Palliative Care in Ontario:
A Population-Based Study across Health Sectors using Health Administrative Databases

Applied Health Research Question Series

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

Report prepared by: Peter Tanuseputro, Suman Budhwani, Yu Qing Bai, Walter P. Wodchis

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Executive Summary

With recognition of an aging population, significant efforts are underway to understand and improve palliative and end-of-life care in Ontario. This report was requested by the Central East Local Health Integration Network (LHIN) on behalf of a provincial palliative and hospice care collaborative. This report follows an HSPRN Applied Health Research Question Evidence Brief, *Understanding the Provision of End-of-Life and Palliative Care Services in Ontario*.[1] Our previous work developed codes to capture end-of-life and palliative care in administrative databases. We now expand data on health care use and cost in the last year of life across a range of health care sectors. We also further examine the characteristics of palliative care delivered in Ontario, and describe its association with health care use and cost. Specifically, we have set out to achieve 3 objectives:

1) Describe overall health care utilization of individuals in their last year of life across a variety of health care sectors.
    - A total of 175,478 out of 177,817 (98.7%) decedents were recorded to have at least one health care use in their last year of life.
    - About one quarter of decedents (24.1%) used long-term care in their last year of life, while about 3 out of 5 (59.5%) used home care. Only 9.9% and 1.5% of decedents used complex continuing care and rehabilitation, respectively.
2) Determine distribution of palliative care encounters across identified settings.
    - Slightly more than half (51.9%) of all decedents had at least one record of receiving palliative care in their last year of life.
    - Of those identified to have received palliative care, a large proportion was identified in acute care hospitals and through outpatient physician claims (84.9% and 63.9%, respectively). Only a little more than one-third of the palliative cohort (37.2%) received palliative home care through the Continuing Care Access Centers.
    - Less than 10% of decedents had a record of a palliative care home visit from a physician in their last year of life. More than half of these visits occurred in the month prior to death.
    - Among 92,276 decedents receiving palliative care, an average of 35 days of palliative care was delivered in the last year of life. About half (49.1%) of all days of palliative care delivered was performed in the last 2 months prior to death.

- Home care and inpatient acute care contributed the largest number of total palliative care days delivered (44.2% and 37.5%, respectively).

<u>Time of initiation, continuity, intensity, and cost associated with palliative care</u>

- *Initiation:* Of those receiving palliative care, 50.8% had their care initiated in the last 2 months of life.
- *Continuity:* Among patients receiving palliative care, 78% had at least 2 days of palliative care (from time of initiation) each month until death.
- *Intensity:* Despite an average of 35 total palliative care days in the last year of life (among those who received at least 1 day), a significant number received 2 or less days and more than a third received less than 1 week.
- *Cost:* the total average cost (for all health sectors) in the last year of life among those who received palliative care ($57,424) was higher than the average cost among those who did not ($44,023). Average cost among palliative care patients rose steadily with earlier initiation of palliative care. The majority of this difference is attributed to the higher cost of inpatient care in the palliative care cohort. These results can largely be explained by the method of data capture; palliative care was captured using claims of health care use, which in turn contributes directly to total costs, and is related to disease severity. This tautological definition limits our ability to draw conclusions about the overall effect of palliative care on costs at the end-of-life.

3) Measure and compare regional and sub-regional differences in end-of-life and palliative care across identified settings.
   - The proportion of decedents receiving palliative care in their last year of life in any sector ranged across LHINs from 48.3% to 54.6%.
   - The proportion of decedents who used long-term care ranged from 20.8% to 27.6% across LHINs; home care at any time in the last year of life ranged from 56.7% to 67.3%.
   - For complex continuing care and rehabilitation, the proportion ranged 5 to 6 fold from 4.0% to 19.8% and from 0.4% to 2.7%, respectively.
   - Sector-specific palliative care varied significantly in the home setting. The proportion of decedents in each LHIN receiving physician-delivered, outpatient palliative care varied from 27.3% to 42.9%; the proportion of decedents receiving physician palliative home

visits ranged from 3.2% to 14.5%. For home care organized by Community Care Access Centers, the proportions ranged from 15.2% to 23.9%.

We examined the provision of end-of-life and palliative care using administrative databases across a wide range of health sectors. Inpatient acute care dominated total cost in the last year of life for all decedents, followed by long-term care and physician services. We have noted some limitations of our methods, which are largely descriptive and lack the adjustments required to isolate the true effect of palliative care on overall health care use and cost. Nevertheless, our results suggest that palliative care is likely underutilized, especially in the home setting. Furthermore, the significant regional variations in the provision of palliative care show that there are likely best practices that can be adopted to improve the reach of palliative care in the dying population.

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Context:

The document *Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action* (2011) describes the vision for palliative care in Ontario based on the collaborative viewpoint of over 80 stakeholders. This document highlights the goals and actions necessary to ensure the provision of high quality care to Ontarians at the end of life. The proposed improvements focuses on providing adults and children who have advanced progressive conditions with the care and support required to ensure proactive, holistic, patient and family focused services delivered in a coordinated manner, independent of health care settings.

To help achieve this vision, a Provincial Hospice Palliative Care Steering Committee was formed to guide collaborative efforts to improve hospice palliative care across Ontario. A Data and Performance Subcommittee was also established with the responsibility of developing and implementing a data and performance measurement strategy. The Central East LHIN led this work in collaboration with Cancer Care Ontario. To inform the work of the Committee, the Central East LHIN, on behalf of the province of Ontario, submitted two Applied Health Research Questions (AHRQ) to the Health System Performance Research Network (HSPRN), seeking to understand the current state of palliative and end-of-life care in Ontario. The first AHRQ examined the feasibility of using health administrative databases to assess the provision of palliative and end-of-life care in Ontario. The findings have been summarized in an Evidence Brief Report [1]. This follow-up AHRQ builds on the previous findings to examine in greater detail the provision of palliative care services across the continuum of health care settings.

Objectives:

We seek to identify Ontarians receiving palliative and end-of-life care and to describe health care use and costs across the continuum of care sectors. We provide a specific focus on continuing care sectors that were not examined in the first AHRQ. This includes health care utilization and cost of long-term care (LTC), home care, rehabilitation, and complex continuing care (CCC). Specifically, this research project has 3 main objectives:

1) Describe the characteristics and overall health care utilization of individuals in their last year of life across a variety of health care sectors, as captured by health administrative databases in Ontario. This includes an in-depth examination of health care use in the last year of life in continuing care sectors (LTC, home care, rehabilitation, and CCC). The analysis is stratified by those who received and those who did not receive palliative care in their last year of life.
2) Determine distribution of palliative care encounters across identified settings.
3) Measure and compare regional and sub-regional differences in end-of-life and palliative care across identified settings.

Methods:

Using Ontario's Registered Persons Database (RPDB), all deaths occurring in Ontario between April 1, 2010 and March 31, 2012 (Fiscal Year (FY) 2010/11 to 2011/12) were captured. For each decedent, we retrospectively examined the provision of palliative and non-palliative health care services 3, 6, and 12 months prior to death.

Health Care use of Decedent Cohort in the Continuing Care Sectors

We examined the socio-demographic characteristics of the entire decedent cohort, and of the decedent cohort that utilized (at least on one occasion) LTC, home care, CCC, or rehabilitation in the last year of life. Neighborhood income and rurality were determined using the postal code of each decedent one year prior to death.

Palliative Care

Palliative care was captured through billing and diagnostic codes in the various health administrative databases examined (see Appendix A for list of databases and codes). We used codes that implied that some form of palliative care was provided. Health care data used to identify palliative care included: physician services, home care provided publically through Community Care Access Centers, LTC, CCC, emergency departments, and inpatient hospital admissions.

We updated some of the palliative care codes used from our initial AHRQ. These changes include: further specifying and attributing OHIP billing codes by location of care (office, hospital, LTC, CCC, and rehabilitation); examining a subset of home-based palliative care OHIP physician billing codes (i.e., by applying travel codes, telephone consults); including Main Patient Service code of palliative care for inpatient hospitalizations and palliative care consult service in emergency rooms; including home care patients staying in hospice or palliative care units; and including both Service Recipient Code (SRC) service and discharge codes for palliative care (in addition to SRC admission codes).

There are many reasons why some patients do not receive palliative care prior to death, including the unexpected or rapid nature of some deaths. Health care practitioners may also fail to recognize that a person is near the end of life. Furthermore, even when practitioners do recognize end of life, care that is palliative in nature may not be coded in the health administrative databases as such. For example, since not all physicians are aware of specific palliative care billing codes, a physician may provide palliative care in an outpatient setting, but may bill for a regular visit code.

Distribution of Palliative Care Encounters across Identified Settings

We first examined the socio-demographic characteristics of those who were recorded to have received at least one palliative care claim in the last year of life across all health sectors. We then examined the number of decedents receiving at least one record of palliative care in each of the sectors examined.

For each health care sector, we then tallied the total number of days on which palliative care was recorded. We did this for each decedent, then summed the total days for all decedents. If a decedent received multiple services from the same sector on a given day, only one day was counted. For example, for each decedent, we summed the total number of days on which physicians billed for palliative care. If a decedent received multiple physician visits in a day, only one day or visit would be counted. If on a given day a decedent received palliative care from more than one sector (e.g., from home care and from a physician home or outpatient visit), the record would be captured for each sector, but would again be counted as one day when determining the total number of palliative care days for each decedent.

For inpatient hospitalizations, we counted the entire length of stay for admission with palliative care as the most responsible diagnosis or the main patient service; all other codes for inpatient palliative care were counted on the day it was captured. For LTC and CCC, we counted the number of days during which a palliative care code, primarily from physician billings, was recorded. For all settings, we did not capture palliative care services delivered by other health practitioners such as nurses or personal support workers. The exception is for home care, where services from various types of practitioners were captured for decedents with an end-of-life service code (Appendix A).

For all health sectors, we examined the total number of palliative care days delivered by month prior to death. This allows us to examine the intensity of palliative care days for the entire cohort, leading up to death.

For each decedent who was recorded to have received palliative care, we further examined the intensity, time of initiation, and continuity of palliative care. We defined intensity as the total number of palliative care days delivered in the last 360 days of life, removing any overlap of multiple services (whether from the same or different health sector) delivered on the same day. We defined initiation for each individual as the furthest date from date of death on which palliative care were delivered, within the last year of death. Finally, we defined continuity of care as the proportion of months since month of initiation during which at least 2 days of palliative care were delivered, leading up to death. We examined the distribution of intensity, time of initiation, and continuity of care across all decedents who received palliative care.

Health Care Use and Cost for Decedents Receiving and Not Receiving Palliative Care

We examined the total and sector-specific health care cost of those who received at least one claim for palliative care, and compared them to costs incurred by those who did not receive palliative care. Costs were derived using costing macros developed at the Institute for Clinical Evaluative Services (ICES), and are the sum of costs from a variety of sectors including: LTC, home care, CCC, rehabilitation, inpatient services, outpatient services, OHIP billings, and drugs and devices (costs covered by the provincial government). We also examined costs by month prior to death that palliative care was initiated (time of initiation). The costing methods used are described elsewhere [2]. Briefly, we have taken a payer (provincial government) costing perspective, using person-level health care expenditures that account for data for health care utilization and cost information per use. Cost information for sectors that have global budgets (e.g., hospitals, complex continuing care, rehab) were determined using a top-down approach through case-mix methodology. Sectors that have fee payments associated with each use (e.g., drug cost, or cost paid out to physician) were estimated directly. All costs were expressed in 2013 Canadian dollars; we inflated past costs using health care-specific yearly Consumer Price Index reported by Statistics Canada.

Regional Differences in Palliative Care at the End-of-Life

To examine regional variation in health care utilization and in palliative care service among decedents, we first examined the proportion of the entire decedent population in each LHIN that had at least one claim in each of the health care sectors examined. We then examined the proportion of the decedent cohort in each LHIN that received at least one palliative care claim in the last year of life. Finally, we examined the proportion of decedents that had at least one palliative care claim in each of the sectors examined.

Findings:

Health Care Use of Decedent Cohort in the Continuing Care Sectors

Table 1: Socio-demographic characteristics of the decedent population, by health sector use* in the last year of life, Ontario

	Long-term Care Users		Complex Continuing Care Users		Home Care Users		Rehabilitation Users		All Decedents	
	N	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
All Users (% of all decedents)	42,864	(24.1%)	17,616	(9.9%)	105,869	(59.5%)	2,577	(1.4%)	177,817	(100%)
Sex										
Male	14,772	(34.5%)	8,528	(48.4%)	51,286	(48.4%)	1,277	(49.6%)	86,514	(49.3%)
Female	28,092	(65.5%)	9,088	(51.6%)	54,583	(51.6%)	1,300	(50.4%)	88,964	(50.7%)
Age										
<19	0	(0.0%)	< 6	(0%)	368	(0.3%)	0	(0.0%)	1,984	(1.1%)
19-44	56	(0.1%)	198	(1.1%)	1,733	(1.6%)	22	(0.9%)	5,229	(3.0%)
45-54	182	(0.4%)	634	(3.6%)	4,624	(4.4%)	60	(2.3%)	9,183	(5.2%)
55-64	735	(1.7%)	1,559	(8.8%)	10,637	(10.0%)	176	(6.8%)	18,151	(10.3%)
65-74	2,508	(5.9%)	2,847	(16.2%)	17,655	(16.7%)	421	(16.3%)	27,833	(15.9%)
75-84	10,966	(25.6%)	5,608	(31.8%)	31,912	(30.1%)	937	(36.4%)	48,784	(27.8%)
85-94	21,731	(50.7%)	5,881	(33.4%)	32,892	(31.1%)	849	(32.9%)	52,807	(30.1%)
95+	6,686	(15.6%)	886	(5.0%)	6,048	(5.7%)	112	(4.3%)	11,507	(6.6%)
Neighborhood income**										

Q1	10,284	(24.0%)	4,074	(23.1%)	23,715	(22.4%)	600	(23.3%)	40,363	(23.0%)
Q2	8,189	(19.1%)	3,849	(21.8%)	22,205	(21.0%)	551	(21.4%)	36,399	(20.7%)
Q3	8,287	(19.3%)	3,375	(19.2%)	20,341	(19.2%)	459	(17.8%)	33,476	(19.1%)
Q4	8,243	(19.2%)	3,123	(17.7%)	20,051	(18.9%)	494	(19.2%)	32,658	(18.6%)
Q5	7,579	(17.7%)	3,073	(17.4%)	19,064	(18.0%)	464	(18.0%)	30,880	(17.6%)
Rurality										
Urban	36,330	(84.8%)	15,910	(90.3%)	90,256	(85.3%)	2,392	(92.8%)	148,931	(84.9%)
Rural	6,475	(15.1%)	1,694	(9.6%)	15,510	(14.7%)	185	(7.2%)	25,693	(14.6%)

* Decedent cohort includes those who died between April 1, 2010 and March 31, 2012. The number of users in each of the four continuing care sector columns represents the number of decedents who were recorded to have at least one use in the respective sectors in the last year prior to death. Individuals can count as users in multiple sectors if they utilized more than one sector in their last year of life.

** Neighborhood income derived from each decedent one year prior to death, using postal code conversion linked to census data.

- There were a total of 177,817 deaths captured between April 1, 2010 and March 31, 2012. We examined health care use in the year prior to death for each decedent.
- About one quarter (24.1%) of all decedents used long-term care, while about 3 out of 5 (59.5%) used home care.
- Only 9.9% and 1.5% of decedents used complex continuing care and rehabilitation, respectively.
- The proportions of female and male decedents were roughly the same overall and for all sectors with the exception of long-term care where about 2/3 were female. LTC residents were generally also older than the general decedent population.
- Decedents generally lived in lower income neighborhoods one year prior to death. This gradient was observed in all continuing sectors.
- Similar to the survival population, a large proportion of decedents lived in urban settings (data not shown). The use of complex continuing care and rehabilitation was higher among urban decedents.

Distribution of Palliative Care Encounters across Identified Settings

I. Distribution across Socio-Demographic Variables and Health Sectors

Palliative Care among all Decedents

Table 2: Decedent population receiving at least one record of palliative care in any health care sector in the last year of life, Ontario, FY 2010/11-FY 2011/12

	All Palliative Care Patients	No Palliative Care	All Decedents

Females	47,187	42,553	89,740
Males	45,089	42,988	88,077
Total	92,276 (51.9%)	85,541 (48.1%)	177,817

- Slightly more than half (51.9%) of all decedents (n=177,817) had at least one record of receiving palliative care in any of the databases examined (Appendix A), in their last year of life.
- The proportion of patients receiving palliative care was similar for both males and females.

Palliative Care by Health Sector

Table 3: Distribution and proportion of decedents who received at least one palliative care claim across health care sectors in the last year of life, Ontario, FY 2010/11-FY 2011/12

	Physician Home-based Palliative (OHIP)*	All Physician Outpatient (OHIP)	Home Care (RAI-HC/HCD/CA)	Long-term Care (OHIP)	Complex Continuing Care (OHIP &CCRS)	Hospital Inpatient (DAD & OHIP)	Emergency Room (NACRS)
Females	8,752	30,421	16,774	599	3,263	39,343	131
Males	8,207	28,560	17,537	293	2,746	39,001	152
Total	16,959 (18.4%)	58,981 (63.9%)	34,311 (37.2%)	892 (1.0%)	6,009 (6.5%)	78,344 (84.9%)	283 (0.3%)

*Data sources in brackets – see Appendix A for details

- Out of all patients identified to have received palliative care (92,276), a large proportion was identified in acute care hospitals (Hospital Inpatient) and through outpatient physician claims (84.9% and 63.9%, respectively).
- Only 16,959, or less than 10% of the decedent population, received palliative care in the home from a physician in the last year of life. This proportion may be an underestimation, partly due to the under-utilization of palliative care codes from physician making home visits to their dying patients.
- More than one-third of the palliative cohort (37.2%), and less than one in five of the entire decedent cohort, received palliative home care through the CCAC.
- Less than 1% of our palliative cohort was identified to receive palliative care in long-term care or in the emergency room.
- There was roughly an equal distribution of males and females receiving palliative care across the health sectors. The exception was in long-term care where a greater proportion of females vs. males (67% to 33%) was found. This proportion follows the distribution of all long-term care residents.

Palliative Care by Age-Group

Table 4: Number and proportion of decedents receiving at least one palliative care in the last year of life, by age-group, Ontario, FY 2010/11-FY 2011/12

Age-group	Decedents	All Palliative Care (%)	Proportion of Decedents Receiving Palliative Care
0-18	2,751	337 (0.4%)	12.3%
19-44	5,516	1,568 (1.7%)	28.4%
45-54	9,459	4,497 (4.9%)	47.5%
55-64	18,505	10,469 (11.3%)	56.6%
65-74	28,095	16,731 (18.1%)	59.6%
75-84	49,008	27,636 (29.9%)	56.4%
85-94	52,946	26,157 (28.3%)	49.4%
95 +	11,537	4,881 (5.3%)	42.3%
Total	177,817	92,276 (100%)	51.9%

- Less than 25% of the decedent population under 45 years received palliative care. This low proportion is likely a reflection of the high number of sudden deaths in the younger age groups (injuries are the leading cause of death in those under 45 in Canada) [3].
- The proportion receiving palliative care increased with age, peaking at 65-74 (59.6%) followed by subsequent decline at older age groups.
- Distribution of palliative care across age groups was fairly consistent for all sectors, with the exception of LTC where there was prominence among older age groups (data not shown).

Palliative Care by Neighborhood Income Quintile

Table 5: Income quintile distribution of decedents receiving at least one palliative care in the last year of life, by age group, Ontario, FY 2010/11-FY 2011/12

Income Quintile*	Palliative Cohort	(%)	No Palliative	(%)	All Decedents	(%)
1 (Lowest)	20,484	22.3%	20,226	24.4%	40,710	23.3%
2	19,450	21.2%	17,270	20.8%	36,720	21.0%
3	17,593	19.2%	16,110	19.4%	33,703	19.3%
4	17,449	19.0%	15,423	18.6%	32,872	18.8%
5 (Highest)	16,734	18.2%	14,033	16.9%	30,767	17.6%
Total	91,710	100.0%	83,062	100.0%	174,772	100.0%

*Each decedent was assigned a neighborhood income, based on their postal code of residence one year prior to death.

- Decedents generally resided in lower income neighborhoods one year prior to death.
- This pattern was generally more pronounced in those who did not receive palliative care.

- Decedents receiving palliative home care did not exhibit any significant patterns across income quintiles, with 19.9% and 19.6% residing in quintile 1 and 5, respectively (data not shown).
- The pattern in decedents receiving home-based palliative physician care was opposite to the overall trend; 17.8% and 22.5% of these decedents resided in income quintile 1 and 5, respectively (data not shown).

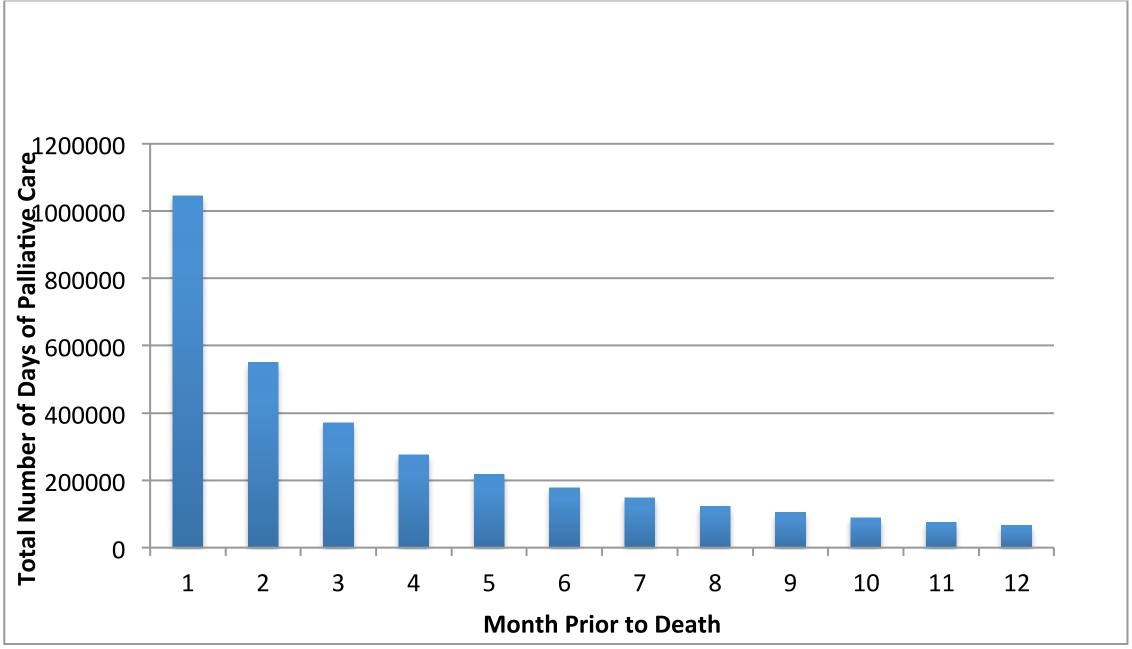
Palliative Care Delivered in Urban/Rural Settings

- 85.3% of all decedents resided in urban settings.
- 86.4% of all decedents receiving palliative care resided in urban settings; this proportion was highest for complex continuing care, emergency room, and physician based home care (92.9%, 95.4%, and 89.1%, respectively).
- Overall, decedents residing in urban settings were slightly more likely to receive palliative care in their last year of life (53.1% versus 48.4%).

II. Delivery of Palliative Care Leading to Death

Overall

Figure 1: Total number of palliative care days, by month before death, all Ontario decedents with palliative services, FY 2010/11-FY 2011/12



- Among 92,276 decedents receiving palliative care, an average of 35 days of palliative care was delivered in the last year of life (Table 6).
- The number of days on which palliative care was delivered rose sharply in the last 3 months of life (Figure 1).
- In the last month of life, 94.0% of the entire palliative care cohort received at least 1 day of palliative care. In the last 2nd and 3rd months of life this proportion decreased to 49.4% and 36.5%, respectively. Nine percent (9.2%) of the palliative cohort received palliative care in the 12th month prior to death.
- About half (49.1%) of all days of palliative care delivered was performed in the last 2 months prior to death.
- Among those receiving at least one palliative care day in the nth month prior to death, the mean number of days rose steadily from 7.9 to 12.1 from the 12th to 1st month prior to death.

Table 6: Delivery of palliative care (PC) by month leading to death, Ontario, FY 2010/11-FY 2011/12

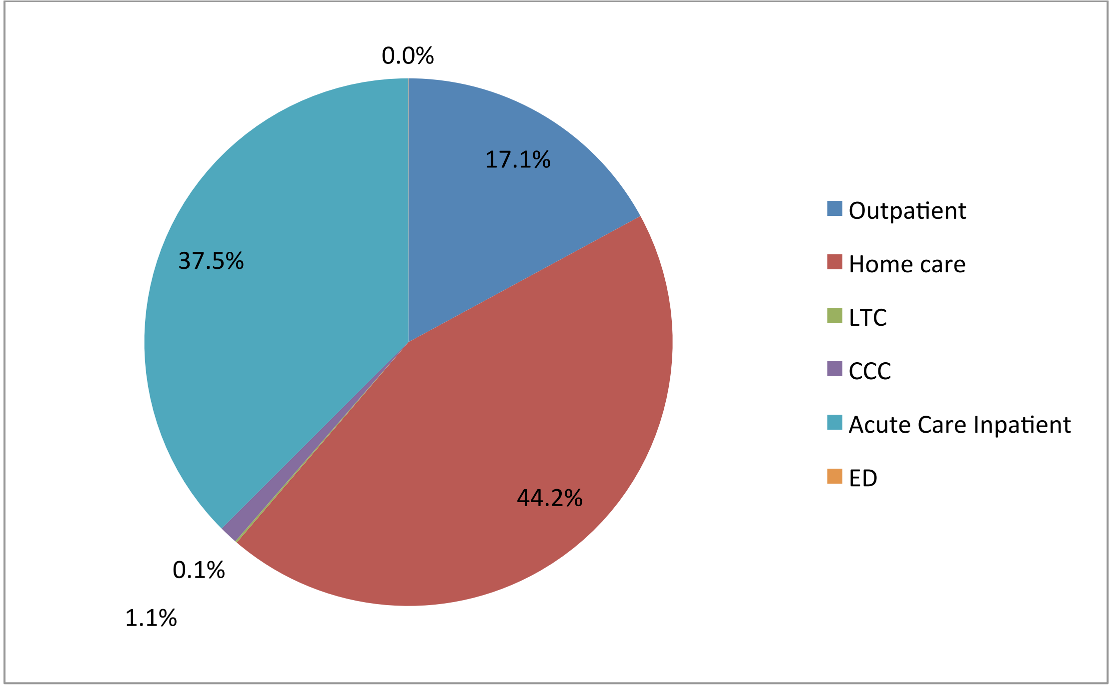
Month prior to death	Number of Decedents	Total Palliative Care Claims	Unique Days of PC Delivered	(%)	Average # Days for Entire PC Cohort*	Average # Days among Monthly Recipients**
1	86,703	1,251,618	1,045,467	32.2%	11.3	12.1
2	45,612	624,671	549,822	16.9%	6.0	12.1
3	33,637	410,655	371,031	11.4%	4.0	11.0
4	27,001	299,861	276,365	8.5%	3.0	10.2
5	22,514	233,344	217,213	6.7%	2.4	9.6
6	19,355	190,036	177,923	5.5%	1.9	9.2
7	16,497	156,867	147,665	4.6%	1.6	9.0
8	14,333	130,297	123,385	3.8%	1.3	8.6
9	12,524	110,060	104,403	3.2%	1.1	8.3
10	10,958	93,308	88,960	2.7%	1.0	8.1
11	9,608	79,259	76,012	2.3%	0.8	7.9
12	8,504	69,618	67,055	2.1%	0.7	7.9
Total	92,276	3,649,594	3,245,301	100%	35.2	35.2

* Average # Days for Entire PC Cohort is calculated by dividing the Total Palliative Care Claims for each month by the total number of palliative care decedents (92,276).

**Average # of Days among Monthly Recipients *for each month* is calculated by dividing the number of Unique Days of PC Delivered by the Number of Decedents receiving palliative care in that month.

By Health Sector

Figure 2: Proportion of total days of palliative care delivered to all decedents in the last year of life by health sector, Ontario, FY 2010/11-FY 2011/12



*See methods for more details on how palliative care days were counted for each health sector.

- Home care and inpatient acute care contributed the largest number of palliative care days delivered in the last year of life (44.2% and 37.5%, respectively).
- Physician-based outpatient palliative care days were next at 17.1%, while complex continuing care and emergency room visits represented an insignificant proportion.

Table 7: Delivery of palliative care by month prior to death, by health sector, Ontario, FY 2010/11-FY 2011/12

	Home-Based Physician Services			All Physician Outpatient Services			Home Care		
Month prior to death	Number of Decedents	Unique Days of PC Delivered	(%)	Number of Decedents	Unique Days of PC Delivered	(%)	Number of Decedents	Unique Days of PC Delivered	(%)
1	13,769	41,862	50.9%	52,320	218,303	35.0%	28,016	381,574	23.7%
2	6,144	13,684	16.6%	24,409	98,098	15.7%	21,814	278,787	17.3%
3	3,701	7,586	9.2%	17,802	66,864	10.7%	16,931	204,294	12.7%
4	2,496	4,912	6.0%	13,808	49,751	8.0%	13,612	159,746	9.9%
5	1,862	3,487	4.2%	11,327	39,977	6.4%	11,293	128,385	8.0%
6	1,445	2,635	3.2%	9,552	33,197	5.3%	9,427	105,036	6.5%
7	1,186	2,076	2.5%	7,978	27,352	4.4%	7,891	87,890	5.4%
8	945	1,629	2.0%	6,901	23,231	3.7%	6,686	73,099	4.5%
9	805	1,395	1.7%	5,981	19,984	3.2%	5,630	61,195	3.8%

10	655	1,120	1.4%	5,299	17,475	2.8%	4,743	51,650	3.2%
11	598	988	1.2%	4,644	15,032	2.4%	4,016	43,909	2.7%
12	499	870	1.1%	4,153	13,743	2.2%	3,305	37,478	2.3%
Total	16,959	82,244	100%	58,981	623,007	100%	34,311	1,613,043	100%

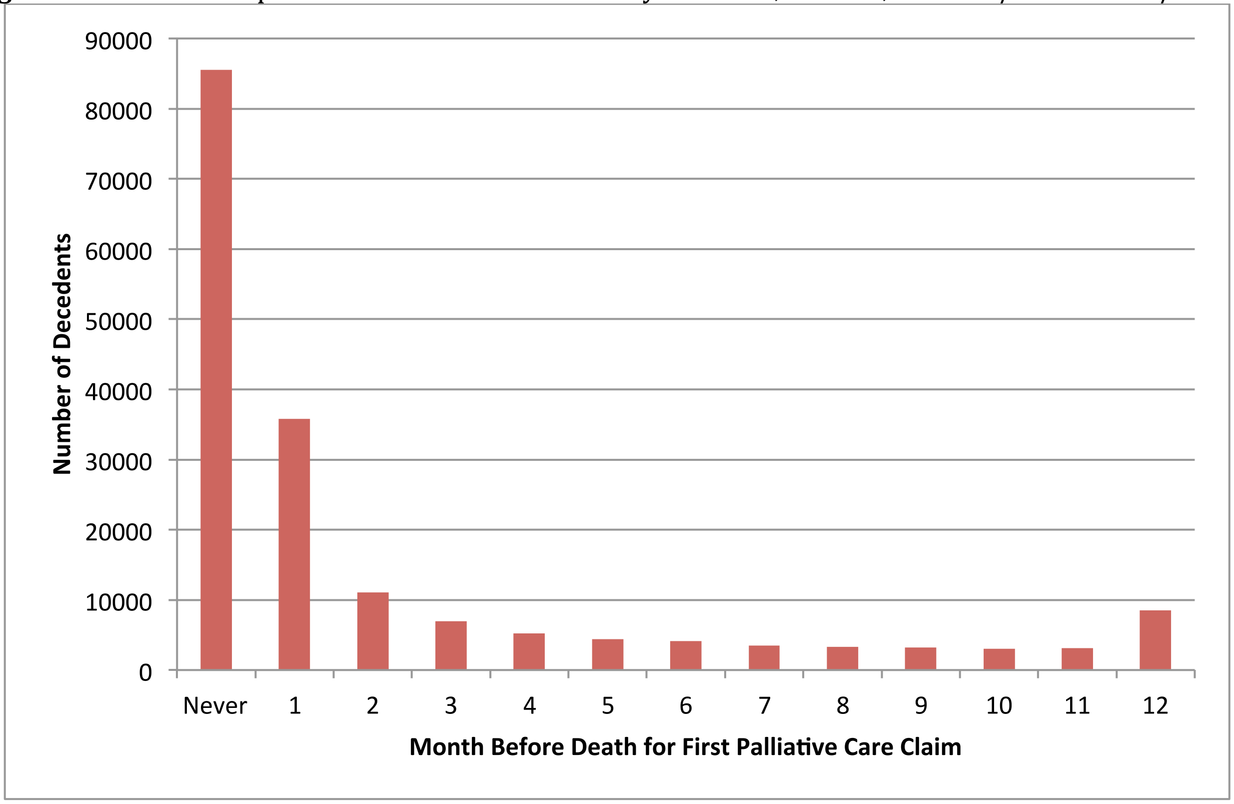
	Complex Continuing Care			Inpatient Hospital		
Month prior to death	Number of Decedents	Unique Days of PC Delivered	(%)	N	Unique Days of PC Delivered	(%)
1	4,425	20,079	48.7%	64,584	629,616	46.0%
2	1,712	7,567	18.3%	23,919	239,645	17.5%
3	884	4,226	10.2%	14,396	134,903	9.9%
4	512	2,868	7.0%	10,182	87,195	6.4%
5	358	1,867	4.5%	7,849	62,922	4.6%
6	235	1,278	3.1%	6,658	50,343	3.7%
7	193	1,017	2.5%	5,530	40,443	3.0%
8	137	679	1.6%	4,624	33,144	2.4%
9	106	533	1.3%	4,073	28,225	2.1%
10	83	445	1.1%	3,541	23,612	1.7%
11	71	353	0.9%	3,062	19,855	1.5%
12	61	336	0.8%	2,788	17,963	1.3%
Total	6,009	41,248	100%	78,344	1,367,866	100%

- Compared to all outpatient palliative care services, home-based physician care occurred more proximal to death. More than half (50.9%) of home-based physician services occurred in the month prior to death, compared to 35% for all physician outpatient services (which includes home-based physician care) and 23.7% for home care.
- The vast majority of palliative care is delivered in the last six months of life; the proportion of palliative care days delivered in the last six months prior to death was 90.2%, 81.2%, and 78.0% for home-based physician care, all physician outpatient care, and home care, respectively.
- Almost half of the palliative care delivered in acute care hospitals (46.0%) and in complex continuing care facilities (48.7%) is delivered in the last month prior to death.
- The proportion of palliative care days delivered in the last 6 months prior to death was 88.1% and 91.8% for inpatient hospital care and complex continuing care, respectively.

III. Initiation, Continuity, and Intensity of Palliative Care

Initiation

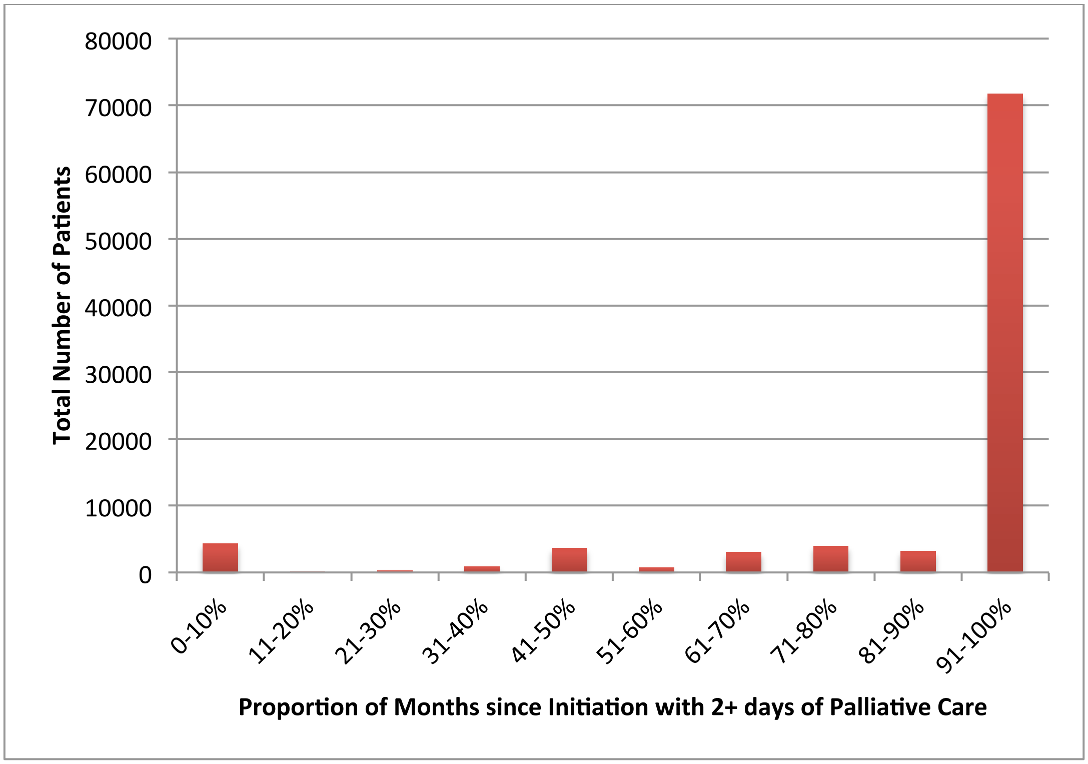
Figure 3: Time of first palliative care claim in the last year of life, Ontario, FY 2010/11-FY 2011/12



- Slightly less than half of the 177,817 decedents (48.1%) never received a palliative care claim in the last year of life. For those who received palliative care, the first claim emerged most commonly within 1 month prior to death (n=35,824), followed by at 2 months prior to death (n=11,093).
- Of those receiving palliative care, 50.8% had their care initiated in the last 2 months of life.

Continuity

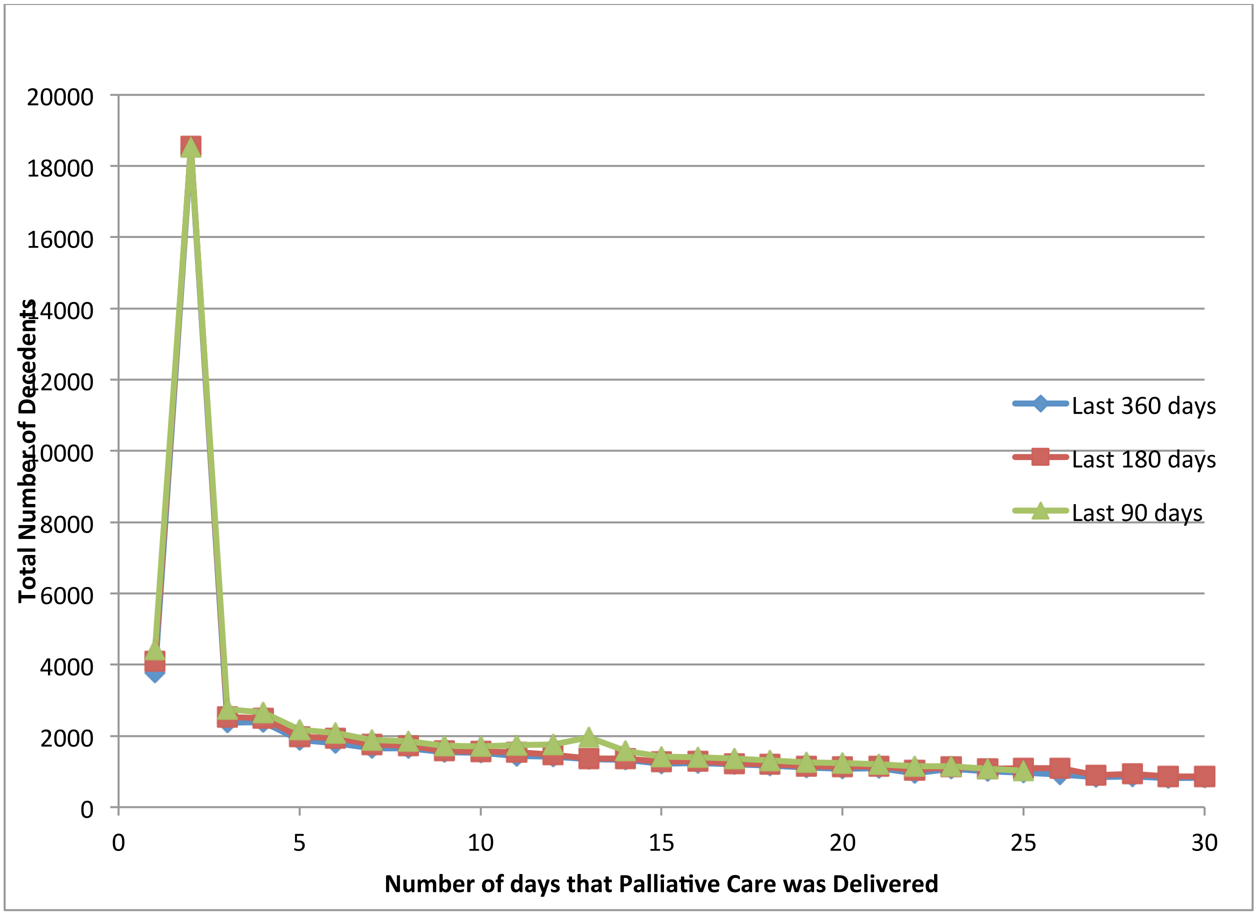
Figure 4: Proportion of months since time of initiation where 2+ days of Palliative Care were delivered, Ontario, FY 2010/11-FY 2011/12



- Among patients receiving palliative care, 78% had at least 2 days of palliative care each month (from time of initiation) until death. This high proportion is partly related to the large proportion of decedents who had palliative care initiated within only 1-2 months prior to death.
- For about 9 in 10 (89.9%) patients, at least 2 days of palliative care were delivered during more than 50% of months prior to death.

Intensity

Figure 5: Distribution of total number of palliative care claims per patient in the last 360, 180, and 90 days prior to death, Ontario, FY 2010/11-FY 2011/12



- We examined the total number of unique days of palliative care each decedent had in their last 90, 180, and 360 days of life (see methods for additional details). We then summed the number of decedents who had x total number of days in these three periods (the three lines in Figure 5).
- The 3 lines largely over-lapped, suggesting that the majority of palliative care occurred in the last 90 days.
- The greatest frequency of number of claims was by far 1 and 2 claims (4.9% and 20.5% of all palliative care patients for last 90 days).
- For all 3 lines, the number of patients gradually and steadily declined as the number of days increased past 30 days (data not shown).

Distribution of Initiation, Continuity and Intensity

Table 8: Average values of Initiation, Continuity, and Intensity among Quintiles* of Palliative Care Patients

Quintiles Among Values of Initiation days, Continuity %, and Intensity Days	**Initiation (Days Prior to Death)**	**Continuity (% months 2+ days of PC)**	**Intensity (Total # days w/ claim) Last 360 days**
	(Average Value)	(Average Value)	(Average Value)

Q1	3.7	47.8	1.8
Q2	18.1	88.6	6.1
Q3	59.2	100	17.9
Q4	159.9	N/A	39.3
Q5	314.5	N/A	112.8

* Quintiles are derived for each measure (initiation, continuity and intensity) by ordering each decedent's values for the respective measure, and generating five groups for each measure with equal number of decedents. For initiation, for example, we ordered all decedents based on days prior to death that palliative care was initiated, and created 5 groups (quintiles) containing decedents from the lowest number of days (Q1) prior to death to the highest (Q5). We then calculated the average value of days prior to death for palliative care initiation for all decedents within each quintile.

- Among 20% of palliative care patients, palliative care was initiated on average 3.7 days prior to death. This was in contrast to the top 20% where palliative care was initiated on average 314.5 days prior to death.
- Continuity of care was heavily skewed to 100% since 78% of the population had at least 2 days of palliative care in every month since the initiation of palliative care.
- Among the 20% who received the most days of palliative care in the last 360 days of life, palliative care was delivered on an average of 112.8 days or just less than 3 months. In contrast, for the bottom 20%, an average of less than 2 days (1.8) of palliative care were delivered.

Health Care Utilization and Cost of Decedents Receiving and Not Receiving Palliative Care

Table 9: Average Cost among those receiving palliative care in the last year of life, by time of palliative care initiation, Ontario, FY 2010/11-FY 2011/12

Palliative Care Initiation - Days Prior to Death	Decedents (n)	Average Cost*
0 – 7 days	16,422	$38,570
8 – 30 days	19,949	$45,692
31 – 60 days	10,847	$52,292
61 – 90 days	6,886	$58,513
91 – 180 days	13,636	$66,074
181 – 360 days	24,536	$76,739
All Palliative Care Patients	92,276	$57,424
No Palliative Care	83,199	$44,023

*Health care direct costs (from the provincial payer perspective) were calculated for each decedent, in their last year of life. Costs were totaled across 11 health care sectors: long-term care, complex continuing care, home care, rehabilitation, inpatient acute care, emergency department, outpatient clinics, physician billings, non-physician billings, laboratory and drugs/devices. More information on these methods can be found elsewhere [4].

- The total average cost in the last year of life among those who received any palliative care in their last year of life ($57,424) was higher than the average cost among those who did not ($44,023).

- Average cost among palliative care patients rose steadily as days prior to death of palliative care initiation increased.
- Those who had palliative care initiated very late (in last 7 days of life) had less average cost than those who did not receive palliative care. Those who had palliative care initiated between 181-360 days prior to death had 1.7 times higher average cost than those who did not have any palliative care.

Table 10: Proportion of palliative care cohort who used each health sector at least once in the last year of life, and the associated sector-specific cost, Ontario, FY 2010/11-FY 2011/12

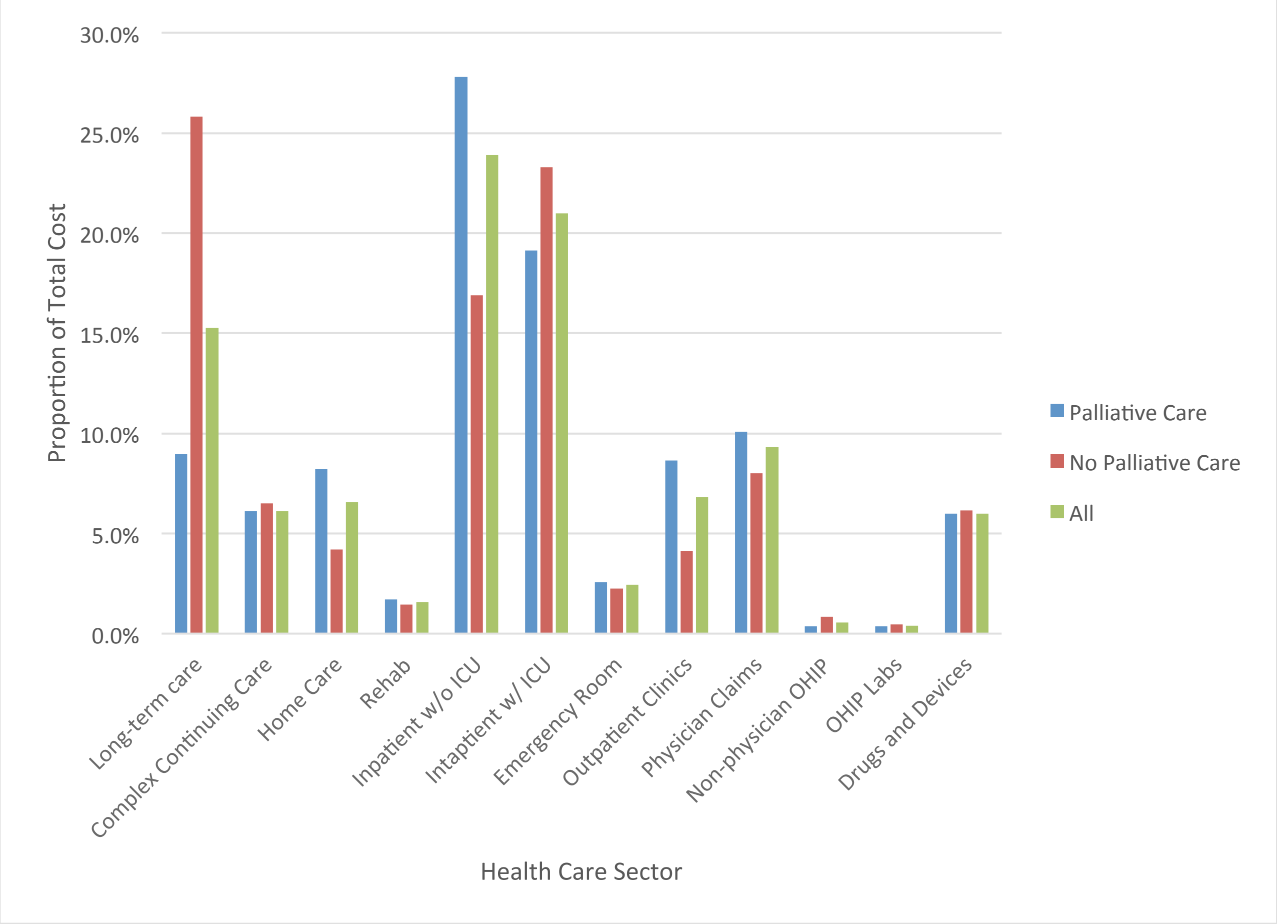
	Palliative Care Cohort				No Palliative Care Cohort			
Sector	Decedents (n)	% of cohort	Total Cost (millions)	% of Total Cost for all Sectors	Decedents (n)	% of cohort	Total Cost (millions)	% of Total Cost for all Sectors
Long-term care	15,606	16.9%	$474.6	9.0%	27,268	32.8%	$945.4	25.8%
Complex Continuing Care	14,278	15.5%	$324.1	6.1%	5,048	6.1%	$238.6	6.5%
Home Care	70,489	76.4%	$436.5	8.2%	35,380	42.5%	$154.4	4.2%
Rehab	3,660	4.0%	$90.7	1.7%	2,459	3.0%	$52.8	1.4%
Inpatient w/o ICU	62,705	68.0%	$1,473.0	27.8%	30,351	36.5%	$618.7	16.9%
Inpatient w/ ICU	19,649	21.3%	$1,014.0	19.1%	18,987	22.8%	$852.5	23.3%
Emergency Room	84,763	91.9%	$136.6	2.6%	62,000	74.5%	$81.9	2.2%
Outpatient Clinics	43,951	47.6%	$458.5	8.7%	15,390	18.5%	$151.1	4.1%
Physician Claims	92,245	100.0%	$534.9	10.1%	82,192	98.8%	$293.1	8.0%
Non-physician OHIP	41,861	45.4%	$19.7	0.4%	43,489	52.3%	$31.4	0.9%
OHIP Labs	75,420	81.7%	$19.1	0.4%	64,516	77.5%	$17.2	0.5%
Drugs and Devices	86,445	93.7%	$317.3	6.0%	70,667	84.9%	$225.6	6.2%
Total	92,276	100%	$5,298.9	100%	83,199	100%	$3,662.7	100%

*Note: Inpatient with ICU signifies patients who were hospitalized with at least one intensive care unit (ICU) visit in the last year of life.

- Total cost in the last year of life in the entire decedent cohort was $8.96 billion. The palliative care cohort consumed 59.1% of total cost ($5.3 billion).
- The majority of cost in the entire decedent cohort was inpatient costs, followed by long-term care, physician visits, outpatient clinics, home care, complex continuing care, and drugs and devices.
- The proportion of total cost spent on long-term care in the palliative care cohort was lower than in the no palliative care cohort (9.0% vs. 25.8%).

- Conversely, the proportion of total cost spent on home-care and on hospital admissions without an ICU stay was higher in the palliative care cohort (8.2% vs. 4.2% for home care and 27.8% vs. 16.9% for admissions without ICU).
- More than $1 billion of the absolute difference in total cost between the palliative and no palliative cohorts can be attributed to the use of inpatient services in the last year of life. About half of the $1.64 billion difference can be accounted by the $854 million difference in hospitalization costs among those without an ICU visit in the last year. This was largely due to the higher proportion of the palliative care cohort who used this service (68.0% versus 36.5%).
- $161 million, $282 million, and $307 million of the rest of the difference is attributed to those who used inpatient services with an ICU stay in the last year, for physician services, and for home care, respectively.

Figure 6: Proportion of total cost for palliative and non-palliative care cohort, Ontario, FY 2010/11-FY 2011/12



- Forty-four percent (44.2%) of total cost in the decedent population was attributed to acute inpatient hospital services. This proportion for the palliative and non-palliative decedent cohort was 46.9% and 40.2%.
- The next five total cost sectors for the entire decedent cohort were long-term care (15.8%), physician claims (9.2%), outpatient clinics (6.8%), home care (6.6%), and complex continuing care (6.3%).
- For the palliative cohort, the next five sectors were physician claims (10.1%), long-term care (9.0 %), outpatient clinic (8.7%), home care (8.2%), and complex continuing care (6.1%).
- For the non-palliative cohort, the next five sectors were long-term care (25.8%), physician claims (8.0%), complex continuing care (6.5%), drugs and devices (6.2%), and home care (4.2%).

Table 11: Sector-specific mean cost for the last year of life for those identified with palliative care and those without palliative care, by time of initiation and by health sector, Ontario, FY 2010/11-FY 2011/12

	Continuing care							
	Long-term Care		Complex Continuing Care		Home Care		Rehabilitation	
Palliative Care Initiation - Days prior to death	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**
0 – 7 days	4,584	$34,076	1,047	$32,895	8,682	$4,499	451	$22,269
8 – 30 days	3,689	$33,565	2,080	$13,860	12,627	$4,022	546	$23,069
31 – 60 days	1,199	$29,824	1,919	$11,267	8,560	$3,997	306	$23,503
61 – 90 days	753	$25,655	1,399	$15,679	5,941	$4,515	274	$25,110
91 – 180 days	1,742	$24,024	2,881	$21,937	12,175	$5,889	713	$26,495
181 – 360 days	3,639	$26,839	4,952	$31,109	22,504	$9,506	1,370	$25,594
All Palliative Care	15,606	$30,413	14,278	$22,698	70,489	$6,193	3,660	$24,772
No Palliative Care	27,268	$34,670	5,048	$47,262	35,380	$4,365	2,459	$21,468
Total	42,874	$33,120	19,326	$29,114	105,869	$5,582	6,119	$23,444

	Acute care					
	Inpatient without ICU		Inpatient with ICU		Emergency Room	
Palliative Care Initiation - Days prior to death	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**
0 – 7 days	9,531	$11,309	4,849	$22,385	14,843	$1,429
8 – 30 days	13,317	$17,908	4,868	$45,369	18,592	$1,369
31 – 60 days	7,839	$23,838	2,005	$67,150	10,102	$1,389
61 – 90 days	4,986	$26,903	1,189	$73,910	6,387	$1,553
91 – 180 days	9,825	$29,078	2,406	$71,535	12,677	$1,750
181 – 360 days	17,207	$30,223	4,332	$66,932	22,162	$1,973

All Palliative Care	62,705	$23,491	19,649	$51,604	84,763	$1,611
No Palliative Care	30,351	$20,384	18,987	$44,901	62,000	$1,321
Total	93,056	$22,478	38,636	$48,310	146,763	$1,489

	Outpatient Care									
	Outpatient Billings		Physician billings		Non-physician OHIP Billings		OHIP Laboratory		Drugs/Devices	
Palliative Care Initiation - Days prior to death	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**	N*	Mean Cost**
0 – 7 days	4,118	$10,028	16,406	$3,500	9,056	$649	13,528	$269	15,083	$3,175
8 – 30 days	6,762	$8,095	19,941	$4,610	9,784	$526	16,409	$252	18,400	$2,976
31 – 60 days	5,181	$7,692	10,844	$5,571	4,627	$382	8,884	$234	10,056	$2,862
61 – 90 days	3,899	$8,219	6,886	$6,255	2,816	$335	5,682	$235	6,477	$2,875
91 – 180 days	8,350	$9,654	13,636	$6,900	5,656	$329	11,304	$240	12,960	$3,556
181 – 360 days	15,641	$13,422	24,532	$7,663	9,922	$418	19,613	$265	23,469	$5,163
All Palliative Care	43,951	$10,431	92,245	$5,799	41,861	$472	75,420	$253	86,445	$3,671
No Palliative Care	15,390	$9,815	82,192	$3,566	43,489	$723	64,516	$266	70,667	$3,192
Total	59,341	$10,271	174,437	$4,747	85,350	$600	139,936	$259	157,112	$3,455

*Ns represent the number of decedents who were recorded to have at least one use of each of the respective sectors in the last year of life. For example, there were 42,874 decedents who used LTC in their last year of life, and 15,606 of these decedents received palliative care.

** Costs were mean cost for each sector in the last year of life, among those who had at least one use of each of the respective sectors in the last year of life. For example, among the 42,874 decedents who used LTC in their last year of life, their mean cost in the LTC sector was $33,120.

- In the acute care sectors, a general trend was observed of gradually increasing mean sector-specific total cost in the last year of life with increasing time span between the initiation of palliative care and death (measured in days prior to death) (Table 9). This trend likely reflects our method of identifying palliative care using health services use, which in turn is related to illness severity and health care cost (see discussion).
- The same trend is also generally observed in outpatient settings, with the exception of a higher mean cost in 4 out of 5 of these sectors for those whose palliative care was initiated between 0-7 days compared to 8-30 days.
- The majority of the continuing care sectors had a mildly "U" shaped distribution of mean costs, with the highest mean cost for those with palliative care initiated very early and very late.

Regional Differences in Care at the End-of-Life

Table 12: Number and proportion of all decedents with at least one use (palliative or not) in the last year of life, in continuing care sectors, by Local Health Integration Network (LHIN), Ontario, FY 2010/11-FY 2011/12

	Long-term Care	Complex Continuing Care	Home Care	Rehabilitation	All

LHIN*	n	%	n	%	N	%	n	%	n	%
ESC	2,576	(24.5%)	1,205	(11.4%)	6,776	(64.4%)	193	(1.8%)	10,526	(6.0%)
SW	4,244	(27.6%)	1,436	(9.3%)	9,359	(60.9%)	135	(0.9%)	15,362	(8.8%)
WW	2,330	(25.7%)	966	(10.6%)	6,117	(67.3%)	137	(1.5%)	9,083	(5.2%)
HNHB	6,010	(25.7%)	3,114	(13.3%)	14,073	(60.1%)	269	(1.1%)	23,413	(13.3%)
CW	1,575	(22.4%)	439	(6.2%)	4,208	(59.9%)	77	(1.1%)	7,030	(4.0%)
MH	2,212	(21.0%)	1,138	(10.8%)	6,599	(62.5%)	285	(2.7%)	10,551	(6.0%)
TC	2,965	(20.8%)	2,126	(14.9%)	7,874	(55.1%)	225	(1.6%)	14,278	(8.1%)
CENT	3,814	(22.4%)	2,050	(12.0%)	10,191	(59.9%)	277	(1.6%)	17,017	(9.7%)
CE	5,095	(25.5%)	1,652	(8.3%)	12,281	(61.4%)	457	(2.3%)	20,014	(11.4%)
SE	2,382	(26.0%)	1,092	(11.9%)	5,374	(58.8%)	48	(0.5%)	9,146	(5.2%)
CHAM	4,112	(25.1%)	653	(4.0%)	9,800	(59.8%)	291	(1.8%)	16,395	(9.3%)
NSM	1,864	(26.4%)	477	(6.8%)	4,296	(60.9%)	90	(1.3%)	7,058	(4.0%)
NE	2,663	(24.8%)	459	(4.3%)	6,531	(60.9%)	75	(0.7%)	10,719	(6.1%)
NW	963	(23.9%)	797	(19.8%)	2,287	(56.7%)	18	(0.4%)	4,032	(2.3%)
All	42,864	(24.1%)	17,616	(9.9%)	105,869	(59.5%)	2,577	(1.4%)	177,817	(100%)

*ESC = Erie St. Clair; SW = South West; WW = Waterloo Wellington; HNHB = Hamilton Niagara Haldim and Brant; CW = Central West; MH = Mississauga Halton; TC = Toronto Central; CENT = Central; CE = Central East; SE = South East; CHAM = Champlain; NSM = North Simcoe Muskoka; NE = North East; NW = North West.

- The proportion of decedents who used long-term care at any time in the last year of life was fairly consistent across LHINs, ranging from 20.8% in TC to 27.6% in SW.
- The proportion receiving home care was also fairly consistent, ranging from 56.7% in SW to 67.3% in WW.
- The proportion entering complex continuing care and rehabilitation in the last of life showed much greater variation. The proportion across LHINs ranged five-fold from 4.0% in CHAM to 19.8% in NW. For rehabilitation, the proportion of decedents ranged six-fold from 0.4% in NW to 2.7% in MH.

Table 13: Number and proportion of decedents who received palliative care in the last year of life, by Local Health Integration Network (LHIN), Ontario, FY 2010/11-FY 2011/12

LHIN*	Palliative Care (n)	(%)	No Palliative Care (n)	(%)	All Decedents
ESC	5,755	54.4%	4,826	45.6%	10,581
SW	7,901	51.2%	7,545	48.8%	15,446
WW	5,000	54.6%	4,161	45.4%	9,161
HNHB	12,116	51.6%	11,354	48.4%	23,470
CW	3,475	49.1%	3,606	50.9%	7,081
MH	5,699	53.7%	4,921	46.3%	10,620
TC	7,858	54.4%	6,600	45.6%	14,458
CENT	9,258	54.3%	7,800	45.7%	17,058
CE	10,648	53.0%	9,441	47.0%	20,089
SE	4,622	50.2%	4,580	49.8%	9,202
CHAM	8,947	54.1%	7,587	45.9%	16,534

NSM	3,600	50.9%	3,475	49.1%	7,075
NE	5,224	48.5%	5,555	51.5%	10,779
NW	1,962	48.3%	2,103	51.7%	4,065
Missing	211	9.6%	1,987	90.4%	2,198
All	92,276	51.9%	85,541	48.1%	177,817

*ESC = Erie St. Clair; SW = South West; WW = Waterloo Wellington; HNHB = Hamilton Niagara Haldim and Brant; CW = Central West; MH = Mississauga Halton; TC = Toronto Central; CENT = Central; CE = Central East; SE = South East; CHAM = Champlain; NSM = North Simcoe Muskoka; NE = North East; NW = North West.

- The proportion of decedents receiving palliative care in their last year of life in any sector ranged from 48.3% (NW) and 48.5% (NE) to 54.4% (ESC and TC) and 54.6% (WW), respectively.

Table 14: Proportion of decedents in each LHIN who received at least one palliative care record in the last year of life, by health sector, Ontario, FY 2010/11-FY 2011/12

LHIN*	Home based PC (OHIP)**	All outpatient (OHIP)	Home Care (RAI-HC/HCD/CA)	LTC (OHIP)	CCC (OHIP &CCRS)	Hospital inpatient (DAD & OHIP)	ER (NACRS)
ESC	9.9%	28.4%	21.9%	0.8%	4.1%	43.7%	0.0%
SW	7.2%	33.6%	17.1%	0.6%	2.3%	43.9%	0.0%
WW	9.1%	34.2%	23.3%	0.4%	2.5%	47.3%	0.0%
HNHB	6.9%	27.6%	19.9%	0.5%	5.1%	40.9%	0.1%
CW	9.7%	38.5%	17.3%	0.2%	0.9%	43.2%	0.3%
MH	11.7%	42.9%	22.4%	0.4%	3.8%	45.3%	1.0%
TC	13.4%	36.0%	16.2%	0.4%	6.2%	48.5%	0.1%
CENT	13.6%	38.9%	19.3%	0.5%	4.3%	47.9%	0.0%
CE	7.5%	34.1%	18.5%	0.4%	3.3%	47.0%	0.1%
SE	6.6%	27.8%	17.9%	0.8%	3.5%	42.3%	0.2%
CHAM	14.5%	33.9%	21.4%	0.6%	0.8%	44.9%	0.1%
NSM	10.1%	34.6%	23.9%	0.3%	3.3%	41.6%	0.3%
NE	6.9%	31.4%	19.0%	0.5%	0.8%	39.5%	0.1%
NW	3.2%	27.3%	15.2%	0.2%	6.3%	44.5%	0.0%
All	9.5%	33.2%	19.3%	0.5%	3.4%	44.1%	0.2%

*ESC = Erie St. Clair; SW = South West; WW = Waterloo Wellington; HNHB = Hamilton Niagara Haldim and Brant; CW = Central West; MH = Mississauga Halton; TC = Toronto Central; CENT = Central; CE = Central East; SE = South East; CHAM = Champlain; NSM = North Simcoe Muskoka; NE = North East; NW = North West.
** Data sources are indicated in brackets for each sector. Please see appendix A for details.

- Less than 10% of all decedents in Ontario received physician palliative home care in the last year of life. There was significant variation across the LHINs (range 3.2% in NW to 14.5% in CHAM).
- About 1 in 3 decedents received palliative care by a physician in any outpatient setting (including home). The variation in this figure was less (from 27.3% in NW to 42.9% in MH).
- About 6 in 10 Ontarians come into contact with home care in the last year of life (Table 1). Less than 1 in 5 (19.3%) receive palliative home care prior to death. The range across LHINs was between 15.2% (NW) to 23.9% (NSM).

- Palliative care was identified in 44.1% of Ontario decedents in the hospital inpatient setting in the last year of life. The variation across LHINs was small.
- Palliative care was identified at a very low level in the LTC and ER settings, using the codes identified in the health administrative databases (Appendix A).

Discussion and Conclusions

This report describes the provision of health care services near the end of life within different health care settings. We have expanded the findings of our previous report, and have examined end-of-life health care use across long-term care, home care, complex continuing care, and rehabilitation. We have shown that about 3 out of 5 decedents used home care in their last year of life and only about 1 in 4 use long-term care. Complex continuing care and rehabilitation is used by a small proportion of the decedent population in the last year of life. Inpatient acute care dominates total cost in the last year of life, followed by long-term care and physician services.

We worked on refining the codes used to identify palliative care in the health administrative databases available in Ontario. There are challenges to using the health administrative datasets to accurately capture Ontarians who are truly receiving a set of palliative care services aimed at providing comfort as end of life is recognized. Nevertheless, we have identified that about half of the population is recorded as receiving some form of palliative care, as captured by the health administrative databases examined.

When we looked back and considered the 12 months prior to death, we observed that about half of the palliative care cohort had palliative care initiated in the last two months of life. Despite the recognized role of palliative care beyond end-of-life care, the majority of palliative care across health sectors focuses on the last few months of life. Among the palliative care cohort, even though there was on average about 35 days of palliative care delivered in the last year of life, we have also shown that a significant portion of this population received palliative care for less than 7 days.

We have shown that the total health care cost among those patients that received palliative care was higher than among those that did not. Furthermore, average cost generally rose with earlier initiation of palliative care. These results can largely be explained by the fact that palliative care was captured using claims of health care use, which in turn contributes to total costs, and is also likely related to disease severity. This tautological definition limits our ability to draw conclusions about the overall effect of palliative care on costs at the end of life. For example, we obtained a large proportion of information on records and days of palliative care from hospitalization data. A large portion of the difference in health care cost between the palliative and non-palliative cohorts, however, was attributed to costs associated with inpatient hospitalizations. Furthermore, a decedent that had palliative care initiated far in advance of death may on average have been sicker, with a death trajectory associated with morbidity and high health care use. We are thus unable to isolate the effect of palliative care on health care use; such work would need to adjust for several factors, including demographics, chronic conditions, and disease trajectory.

Despite these limitations, this largely descriptive work has continued to unpack the health care use of those who receive palliative care across the health care sectors. We have also shown the patterns of care across those patients receiving palliative care, and have highlighted that a considerable proportion among those who receive palliative care likely did not receive a meaningful intensity of care. This includes the generally small numbers of palliative care days delivered in home settings through home care and physician services. The majority of the dying population is also receiving palliative care close to death. A portion of these gaps can be explained by the under-utilization of palliative care services; another portion can be explained by to the underuse of palliative care codes by health care practitioners who actually do perform palliative care services. Further work has shown that less than twenty percent of Ontario decedents ever receive a physician home visit for any reason in their last year of life. Work is also ongoing to examine the effect of palliative home care on end-of-life outcomes, such as location of death and places of care, using health administrative databases. The true mix of these explanatory causes is likely best studied through an in-depth look at palliative care practices at the community level.

Finally, we presented variations of care across LHINs that are responsible for planning, integration, and funding of health care services within geographical regions. We observed large variations in some sectors, including in the use of complex continuing care and rehabilitation for overall end-of-life care. For palliative care there was a similarly large variation for complex continuing care, and also for physician-based home care. Smaller, yet apparent, variations were observed for palliative services delivered through home care and inpatient acute care settings.

The data presented provide an overview of the patterns and costs associated with end-of-life and palliative health care services across the province. This work continues to inform efforts that aim to improve care at the end of life. Work extending from this report will further define and identify frail cohorts who are nearing the end of life. We also aim to better evaluate the effects of specific palliative care services, such as palliative home care delivered by CCAC and by physicians. The collective goal of this work is to improve our ability to identify those who will benefit most from improved palliative and end-of-life care; to improve the appropriateness of services provided, and ultimately to improve the quality of life at the end of life.

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Appendix A

Codes used to Identify the Provision of Palliative Care

1) Outpatient physician billings (OHIP) for palliative care: Provision of services by physicians under OHIP codes:
    - A945 = consultation clinic, office, home
    - K023 may be used to add time for longer consultations following a code for A945, or for any PC support visit. Exclude if patient is in hospital, LTC, CCC, or Rehab
    - G512 (weekly supervision), G511 (telephone consultations);
    - B966 (Travel premium), B998 (home visit), B997 (home visits),
    - K700 (Palliative care out-patient case conference)
2) For subset of primary care dealing with home based palliative care (OHIP) - use travel codes B966, B997, B998 & Telephone consult G511
3) Hospital admissions:
    a) Discharge Abstract Database (in-patient):
        - any diagnosis “palliative” ICD-10 Code: Z51.5, ICD-9 Code: V66.7
        - main patient service = “palliative care”: PATSERV = 58
        - any provider/intervention Service Number “palliative medicine”: PRVSERV[1-8] or INSERV[1-20] = 00121.
    b) OHIP billing codes for inpatient physician services:
        - C945 = PC consultations; {Note that K023 may be used to add time for longer consultations following a code for C945, or may be billed alone};
        - C882 = Routine hospital PC family MD visit,
        - C982 = Routine hospital PC specialist visit;
        - E083 = Premium for PC during subsequent visits: C982 or C882 or C122, C123, C124, C142, C143
        - K023 if patient was in hospital during date of claim
4) NACRS (ER visits):
    - Provider Service Code = 00121 (Palliative Medicine)

- Consult service = palliative medicine (CONSULTSERV1 to CONSULTSERV3 = 00121)

5) Home Care:
   a) RAI-CA – Contact Assessment:
      - B2c=1 referral to initiate/continue PC,
      - B4 = 12 (expected place of stay during service = Hospice facility/PCU)
   b) RAI-HC:
      - P2S=1 or 2 (complete or partial adherence to special treatment: hospice)
      - CC3f goals of care = palliative
   c) HCD:
      - SRC_admission = 95: Service care goal = end of life
      - Service_RPC = 95 Service care goal = end of life
      - Residence_type = 2000 (Hospice Facility/Palliative Care Unit)
      - SRC_discharge = 95: Service care goal = end of life
6) Long-Term Care Homes:
   - OHIP billing codes, LTC subsequent visits: W872 (Palliative care, family med); W972 (specialist)
   - K023 if in LTC
7) Chronic Care or Convalescent Hospital (CCC):
   - Complex Continuing Care W882 (palliative care, family med); W982 (specialist))
   - K023 if in CCC or NRS
   - Last 14 days received hospice care: CCRS_P1AO = 1