terms of intensity, the terminal illness trajectory had palliative care on 37% of days after initiation versus 25% and 23% in organ failure and frailty decedents. (Table 3)

Multivariable analyses of odds of using any palliative care services

When examining the odds of using any palliative care services in the last year of life, decedents with a terminal illness trajectory have an odds ratio of 17.0 (OR 95% CI: 17.03, 17.09) when compared to those with a frailty trajectory controlling for sex, age, income quintile,

rurality, and number of comorbidities. (Table 3) Decedents in the organ failure trajectory are nearly twice (OR 1.7, 95% CI: 1.68-1.72) as likely to use any palliative care compared to frailty trajectory.

Multivariable analyses of number of palliative care days received

Negative binomial regression analysis shows that decedents in the terminal illness trajectory receive seven times more days of palliative care (IRR: 6.94, 95% CI: 6.91, 6.97) in the last year of life than decedents with a frailty trajectory. Increasing comorbidity was associated with higher number of days of palliative care received in the last year of life.

Comparison to palliative care access in other countries

In our cohort, among those who received any palliative care services, 55% died from terminal illness, 27% from organ failure, and 18% from frailty illness trajectories. Whereas among those who received the Medicare Hospice Benefit in the US, 27% had cancer, 17% had dementia, and 30% had cardiac, circulatory or respiratory failure.[32] (Table 4) Data from Western Australia shows 69% of cancer patients and 14% of non-cancer patients had access to specialist palliative care services [33] (compared to 88% of cancer and 39% non-cancer in Ontario, Canada). In UK, among palliative care in-patient admissions, 88% had cancer.[34]

Length of stay also varies by country. In Ontario, UK, and Western Australia, cancer patients had longer median lengths of stays (range 37-107 days) than other disease trajectories (range 6-43 days).[33,34] However in the US, the trend is the opposite, with dementia patients having the longest median lengths of stay (56 days), and cancer patients have the shortest (19 days).[32]

Discussion:

Our population-based analysis of decedents in Ontario, Canada shows that while nearly half of decedents receive at least 1 palliative care service, there are large disparities based on dying trajectory. 88% of those dying in the terminal illness trajectory (predominantly cancer deaths) received palliative care services, compared to organ failure (44%) or frailty trajectories

(32%). The terminal illness group also received twice as many palliative care services, and four times earlier than the other two trajectories. In our universal insured hospital and physician system that does not require patients to forego curative treatment to receive palliative care, the median time from first palliative care service to death is 107 days for terminal illness, 22 days for organ failure, and 24 days for frailty trajectories.

Our hypotheses were incorrect. While our Canadian data demonstrated terminal illness (predominantly cancer) patients received palliative care much earlier before death than in the US, non-cancer patients in Ontario were identified closer to death than in the US. Importantly, the type of palliative care services offered, the training of providers, and the organization of the delivery system are not equivalent between countries or within Canada.[35] Nonetheless comparing similar statistics between geographic areas can generate hypotheses on how different eligibility criteria and health systems may explain differences in results. For instance, the in-home visiting hospice insured services offered in the US includes extensive teams of specialist physicians and nurses, and inter-professional providers, which is more comprehensive and coordinated than the services offered across Ontario, Canada.[36] Indeed our results show the vast majority of palliative care services were delivered in hospital in-patient units, not the home as in the US. Yet the requirement to forego curative treatment to receive hospice care in the US, may be a factor in its relatively late initiation for cancer patients, particularly with advancements in cancer treatment. Conversely, the comprehensive home-based focus of the US hospice insured benefit may explain the higher proportion of non-cancer patients using it and for longer, compared to Ontario, Canada which does not have widespread access to home-based fully insured palliative care teams.

Our data is also interesting compared to UK (universal health system) and Western Australia (mix of public and private health systems), which also have no requirements for an expected death certification or to forego curative treatments. Despite this similarity in eligibility, access to palliative care, utilization by disease trajectories, initiation before death, and intensity and type of service use, differ. The physician ratio is lower in Ontario, Canada than the other countries. The UK and USA have more physician specialists (75%) to generalists (25%) (all specialties), compared to Western Australia and Ontario, which is half-half. (OECD, 2016)

The availability of human resources and their training likely affects palliative care access and the delivery model (i.e. specialist or generalist-driven). For instance, in Ontario, one study showed that there were only 276 of 9,732 family physicians, where palliative care services comprised more than 10% of their billings (40% of the cohort billed no palliative care at all).[37] Indeed receipt of physician home-based visits for palliative care was very low across all disease trajectories in our data, which may be related to inadequate billing fees for home visits.[38] The limited availability of palliative care physician specialists may explain preferential access to terminal illness patients, who may traditionally be easier to identify as needing palliative care. Considering the growing body of evidence of efficacious palliative care interventions for non-cancer diseases[17,18,19,20,39] the marked disparities in access to non-cancer patients ought to be a policy priority, and will likely require overcoming the stigma of imminent death and medical failure as well as education on the benefits of early integration.[40,41]

Limitations of using administrative health data to capture the use of palliative care include the potential under-coding of palliative care delivered, particularly in the community and long-term care.[25] In the community, despite financial incentives to use specialized billing codes for palliative care, physicians may provide care reflecting palliative intent or elements of a palliative approach, but not bill as such. This may include discussions about coping, basic symptom management, etc. In long-term care, palliative care billing codes are uncommon, rather monthly management codes and subsequent visit codes are used.[25,42,43] There are potential issues with reliability and validity when using cause of death data to group decedents into disease trajectories, particularly with the non-terminal illness trajectories. For example, not all stroke recovery follow the trajectory pattern of organ failure. We cannot describe the quality of care or include services provided by volunteers, family members, or private care that is not recorded in the health administrative databases. We also do not have an administrative database for hospice services and cannot account for care provided in a residential hospice. However, only 1-3% of deaths occur in a residential hospice, and the majority of hospice care occurs after initiation of palliative home care services—which is included in our study.

In conclusion, our study quantifies a large disparity in access to palliative care for those dying from organ failure and frailty trajectories. Decedents with a terminal illness trajectory,

exemplified by a cancer diagnosis, are significantly more likely to receive palliative care services than the other dying trajectories; they receive more services (intensity) both in hospital and community, and these services are initiated earlier in the dying trajectory. All trajectories could benefit from increased access to palliative home care services and physician home visits. This data will be useful to compare to in the future since a national palliative care framework was an identified need [44]and has recently been passed into law.[45] This data also serves as a useful comparison for other countries with similar and different health care systems and eligibility criteria to explore palliative care access across disease trajectories.

Author Contributions: H.S. and P.T. conceptualized the study and R.P performed the data abstraction, and analysis. All authors contributed to interpretation and critical analysis of results. E.O and H.S. drafted the first manuscript and all authors were responsible for contributing to the critical content and review of the manuscript. 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 this study as planned have been explained. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

Data Sharing: Using encrypted health card numbers as unique identifies, 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 analyses at ICES, a prescribed entity for the purposes of section 45 of Ontario's Personal Health Information Privacy Act

Declaration of conflicting interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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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Table 1. Cohort Demographics by End-of-Life Disease Trajectory

	Terminal Illness		Organ Failure		Frailty		Other		Sudden Death		Overall	
	N	%	N	%	N	%	N	%	N	%	N	%
Total cohort‡	75,657	32	72,363	31	67,513	29	11,784	5	7,842	3	235,159	100
Sex												
Male	39,125	52	34,371	48	30,703	45	5,295	45	4,987	64	114,481	49
Female	36,532	48	37,992	53	36,810	55	6,489	55	2,855	36	120,678	51
Age												
<19	172	<1	691	1	47	<1	827	7	435	6	217	1
19-44	1,886	2	1,601	2	479	1	332	3	2,636	34	6,934	3
45-54	5,454	7	3,247	4	1,738	3	442	4	1,547	20	1,242	5
55-64	12,311	16	6,631	9	4,193	6	730	6	1,090	14	24,955	11
65-74	18,042	24	10,885	15	7,472	11	1,229	10	676	9	38,304	16
75-84	22,790	30	21,447	30	18,990	28	2,959	25	780	10	66,966	28
85-94	13,730	18	23,514	32	27,641	41	4,257	36	592	8	69,734	30
95+	1,272	2	4,347	6	6,953	10	1,008	9	86	1	1,366	6
Income*												
Lowest	16,014	21	17,288	24	15,637	23	2,545	22	2,008	26	53,492	23
Low	15,931	21	15,344	21	13,634	20	2,317	20	1,626	21	48,852	21
Middle	14,698	19	13,727	19	13,059	19	2,086	18	1,474	19	45,044	19
High	14,621	19	13,074	18	12,884	19	2,063	18	1,358	17	44,000	19
Highest	13,996	19	12,136	17	11,850	18	1,967	17	1,258	16	41,207	18
Urban*												
Urban	64,302	85	61,171	85	57,853	86	9,752	83	6,564	84	199,642	85
Rural	1,123	15	1,074	15	9,558	14	1,286	11	1,211	15	34,027	14
No. of Chronic Diseases												
0	348	<1	2,049	3	1,649	2	1,166	10	1,791	23	7,003	3
1	6,496	9	3,732	5	3,674	5	672	6	1,891	24	16,465	7
2	11,388	15	6,463	9	7,144	11	1,150	10	1,358	17	27,503	12
3	14,846	20	9,543	13	9,710	14	1,559	13	1,022	13	36,680	16
4	14,238	19	11,296	16	11,059	16	1,815	15	674	9	39,082	17
5	11,260	15	11,772	16	10,730	16	1,740	15	457	6	35,959	15
6+	17,081	23	27,508	38	23,547	35	3,682	31	649	8	72,467	31

*Does not equal 100%: a small number of records are missing this information

‡ Percentages of 'Total cohort' row represent the proportion of the whole cohort. All other percentages in each descriptive category are representative of the proportion of patients in each category under each trajectory and are not summative across a whole row.

Table 2. Use (≥1 encounters) of palliative care by end of life trajectory and sector in the last year of life

Sector and Setting of Palliative Care	End of life trajectory: TERMINAL ILLNESS (N=75,657)	ORGAN FAILURE (N=72,363)	FRAILTY (N=67,513)	OVERALL* (N=235,159)
ANY PALLIATIVE CARE IN ANY SETTING	88.0%	44.4%	32.4%	53.6%
PALLIATIVE CARE IN AN INSTITUTIONAL CARE SETTING				
Any Institutional Care†	76.4%	39.9%	26.1%	46.5%
Hospital Inpatient	75.6%	39.4%	25.2%	45.9%
Complex Continuing Care	6.0%	1.4%	1.1%	2.7%
Long-term Care	0.4%	0.4%	0.9%	0.5%
Emergency Room	0.2%	<0.1%	<0.1%	0.1%
PALLIATIVE CARE IN A COMMUNITY CARE SETTING				
Any Community Care†	68.6%	17.2%	15.1%	32.4%
Outpatient	52.7%	12.4%	11.9%	24.8%
Home Care	46.8%	6.0%	3.4%	18.0%
Physician Home Visits	14.8%	2.5%	1.9%	6.2%
AMONG USERS of PALLIATIVE CARE				
Mean days of Institutional Care	16.54	12.02	10.71	14.10
Mean days of Community Care	32.08	10.74	9.68	21.59
INITIATION AND INTENSITY				
Median number of days before death to palliative care initiation (IQR)	107 (33, 246)	22 (6, 124)	24 (6, 132)	59 (13, 200)
Proportion of days following initiation in which palliative care was recorded (IQR)	37% (0.18,0.67)	25% (0.1, 0.7)	23% (0.1,0.64)	33% (0.14,0.67)

*Overall includes the sudden death (3%) and other (5%) trajectories which account for 8% of the total cohort. These are not individually shown here.

†Multiple services received on the same calendar day are counted as a single unit of 'Any community care' or 'Any institutional care'. This avoids double counting palliative care in a single day, and prevents decedents from having more service days than total days.

Table 3. Predictive models for the use of palliative care

Exposure	Use of Palliative Care (Yes/No)‡ Odds ratio (95% CI)		Number of Palliative Care days* Incident Rate Ratio (95% CI)	
Trajectory				
Terminal Illness	17.06	(17.03, 17.09)	6.94	(6.91, 6.97)
Organ Failure	1.70	(1.68, 1.72)	1.56	(1.54, 1.58)
Frailty	REF.		REF.	
Other	1.60	(1.56, 1.64)	0.97	(0.93, 1.01)
Sudden Death	0.35	(0.27, 0.43)	0.22	(0.16, 0.28)
Sex				
Female	1.06	(1.04, 1.08)	1.08	(1.06, 1.10)
Male	REF.		REF.	
Age				
<19	0.72	(0.64, 0.80)	0.78	(0.72, 0.84)
19-45	0.89	(0.84, 0.94)	0.98	(0.93, 1.03)
45-54	REF.		REF.	
55-64	1.08	(1.04, 1.12)	0.97	(0.93, 1.01)
65-74	1.17	(1.13, 1.21)	0.95	(0.92, 0.98)
75-84	1.16	(1.12, 1.20)	0.90	(0.86, 0.94)
85-94	1.00	(0.84, 1.16)	1.67	(1.55, 1.79)
>=95	1.10	(1.05, 1.15)	0.91	(0.86, 0.96)
Income Quintiles				
Q1	REF.		REF.	
Q2	1.05	(1.02, 1.08)	1.09	(1.06, 1.12)
Q3	1.01	(0.98, 1.04)	1.08	(1.05, 1.11)
Q4	1.07	(1.04, 1.10)	1.10	(1.07, 1.13)
Q5	1.09	(1.06, 1.12)	1.19	(1.16, 1.22)
Rurality				
Rural	REF.		REF.	
Urban	1.28	(1.25, 1.31)	1.23	(1.2, 1.26)
No. of Comorbidities				
0	REF.		REF.	
1	3.27	(3.18, 3.36)	2.82	(2.75, 2.89)
2	3.74	(3.65, 3.83)	3.13	(3.06, 3.20)
3	4.12	(4.03, 4.21)	3.43	(3.36, 3.50)
4	4.53	(4.44, 4.62)	3.69	(3.62, 3.76)
5	4.75	(4.66, 4.84)	3.97	(3.90, 4.04)
≥6	5.40	(5.31, 5.49)	4.83	(4.76, 4.90)

‡ Multivariable logistic regression was used to determine odds ratio

* Negative binomial regression was used to determine incident rate ratio

Table 4: Comparison of Palliative Care (PC) access and initiation across geographic areas

	Ontario	UK	USA	Western Australia
Criteria to access Palliative care (PC)	• 94,000 deaths in Ontario 2014/2015 • universal insured hospital and physician system • No restrictions on curative along with PC • No written document required to initiate PC, though often the "surprise question" of expected death of 1 year to 6 months is used to initiate care [46] • provided by general practitioners, specialists and homecare providers	• 548,000 deaths 2015 • Primary care delivered heavily by general practitioners and primary care trusts • Universal Health Insurance Patients may be terminal (expected to die within 12 months, have a life-limiting illness or chronic condition with a trajectory that has a sharp functional decline or extensive acute episodes, or require extended care) • Can mix palliative and curative care[34]	• 2.6 M deaths in 2015 • Hospice benefit includes visiting inter-professional providers in home, residential hospices, hospitals, long-term care, etc. • Available to Medicare patients • Must have signed physician note stating expected death within 6 months • Must waive access to curative treatments in order to access hospice benefit[32]	• 23,852 deaths in Western Australia in 2009/2010 • Mix of private and government service providers • Use 'normative need' to assess access to PC specialists[33]
Physician ratio	• 2.2 physicians / 1,000 ppl (2015) • 47%/53%: generalists/specialists[47]	• 2.8 physicians / 1,000 ppl (2015) • 29%/71%: generalists/specialists[47]	• 2.5 physicians / 1,000 ppl (2011) • 12%/88%: generalists/specialists[47]	• 3.5 physicians/1,000 ppl (2015) • 45%/47%: generalists/specialists (8%: medical doctors not further defined)[47]
Percent that get Any service	• 54% of decedents between 2010 and 2012 received at least PC services (from billing claims) in any setting. (Table 2)	• 74% of people who are in need of PC receive either specialist or generalist services • 18% of non-malignant access to PC was for chronic respiratory illness, 11% for heart failure[34]	• 46% of Medicare (>65 years old) decedents received ≥1 day of hospice care (via the Medicare hospice benefit) in 2015[32]	• 46% of decedents received any PC[33]
Cancer and non-cancer access	• 88% of terminal illness, 44% of organ failure, and 32% of frailty decedents (or 39% non-cancer) received any PC services (Table 2) • Among those receiving any PC services, 55% died from terminal illness, 27% from organ failure, and 18% from frailty illness trajectories	• 88% of PC inpatients have cancer Diagnosis • 20% of inpatient referrals are for non-cancer[34]	• Among those who received the Hospice benefit, the principal diagnoses were: 27% cancer, 19% cardiac, 16% dementia, and 10% respiratory[32]	• 69% of cancer patients had access to specialist care • 14% of non-cancer patients had access to specialists[33]
Average Length of Stay in PC	Median days of initiation of service to death: • Terminal illness 107 days • Organ failure 22 days • Frailty 24 days (Table 2)	Median days on service in one large study in one region (Leeds, UK): • 37 days for cancer, • 16 days for non-cancer[48]	Mean / (median) days on service • Cancer: 47 / (19) days • cardiac: 76 / (28) days • dementia: 105 / (56) days • respiratory 69 / (19) days • stroke 77 / (20) days[32]	• Median number of days receiving specialist PC was 30 (cancer), 8 (COPD), and 5 (Alzheimers and heart failure)[33] • Median days PC initiated before death: 62 (cancer), 6 (Alzheimers), and 43 (COPD)[33]
Location of service (community, home, hospital)	• 68% of cancer decedents have PC in a community setting • 76% in an acute care setting. • <1% of PC for any trajectory was received in a LTC facility. (Table 2)	• ~ 20% of LTC residents were seen by a PC specialist nurse, 96% were seen by a GP • Poor access in hospitals. Only 21% of hospitals provide face-to-face PC 24x7. • 27% of hospital outpatient PC and 17% of community PC provided to non-malignant disease[34]	• Home 56.0 % • Nursing facility 41.3% • Hospice inpatient facility 1.3% • Acute care hospital 0.5% • other 0.9%[32]	• Organ failure patients (ex. Liver failure) tended to receive care in hospital over community settings. • Motor Neuron and cancer decedents had increased access to community services[33]

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Appendix 1: Top 5 causes of death by disease trajectory

	Terminal Illness	Organ Failure	Frailty	Sudden Death	Other
1	Bronchus and Lung Cancer; N=17,883 (23.6%)	Other chronic obstructive pulmonary disease; N=8,944 (12.4%)	Chronic ischaemic heart disease; N=19,424 (28.8%)	Intentional self-harm by hanging, strangulation and suffocation; N=1,047 (13.4%)	Other septicaemia; N=2,735 (23.2%)
2	Colon cancer; N=5,597 (7.4%)	Stroke, not specified as haemorrhage or infarction; N=7,233 (10.0%)	Acute myocardial infarction; N=13,249 (19.6%)	Accidental poisoning by and exposure to narcotics and hallucinogens; N=714 (9.1%)	Unspecified fall; N=2,329 (19.8%)
3	Breast Cancer; N=5,250 (6.9%)	Unspecified diabetes mellitus; N=4,937 (6.8%)	Unspecified dementia; N=12,025 (17.8%)	Accidental poisoning by and exposure to other unspecified drugs, medicaments and biological substances; N=394 (5.0%)	Other fall on same level; N=1,737 (14.7%)
4	Pancreatic Cancer; N=4,140 (5.5%)	Heart failure; N=3,308 (4.6%)	Alzheimer's disease; N=5,761 (8.5%)	Exposure to unspecified factor; N=347 (4.4%)	Other ill-defined and unspecified causes of mortality; N=891 (7.6%)
5	Prostate Cancer; N=3,816 (5.0%)	Other interstitial pulmonary diseases; N=2,289 (3.2%)	Pneumonia, organism unspecified; N=4,851 (7.2%)	Motor- or nonmotor-vehicle accident; N=335 (4.3%)	Fall on and from stairs and steps; N=541 (4.6%)

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 – title page
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1 – title page
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any pre-specified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	4
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Outcomes – 4 Statistical analysis - 5
Data sources/ measurement	8*	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	4 - 5
Bias	9	Describe any efforts to address potential sources of bias	8
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	13 (table footnote)
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	NA NA

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			
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	NA
		(b) Give reasons for non-participation at each stage	
		(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	Table 1 - 12
		(b) Indicate number of participants with missing data for each variable of interest	Table 1 - 12
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	5,6 table 3,4
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	NA
		Cross-sectional study—Report numbers of outcome events or summary measures	NA
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	5-6, Table 3, Table 4
		(*b*) Report category boundaries when continuous variables were categorized	Table 4
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	7
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	8
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	8
Generalisability	21	Discuss the generalisability (external validity) of the study results	7,8
Other information			
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	10

*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.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is 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 Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.