Understanding the Provision of End-of-Life and Palliative Care Services in Ontario

Applied Health Research Question Evidence Brief

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

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June 2013

Executive Summary

Understanding the provision of palliative care services and the characteristics of those receiving such care is significant for policy and decision-makers. This report was requested by the Central East Local Health Integration Network (LHIN) from the Health System Performance Research Network through their submitted Applied Health Research Question. Specifically, the information in this report aimed to meet the following two objectives:

1) **To assess the ability to identify palliative and end-of-life patients in Ontario using administrative datasets held at the Institute for Clinical Evaluative Sciences (ICES).**

- Several databases at ICES were used in the attempt to identify both palliative and end- of-life patients in the population. These include the Registered Persons Database (RPDB) for deaths, and a set of databases that capture health care services provided in hospital, in physician offices, in other health care institutions, and in the community.
- We were able to effectively capture a cohort of decedents in Ontario using the RPDB, and to examine the health care services provided in the 12 months prior to death.
- This retrospective look is the best method we have of using the available administrative databases to identify end-of-life care. Prospectively, an end-of-life designation is rarely captured in the health administrative databases. This is because only a select number of databases (long-term care, complex continuing care, and home care) assess for end-of- life, and since end-of-life is at times difficult to predict.
- Palliative care services were captured in physician billing codes, in home care services, and in services provided in hospital, in long-term care, and complex continuing care.
- The results indicated that OHIP physician billing data is the most common data source of palliative care provided.
- When looking at the entire Ontario population prospectively, a large proportion of those receiving at least one palliative care service were not in their last year of life.

Further work is required to look at the quality of the palliative care codes used. This may include a literature review of any previous studies that have used/examined these codes, and an examination of the distribution palliative care codes among all recipients, across time.

2) To define and describe the characteristics of identified palliative and end-of-life patients within each of Ontario's major health care settings. This includes a description of their place of death and their trends and patterns of health care utilization and cost across the various health care sectors.

Palliative Care Services & End-of-life Designation

- Both retrospective and prospective methods were used to help identify and define the characteristics of palliative and end-of-life patients
- Using the retrospective approach revealed that out of the 153, 874 individuals who died in Ontario between July 1, 2010 and March 31, 2012, the majority (76%) had some indication of receiving palliative care within the study period. 70% of these individuals did not receive a designation of end-of-life, as captured by the databases discussed.
- Both retrospective and prospective methods indicated that a significant proportion of palliative care services were initiated more than 12 months from death.
- The End-of-life designation was given to only 24.3% of decedents in the last year of life, of whom only 1% did not have any indication of receiving palliative care.
- The proportions of those receiving palliative care, those designated as end-of-life, those who had both statuses, and those had neither were generally similar across LHINs.

Place of Death and Cost at the End of Life

- 71% of Ontarians died in hospital or in long-term care, with the majority (46.1% of the all deaths) dying in an acute care setting
- This contributes to the observation that a significant amount of time in the last 90 days of life in health care institutions. On average Ontarians spend about 2 weeks

(or 15%) of their last 90 days in hospital.

- Significant time and death in hospital carry a significant cost burden to the health care system. Over the last 12 months, the top three cost sectors were inpatient services (51.6%), continuing care (long-term care, complex continuing care, and home care) (21.3%), and physician services (10.9%).
- Half of the total cost incurred in the last year of life occurred in the last 3 months, of which 59.8% was attributed to inpatient services.
- For the 3 months prior to death time period, the highest average cost per patient was for the palliative care only cohort at $30,973/patient.

Prospective Approach

- The prospective approach revealed that almost 700,000 individuals received at least one episode of palliative care between April 1, 2010 and December 31, 2011. Only 47,000 had an EOL designation during this period. This distribution was relatively equal between sex groups as well as across LHINs
- The large number of those receiving palliative care when compared to the decedent cohort suggests that palliative care occurs outside of the last year of life.
- It also revealed once again that the majority of individuals receiving palliative care died within a hospital setting (55%), but contrary to the death cohort, were more likely to remain in the hospital under an ALC state within the last 6 months of their life. Not surprisingly, inpatient costs remained the most significant cost for the palliative cohort in the last 12 months of life for these patients.
- These findings cumulatively reveal a great dependence on hospital settings for the provision of health care services at the end of life.

This report describes the provision of health care services near the end-of-life, within different health care settings. We focused on those who received palliative care, and those designated as being at the end of life. There are challenges to using the health administrative datasets to accurately capture Ontarians who are truly receiving a cadre of palliative care services aimed at providing comfort as end of life is recognized.

Nevertheless, the figures presented provide a good snapshot at the patterns, intensities, and costs of palliative and end-of-life health care services across the province. We hope that this work can be used as a foundation for future efforts to improve palliative care in the province, and to shift care away from health care institutions.

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A. 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 viewpoints 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 their lives, with a focus on care independent of health care settings. To work on these goals, the Central East LHIN, on behalf of the province of Ontario, submitted an Applied Health Research Question to the Health System Performance Research Network, seeking to understand the current state of palliative and end-of-life care in Ontario. This report will summarize the findings for the submitted Applied Health Research Question.

B. Objectives:

1) To assess the ability to identify palliative and end-of-life patients in Ontario using administrative datasets held at the Institute for Clinical Evaluative Sciences (ICES).
2) To define and describe the characteristics of identified palliative and end-of-life patients within each of Ontario's major health care settings. This includes a description of their place of death and their trends and patterns of health care utilization and cost across the various health care sectors.

C. Methods:

This study captured individuals using two approaches. The first captured all deaths using a death registry and retrospectively examines health care use prior to death (retrospective approach). The second approach captured patients in the health care system that is designated as at the end-of-life during clinical/administrative assessments, in addition to all patients who receive palliative care. This second approach then looks forward in time at the care provided until death or last date of follow-up (prospective approach). More details follow below.

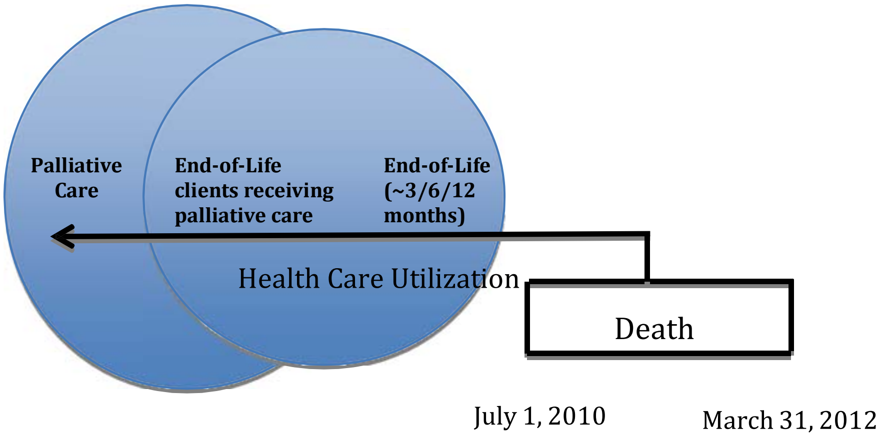
<u>End-of-Life designation:</u> Patients can be deemed as at the end of life either by assessment within a complex continuing care setting (6 or fewer months to live as

indicated on a Resident Assessment Instrument-Long Term Care (RAI-LTC), RAI-Complex Continuing Care (RAI-CCC), RAI-Home Care, or RAI-Contact Assessment) or during enrollment to home care services (home care service type is recorded as end-of-life). Not all patients in the deaths registry will be identified with the end-of-life designation since not all will receive complex continuing care or home care prior to death. End-of-life patients are primary recipients of palliative care, but not all patients designated as end-of-life may receive such care.

Palliative Care Services: Palliative care is health care provided to patients who are thought to be nearing the end-of-life, and is focused on providing comfort measures as opposed to curative care. Palliative care is captured through palliative and/or end-of-life billing and diagnostic codes (see Appendix A for codes). There are many reasons why not all patients prior to death receive palliative care, including the unexpected or rapid nature of some deaths. Conversely, palliative care may begin earlier than when the end-of-life designation is given and palliative care may remain in place longer than 12 months since time to death is sometimes difficult to predict.

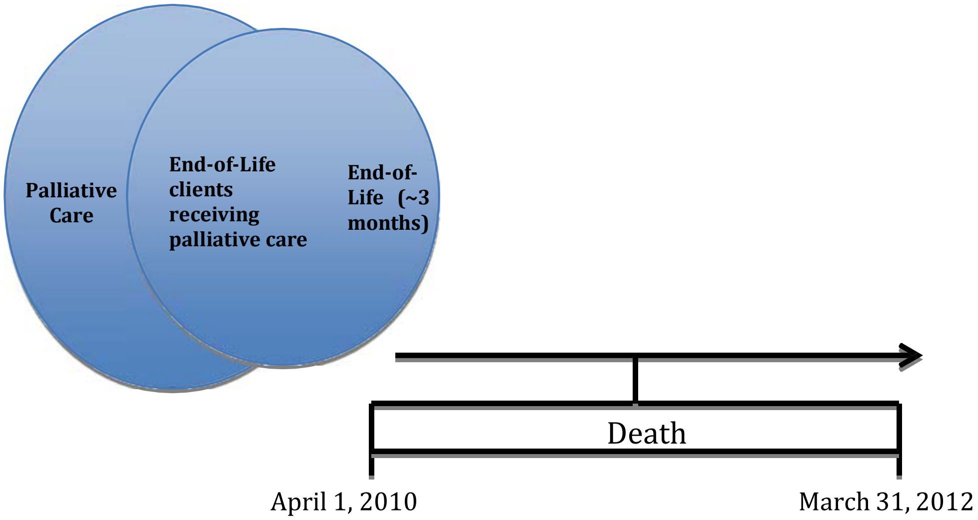
I. Retrospective Approach:

This analysis examined all deaths occurring in Ontario between July 1, 2010 and March 31, 2012. Upon identification of all individuals who died within this time period, the analysis retrospectively looked back in 3, 6, and 12 month intervals to examine the occurrence of end-of-life designation, as well as provision of palliative care and other health care services.



II. Prospective Approach:

This analysis aimed to identify all individuals with either an end-of-life designation in RAI assessment data or a palliative care code in billing and/or diagnostic data (see Appendix A) between April 1, 2010 and December 31, 2011. This analysis then prospectively followed patients until their death or until the last date of data availability (March 31, 2012) to identify their trends of health system utilization.



Cohort Groups:

Four distinct cohort groups were created within both our retrospective and prospective approaches:

1) End-of-Life (EOL) Only: Patients who had been designated as end-of-life in the various RAI databases, but had not received palliative care prior to death or last date of follow-up.
2) Palliative Only: Patients who had received palliative care prior to their death or end of follow-up, but had not been designated in the RAI as End-of-Life. A good example of such patients may be cancer patients who receive palliative care to relieve symptomatic suffering, but may not necessarily be at the end-of-life.
3) Both: Patients who had been designated in the RAI as End-of-Life and had received palliative care prior to death or end of follow-up.
4) Neither: Those who had not been designated in the RAI as End-of-Life, nor had received palliative care prior to death. Patients may appear in this category if their death was sudden or unexpected, such those dying as a result of heart attacks or injuries.

D. Findings:

I. Retrospective Approach:

Table 1: Baseline Characteristics for Death Cohort, Ontario, July 1, 2010-March 31, 2012, with 12 month look-back to capture palliative care services and end-of-life designation

	EOL only	Palliative only	Both	Neither	Total
	N (Row Percent)				
All cohort, N (Row %)	1,810 (1.2)	81,613 (53)	35,533 (23.1)	34,918 (22.7)	153,874 (100)
Sex					
Female	1,332 (1.7)	41,667 (52.8)	18,331 (23.2)	17,560 (22.3)	78,890 (100)
Male	478 (0.6)	39,946 (53.3)	17,202 (22.9)	17,358 (23.1)	74,984
Age, N (%)					
0-17	0 (0)	333 (15)	88 (4)	1,802 (81.1)	2,223 (100)
18-39	< 6 (-)	825 (28.2)	398 (13.6)	1,696 (58)	2,924
40-64	33 (0.1)	10,343 (41.1)	7,647 (30.4)	7,129 (28.3)	25,152
65-79	191 (0.4)	22,160 (52.2)	12,397 (29.2)	7,700 (18.1)	42,448
80+	1,585 (2)	47,952 (59.1)	15,003 (18.5)	16,591 (20.4)	81,131
Mean (sd)	88.14 (8.66)	78.92 (13.82)	74.61 (13.90)	70.82 (23.90)	76.21 (17.00)
LHIN					
ESC	94 (1)	4,716 (51.3)	2,417 (26.3)	1,965 (21.4)	9,192 (100)
SW	192 (1.4)	7,401 (55.7)	2,652 (20)	3,047 (22.9)	13,292
WW	123 (1.5)	3,783 (47.3)	2,156 (27)	1,933 (24.2)	7,995
HNHB	302 (1.5)	10,340 (50.8)	5,046 (24.8)	4,661 (22.9)	20,349
CW	30 (0.5)	3,640 (58.4)	1,173 (18.8)	1,391 (22.3)	6,234
MH	41 (0.4)	4,958 (53.2)	2,404 (25.8)	1,919 (20.6)	9,322
TC	73 (0.6)	7,054 (56.6)	2,717 (21.8)	2,619 (21)	12,463
CENT	90 (0.6)	8,555 (57.2)	3,309 (22.1)	3,007 (20.1)	14,961
CE	225 (1.3)	9,581 (54.7)	3,853 (22)	3,870 (22.1)	17,529
SE	155 (2)	4,255 (53.5)	1,657 (20.8)	1,881 (23.7)	7,948
CHAM	204 (1.4)	7,256 (50.6)	3,566 (24.9)	3,315 (23.1)	14,341
NSM	103 (1.7)	2,944 (48)	1,755 (28.6)	1,331 (21.7)	6,133
NE	139 (1.5)	4,973 (53.4)	2,128 (22.9)	2,069 (22.2)	9,309
NW	38 (1.1)	1,996 (58.2)	653 (19)	741 (21.6)	3,428

Findings:

- Out of the total number of 153, 874 individuals who died in Ontario between July 1, 2010 and March 31, 2012, the majority (76.1%) received at least one billing for palliative care in the last 12 months prior to death.

- Of those receiving palliative care, about 70% (or 53%overall) received palliative care without a designation of End-of-Life and 30% (or 23% overall) received both palliative care and a designation of End-of-Life. 22.7% of the total population had neither.
- The percentage of individuals designated as End-of-Life who did not receive palliative care was very small (1%); the vast majority of individuals, if designated as end-of-life, received palliative care.
- Those who were designated as End-of-Life without palliative care tended to have a higher average age than the remaining 3 cohorts
- The four cohorts had a relatively equal number of males and females. 76.0% of women and 76.2% of men received some sort of palliative care prior to death.
- Those in the neither group tended to have a lower average age of 71, and with a wider range of ages (standard deviation of 23 years)
- The average age declined as we as moved from EOL only to palliative only to both to neither cohorts
- The majority of children and younger adults (0-39 years of age) were found to be in the Neither cohort.
- The average age at death was 76 years
- The distribution of the four cohorts was relatively similar between LHINs
- Between 74.3% to 79.3% of the population, in each LHIN received palliative care prior to death. There were minor variations between the Both and Neither cohorts.

Table 2: Time spent in hospital in an Alternate Level of Care (ALC) state and in an acute care bed, Death Cohort, last 6 months of life, Ontario, July 1, 2010-March 31, 2012

	EOL only	Palliative only	Both	Neither	Total
In last 3 months prior to death					
Total number of days spent in hospital in an acute care bed (Acute Care Length of Stay)					
Total days (row %)	922 (0.1)	1,317,475 (72.9)	441,300 (24.4)	47,740 (2.6)	1,807,437(100)
Total number of days spent in hospital in an ALC state(ALC Length of Stay)					
ALC days (row %)	603 (0.2)	245,822 (73.6)	79,233 (23.7)	8,188 (2.5)	333,846
Between 3-6 months prior to death					
Total number of days spent in hospital in an acute care bed (Acute Care Length of Stay)					
Total days (row %)	366 (0.1)	230,674 (64.3)	123,787 (34.5)	3,921 (1.1)	358,748
Total number of days spent in hospital in an ALC state (ALC Length of Stay)					
ALC days (row %)	193 (0.2)	70,540 (75.9)	20,983 (22.6)	1,237 (1.3)	92,953

Findings:

- Within the death cohort for the time period between July 1, 2010 and March 31, 2012, a total of 2,141,283 days were spent in the hospital within the last 3 months of an individual's life, representing an average of 13.9 days among the 153,874 decedents. This means that Ontarians on average spent about 15.5%, or more than one-seventh, of their last 3 months of life in hospital. A total of 333,846 or 15.6% of those days being spent under ALC status.
- Between 3 and 6 month prior to death, a much smaller total of 451,701days were spent in hospital with 92,953 or 20.6% of those days being spent under ALC status.

  This means that between 3-6 months prior to death, Ontarians spent an average of 2.9 days in hospital, or about one day a month during this time.
- Patients who received palliative care accounted for 97.3% of total hospital and ALC bed days in the population in the last 3 months of life. Between 3-6 months prior to death palliative care patients accounted for 98.5% and 98.8% of overall total hospital and ALC bed days, respectively.

Table 3: Distribution of 153, 874 decedents spending various number of days in Acute Care, Long Term Care (LTC) and Complex Continuing Care (CCC) settings during the last 90 days of life, Death Cohort, Ontario, July 1, 2010-March 31, 2012

	Acute Care	LTC	CCC
Number of individuals with 1+ days in care setting in last 90 days of life (% of total decedent population)	118,031 (76.7)	27,711 (18.0)	15,992 (10.4)
Total number of days in care setting in last 90 days of life	2,610,228	2,009,048	427,549
Among those with 1+ days in care setting: Average (std) number of days in care setting in last 90 days of life	22.1 (18.7)	72.5 (30.1)	26.7 (23.3)
Number of individuals with 1-15 days in care setting in last 90 days of life (% of individuals with 1+ days in each respective setting)	55,792 (47.3)	2,958 (10.7)	6,883 (43.0)
Number of individuals with 16-30 days in care setting in last 90 days of life (%)	32,183 (27.3)	1,632 (5.9)	3,616 (22.6)
Number of individuals with 31-45 days in care setting in last 90 days of life (%)	15,648 (13.3)	1,105 (4.0)	2,188 (13.7)
Number of individuals with 46-60 days in care setting in last 90 days of life (%)	7,900 (6.7)	807 (2.9)	1,429 (8.9)
Number of individuals with 61-75 days in care setting in last 90 days of life (%)	4,105 (3.5)	699 (2.5)	1,025 (6.4)
Number of individuals with 76-90 days in care setting in last 90 days of life (%)	2,403 (2.0)	20,510 (74.0)	851 (5.3)

Findings:

- A large majority (76.7%) of Ontarians who died between July 1, 2010 and March 31, 2012 spent at least one day in an acute care bed in their last 90 days of life.
- Only 18.0% and 10.4% of decedents spent at least one day of their last 90 days in a long term care and complex continuing care setting, respectively.
- Of those spending at least 1 day in an acute care bed, the average total length of stay was 22.1 days. 47.3%of these individuals spent less than 15 days.
- The pattern for decedents in complex continuing care was similar to the acute care setting. The average number of days among those with at least one stay was 26.7

days, with a large proportion spending between 1-15 (43.0%) and 16-30 days (22.6%)

- Of the 18% of decedents spending at least one day in a LTC institution, the average length of stay was 72.5 days. The large majority (74.0%) spent almost all their time (76-90 of 90 days) in these institutions

Table 4: Place of Death for Death Cohort, Ontario, July 1, 2010-March 31, 2012

Place of Death	Acute care	LTC	CCC	Others	Total
Number of People N (%)	70,900 (46.1)	26,725 (17.4)	11,641 (7.6)	44,608 (29.0)	153,874 (100)

Findings:

- The large majority of Ontarians (71%) died in hospital or long-term care
- Acute care setting was the most common place of death (46.1% of the total deaths)

N.B. Administrative data allows identification of the place of death in the settings of acute care (i.e. in hospital), LTC and CCC. Other locations of death include the community, or other institutional care settings. We did not examine whether deaths occurred in Emergency Departments.

Table 5: Total costs (in $) by sector in last 3, 3-6 and 6-12 months prior to death (All costs calculated based on utilization between July 2009 and March 2011*** for patients who died between July 2010 and March, 2011 based on individuals with utilization in each sector*)

Cost prior to death	Cohort: EOL only		
	N	**Total Cost ($)**	**Average Cost per Patient ($) ***
3 months, total	848	11,891,277	14,023
Inpatient	60	686,248	11,437
Outpatient	29	77,434	2,670
Emergency Department (ED)	170	95,601	562
Continuing Care**	838	9,558,147	11,406
Physician	841	684,733	814
Drug &device	812	789,114	972
3-6 months, total	848	9,994,905	11,786
Inpatient	18	229,489	12,749
Outpatient	18	55,489	3,083
ED	89	37,395	420
Continuing Care**	808	8,356,667	10,342
Physician	836	542,926	649
Drug &device	807	772,938	958
6-12 months, total	848	20,205,238	23,827
Inpatient	48	1,147,025	23,896
Outpatient	43	265,836	6,182
ED	145	85,546	590
Continuing Care**	820	16,001,660	19,514
Physician	839	1,065,616	1,270
Drug &device	810	1,639,555	2,024

Cost prior to death	Cohort: Palliative only		
	N	Total Cost ($)	Average Cost per Patient ($) *
3 months, total	34,924	1,081,684,674	30,973
Inpatient	30,020	737,702,077	24,574
Outpatient	6,699	32,917,609	4,914
ED	29,652	29,919,108	1,009
Continuing Care**	24,204	144,581,393	5,973
Physician	34,704	110,274,336	3,178
Drug &device	30,063	26,290,151	875
3-6 months, total	34,924	381,447,618	10,922
Inpatient	9,009	168,727,466	18,729
Outpatient	5,285	32,090,349	6,072
ED	12,036	9,205,532	765
Continuing Care**	18,710	103,050,458	5,508
Physician	33,248	41,228,161	1,240
Drug &device	30,052	27,145,652	903
6-12 months, total	34,924	556,289,808	15,929
Inpatient	9,786	199,732,835	20,410
Outpatient	6,541	53,774,922	8,221
ED	14,283	12,884,501	902
Continuing Care**	18,124	177,445,505	9,791
Physician	33,607	58,587,226	1,743
Drug &device	30,655	53,864,819	1,757

Cost prior to death	Cohort: Both (EOL and Palliative)		
	N	Cost ($)	Average Cost per Patient ($)*
3 months, total	14,909	377,733,259	25,336
Inpatient	10,391	178,918,264	17,219
Outpatient	6,664	22,607,148	3,392
ED	10,601	10,022,640	945
Continuing Care**	14,647	108,365,400	7,398
Physician	14,807	39,379,308	2,660
Drug &device	13,569	18,440,500	1,359
3-6 months, total	14,909	187,119,463	12,551
Inpatient	4,800	70,683,493	14,726
Outpatient	6,504	28,904,045	4,444
ED	6,357	4,949,083	779
Continuing Care**	9,701	44,010,008	4,537
Physician	14,483	23,411,325	1,616
Drug &device	12,675	15,161,510	1,196
6-12 months, total	14,909	254,501,068	17,070
Inpatient	4,814	81,695,798	16,970
Outpatient	6,663	47,766,831	7,169
ED	6,617	6,075,722	918
Continuing Care**	8,142	60,332,348	7,410
Physician	14,450	32,046,829	2,218
Drug &device	12,531	26,583,540	2,121

Cost prior to death	Cohort: Neither (EOL nor Palliative)		
	N	Cost ($)	Average Cost per Patient ($)*
3 months, total	16,995	165,284,096	9,725
Inpatient	3,975	61,369,295	15,439
Outpatient	1,014	5,495,371	5,419
ED	7,454	5,405,202	725
Continuing Care**	7,344	64,576,152	8,793
Physician	15,248	19,091,069	1,252
Drug &device	12,002	9,347,008	779
3-6 months, total	16,995	88,510,753	5,208
Inpatient	437	8,516,086	19,488
Outpatient	802	5,018,855	6,258
ED	1,943	833,645	429
Continuing Care**	6,839	57,176,674	8,360
Physician	14,324	7,682,106	536
Drug &device	11,856	9,283,386	783
6-12 months, total	16,995	169,185,674	9,955
Inpatient	753	14,369,052	19,082
Outpatient	1,249	8,926,242	7,147
ED	2,898	1,534,029	529
Continuing Care**	7,022	110,493,689	15,735
Physician	14,831	14,210,080	958
Drug &device	12,105	19,652,581	1,624

*Average costs based on the number of people with utilization in each sector and alive in FY2010/2011
** Continuing Care costs include costs incurred in Long-term Care, Complex Continuing Care, and Home Care
*** Costs for all care settings in 2011/12 are not yet available.

Findings:

- The total cost in the last year of life for the 9 month (July 2010-March 2011) death cohort was $3.3 billion dollars. 49.5%, 20.2%, and 30.3% of this cost was consumed in the last 3, 3-6, and 6-12 months of life, respectively. Within the last 3 months, a large proportion (59.8%) was consumed by in-patient hospital costs. Following inpatient costs, continuing care (20.0%), physician services (10.4%), outpatient services (3.7%), drugs (3.4%), and emergency department (2.8%) made up of total costs in the last 3 months. In hospital costs were about 3 times larger than continuing care costs; the number of days spent in hospital was only slightly greater than in continuing care (Table 3)
- Between 3-6 months and 6-12 months, the proportion of total cost for inpatient services decreased to 37.2% and 29.7%, while the proportion for continuing care rose to 31.9% and 36.4%, respectively.

- Over the last 12 months, the overall top three cost sectors were inpatient services (46.1%), continuing care (27.4%), and physician services (10.5%)
- The palliative only cohort had the highest total costs across all time periods
- For the 3 months prior to death, the highest average cost per patient was for the palliative only cohort at $30,973/patient
- For the 3-6 month time period, the highest average cost per patient was for the ‘Both’ cohort at $12,551/patient
- For the 6-12 month time period, the highest average cost per patient was for the EOL only cohort at $23,827/patient
- For the EOL cohort, the highest total cost for all time periods was for continuing care, which can be largely attributed to the method of EOL designation.
- For the patients receiving palliative care (palliative only and ‘Both’ cohorts), the greatest cost of care was for in-patient services across all three time periods. The average cost per person is also greatest for this cost centre.

Table 6: Time during which palliative care was initiated, Death Cohort, Ontario, July 1, 2010 - March 31, 2012

Prior to death	0-3 months	3-6 months	6-12 months	12+ months	Total
Palliative indication, N (%)	52,387 (44.7)	15,818 (13.5)	22,081 (18.8)	26,860 (22.9)	117,146 (100)
Age					
0-17	198 (47)	59 (14)	62 (14.7)	102 (24.2)	421 (100)
18-39	430 (35.2)	190 (15.5)	256 (20.9)	347 (28.4)	1,223 (100)
40-64	7,140 (39.7)	2,740 (15.2)	3,886 (21.6)	4,224 (23.5)	17,990 (100)
65-79	14,799 (42.8)	5,028 (14.5)	6,913 (20)	7,817 (22.6)	34,557 (100)
80+	29,820 (47.4)	7,801 (12.4)	10,964 (17.4)	14,370 (22.8)	62,955 (100)
Sex					
Male	25,582 (44.8)	7,820 (13.7)	10,914 (19.1)	12,832 (22.5)	57,148 (100)
Female	26,805 (44.7)	7,998 (13.3)	11,167 (18.6)	14,028 (23.4)	59,998 (100)

Note: look-back period for first palliative visit extended to July 1, 2009.

Findings:

- Among those who received palliative care (patients in the "Palliative only" as well as "Both" cohorts), the largest proportion of patients (44.7%) had palliative care initiated 0-3 months before death. In the next biggest group (22.9%), palliative care was initiated 12+ months prior to death, followed by
- 6-12 months (18.8%) and 3-6 months (13.5%). This suggests that palliative care is often initiated well before death. This trend was also visible within age groups and for both sexes.

II. **Prospective Approach**

This analysis aimed to prospectively identify all individuals with either an end-of-life designation or a palliative care code within the time period of April 1, 2010 to December 31, 2011. This analysis aims to follow identified patients until their death, or up to latest date of March 31, 2012, to identify their trends of health system utilization.

Table 7: Baseline Characteristics for End of Life (EOL) and Palliative Cohorts, Ontario, April 1, 2010 to December 31, 2011

	EOL Indication	Palliative Care Indication
All cohort	47,134	689,330
Sex, N (Column %)		
. Female	24,766 (52.6)	359,777 (52.2)
. Male	22,354 (47.4)	329,532 (47.8)
missing	14 (0)	21 (0)
Age, N (Column %)		
. 0-17	196 (0.4)	58,415 (8.5)
. 18-39	640 (1.4)	66,002 (9.6)
. 40-64	10,707 (22.7)	203,479 (29.5)
. 65-79	16,163 (34.3)	188,865 (27.4)
. 80+	19,414 (41.2)	172,548 (25)
missing	14 (0)	21 (0)
LHIN N (Column %)		
. ESC	3,315 (7)	37,617 (5.5)
. SW	3,456 (7.3)	58,810 (8.5)
. WW	3,227 (6.8)	32,379 (4.7)
. HNHB	6,776 (14.4)	83,276 (12.1)
. CW	1,478 (3.1)	35,624 (5.2)
. MH	3,059 (6.5)	48,949 (7.1)
. TC	3,296 (7)	52,898 (7.7)
. CENT	4,266 (9.1)	69,952 (10.1)
. CE	5,009 (10.6)	73,098 (10.6)
. SE	2,208 (4.7)	32,024 (4.6)
. CHAM	4,866 (10.3)	59,630 (8.7)
. NSM	2,268 (4.8)	28,430 (4.1)
. NE	2,938 (6.2)	44,409 (6.4)
. NW	873 (1.9)	19,818 (2.9)
.missing	99 (0.2)	12,416 (1.8)

Findings:

- Almost 700,000 individuals received palliative care between April 1, 2010 to December 31, 2011, while only 47,000 had a EOL designation

- This is much larger than what was observed in the last year of the death cohort, suggesting that palliative care is commonly coded before the last year of life
- The sex distribution was equivalent in both groups
- The majority of those who had an EOL indication were more likely to be older (65+), while the majority of those who received palliative care were in the middle age demographic (40-64).
- The distribution of individuals in LHINs between the two groups were relatively similar
- The top 5 LHINs with the greatest absolute number of individuals receiving palliative care were HNHB, CE, CENT, CHAM, and SW

Table 8: Time spent in hospital in an Alternate Level of Care (ALC) state and in an acute care bed, Palliative Care and End of Life (EOL) prospective cohorts, last 6 months of life, Ontario, April 1, 2010 to December 31, 2011

	EOL Indication	**Palliative Care Indication**
In last 3 months prior to death		
Total Deaths	26,726	104,708
Total number of days spent in hospital in an acute care bed (Acute Care Length of Stay)		
Total days	462,305	1,956,569
Mean (sd)	17.3 (16.28)	18.69 (18.96)
Total number of days spent in hospital in an ALC state (ALC Length of Stay)		
Total ALC days	81,912	369,517
Mean (sd)	3.06 (11.23)	3.53 (16.97)
In last 3-6 months prior to death		
Total Deaths	11,136	34,352
Total number of days spent in hospital in an acute care bed (Acute Care Length of Stay)		
Total days	136,699	439,627
Mean (sd)	12.28 (12.76)	12.8 (13.65)
Total number of days spent in hospital in an ALC state (ALC Length of Stay)		
Total ALC days	22,279	108,449
Mean (sd)	2 (10.69)	3.16 (17.98)

Findings:

- Among those who had an indication of EOL or palliative care who died in the follow- up period, 20.4 days (22.6%) and 22.2 days (24.7%) of the last 90 days were spent in hospital, respectively.

- Contrary to the death cohort, the majority of days in hospital were spent in an ALC state in both the last 3 and 3-6 months of life.

Table 9: Location of Death among decedent palliative care patients captured, Ontario, April 1, 2010 to December 31, 2011

Location of Death	Acute care	LTC	CCC	Others	Total
N (%)	68,386 (55.3)	15,836 (12.8)	12,129 (9.8)	27,336 (22.1)	123,687 (100)

- As similarly shown from the retrospective approach, the majority (78.9%) of palliative care patients who died did so in institutionalized settings of acute care, long-term care, or complex continuing care.

Table 10: Total costs in Canadian dollars by sector in last 3, 3-6 and 6-12 months prior to death for Palliative Care Patients, Ontario, April 1, 2010 to December 31, 2011

Total costs prior to death by sector	0-3 month		3-6 month		6-12 month	
	N	Total Cost	N	Total Cost	N	Total Cost
Total	**285,510**	**1,898,881,039**	**202,931**	**717,121,449**	**205,220**	**985,741,082**
Inpatient	52,017	1,208,656,445	17,316	310,126,017	17,308	338,865,399
Outpatient	17,689	71,816,589	15,268	78,022,252	17,011	129,417,100
ED	50,991	51,956,077	23,031	18,286,655	25,453	23,301,119
Continuing Care	48,626	313,597,140	34,806	174,608,654	31,948	280,184,357
Physician	61,762	194,805,888	59,449	82,204,340	59,892	113,870,953
Drug& Device	54,425	58,048,900	53,061	53,873,532	53,608	100,102,154

Findings:

- Palliative care patients captured April 1, 2010 to December 31, 2011 who died consumed a total of $3.6 billion dollars in their last year of life. With proportions similar to what was observed among all patients in the retrospective approach, a large proportion of total costs were consumed in the last 3months of life.
- Within the last 3 months, a large proportion (63.7%) was consumed by in-patient hospital costs. Following inpatient costs, continuing care (long-term care, complex continuing care, and home care) (16.5%), physician services (10.3%), outpatient services (3.8%), drugs (3.1%), and emergency department visits (2.7%) composed of total costs in the last 3 months.
- Between 3-6 months and 6-12 months, the proportion of total cost for inpatient services decreased to 43.2% and 34.4%, while the proportion for continuing care
rose to 24.3% and 28.4%, respectively.
- Over the last 12 months, the overall top three cost sectors, accounting for over 75% of all spending, were inpatient services (51.6%), continuing care (21.3%), and physician services (10.9%)

Table 11: Databases where palliative care patients were identified, Ontario, April 1, 2010 to December 31, 2011

Database Name	N	%
CIHI Discharge Abstract Database	58,011	7.35
NACRS - Emergency Room	50	0.01
RAI - HC - Home care	5,119	0.65
RAI –CA	9,138	1.16
Palliative care in HCD service record	35,839	4.54
HC Assessment conducted in hospice/palliative facility	286	0.04
OHIP - Physician Services	681,298	86.27
Total	789,741	100.00

- Out of all total records for palliative care captured, a large proportion (86.27%) were captured in physician billings through OHIP, followed by hospital admission records (7.35%) and RAI - PC (4.54%) in continuing care settings.

E. Conclusions

This report describes the provision of health care services near the end-of-life, within different health care settings. We focused on those who received palliative care, and those designated as being at the end of life. There are challenges to using the health administrative datasets to accurately capture Ontarians who are truly receiving a cadre of palliative care services aimed at providing comfort as end of life is recognized.

Nevertheless, the figures presented provide a good snapshot at the patterns, intensities, and costs of palliative and end-of-life health care services across the province. We hope that this work can be used as a foundation for future efforts to improve palliative care in the province, and to shift care away from health care institutions.

Appendix A

Utilized Billing, Assessment, and/or Diagnostic Codes for the Identification of End-of-Life and Palliative Care Patients

End-of-Life Patients:

1. Primary Care: Not available
2. Hospital: Not available
3. Home Care:
    a. Questions on RAI-CA (E7=2 end of life), RAI-HC (K8e: Prognosis of less than 6 months to live – e.g. physician has told client or client's family that the client has end-stage disease)
    b. Admission SRC of 95
4. Complex Continuing Care Hospitals and Long Term Care Homes: CCRS (CCC and LTC version) J5c=1 (End-stage disease: 6 months or less to live).

Palliative Care:

1. Primary care: Provision of services by physicians under OHIP codes A945 = consultation clinic, office, home), {Note that K023 may be used to add time for longer consultations following a code for A945}; G512 (weekly supervision); G511 (telephone consultations); B966, B998, B997 (all travel premiums for palliative home visits; K700 (Palliative care out- patient case conference)
2. Hospitals:
    a. Discharge Abstract Database (in-patient): any diagnosis "palliative" ICD-10 Code: Z51.5, ICD-9 Code: V66.7 for 3 scenarios:
        i. Patients whose primary diagnosis was palliative and palliative was present on admission (MRD);
        ii. Patients who came to hospital where primary diagnosis was not palliative but had a palliative diagnosis present on admission;
        iii. Patients who became palliative after admission (MRD and type 2)

   b. NACRS (ER) – Provider Service Code = 00121 Palliative Medicine
   c. OHIP billing codes C945 (consultations;), {Note that K023 may be used to add time for longer consultations following a code for C945}; C882 (Routine hospital palliative visit for most responsible physician), C982 (Palliative care); E083 (if subsequent to C982 or C882) ***Note GP Preamble suggests that C882 and C982 are specifically for patients who are in designated palliative care beds*
3. Home Care:
   a. Palliative Clients: questions on RAI-CA (B2c=1), RAI-HC (CC3f goals of care: palliative) forms
   b. Service SRC of 95
   c. Restype on HCD assessment record restype=2000 Hospice Facility/Palliative Care Unit
4. Complex continuing and Long-Term Care Homes:
   a. OHIP billing codes W872 Palliative care; W972 subsequent visit
   b. Complex Continuing Care W882 (palliative care); W982 subsequent visit (palliative)

Addendum/Correction

The designations of palliative care and end-of-life were originally reported to have been captured in the 12 months prior to death for each decedent. Examination of the analyses reveals that a time period of April 1, 2010 to December 31, 2012 was in fact used to capture these designations for each decedent. Altering the capture period for palliative care to 12 months prior to death for each decedent changed the proportion of the population who received palliative care from 76% to 59%. In the upcoming follow-up AHRQ report to further examine palliative care in Ontario, we will use a true 12 month retrospective look-back period for each decedent.