

Title Page

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Trends in site of death and healthcare utilization at the end of life: A population-based cohort study

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Abstract

Background: High rates of healthcare utilization at the end of life may be a marker of care that does not align with patient-stated preferences. We sought to describe trends in end-of-life care and factors associated with dying in-hospital.

Methods: We conducted a population-level retrospective cohort study of adult decedents in Ontario between 2004 and 2014. We used linked administrative datasets to determine healthcare utilization and costs during the 6-months before death and place of death.

Results: In the last 6-months of life, 77% of 962,426 decedents presented to an emergency department, 68% were admitted to a hospital, 19% were admitted to an intensive care unit, and 14% received mechanical ventilation. Forty-five percent of all deaths occurred in hospital, declining marginally over time while receipt of palliative care increased; during terminal hospital admissions, from 14.0% in 2004 to 29.3% in 2014 ($p < 0.001$) and the last 6-months of life (from 28.1% in 2004 to 57.7% in 2014, $p < 0.001$). The proportion of decedents presenting to the emergency room, admitted to hospital or ICU in the last 6-months of life did not change over 11 years. The mean total healthcare costs in the last 6-months of life were highest amongst those dying in hospital, with the majority of costs attributable to inpatient medical care.

Interpretation: Healthcare utilization in the last 6-months of life was substantial and did not decrease over time. Increased capacity for palliative, hospice and home-care

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at the end of life may help to better align health system resources with patient preferences.

Confidential

Background

High-quality end-of-life care is important for patients, families, and is an increasing focus for policy makers and the research community. While there is marked international variability in end-of-life care practices¹⁻³ among industrialized countries, including Canada, there are high rates of deaths in hospital and use of resource intensive services, including admissions to an intensive care unit (ICU).¹ This resource-intensive care often does not align with patient-stated preferences and accounts for a significant proportion of healthcare expenditures.⁴⁻⁶

Earlier reports have emphasized gaps in the provision of quality end-of-life care for dying Canadians and their families.^{7, 8} Amidst a rapidly aging Canadian population and accompanied large increase in the prevalence of chronic diseases and frailty, whether and to what extent these gaps remain is largely unknown. Measuring trends and current healthcare practices at the end of life is essential to better align patient preferences and health needs with health system resources and policies. However, estimates of temporal trends in healthcare resource use at the end of life are conflicting. For example, some studies suggest declining rates of hospital death,^{9, 10} while others do not.^{11, 12} In Canada, analyses between 1994 and 2004 found decreasing rates of hospital deaths,⁹ however, whether this trend has continued or how it applies to other markers of end-of-life care is unclear. We sought to describe contemporary temporal patterns in place of death, health care utilization and costs at the end of life and to identify factors associated with dying in a hospital in Ontario.

Methods

Design and Settings

We conducted a population-based cohort study in Ontario, Canada's largest province (population 13.6 million, of whom approximately 16% are 65 years or over). Most physician and hospital services are universally insured for all residents of Ontario, through the province's single-payer publicly funded health system, with health services planning and delivery coordinated by the provinces 14 Local Health Integration Networks (LHINs).

We identified individuals (≥ 18 years) who died between April 1, 2004 and March 31, 2015, using the Registered Persons Database (RPDB), which contains vital statistics data on all residents of Ontario, including date of and age at death. We used the Office of the Registrar General for Deaths (ORGD) database to identify cause of death. To describe healthcare utilization and costs prior to death, information on decedents were linked to population-based health administrative datasets using unique encrypted identifiers. These datasets included the Canadian Institute for Health Information's Discharge Abstract Database (DAD), which captures data on all acute care hospital admissions in Ontario; the National Ambulatory Care Reporting System (NACRS), which contains information on hospital-based ambulatory services, including emergency department visits, day surgery and outpatient clinics; the Continuing Care Reporting System (CCRS) which includes demographic and clinical information on individuals receiving facility-based continuing care services; and the Home Care Database (HCD), which captures data on receipt of publicly

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3 funded home care services, including date and type of services. Information on
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5 physician services, including date and type of medical services provided, and billing
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7 claims for inpatient and outpatient services were obtained from the Ontario Health
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9 Insurance Plan (OHIP) database. Healthcare cost data were from a health care
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11 payer perspective (Ontario Ministry of Health and Long-term Care - MOHLTC) and
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13 were estimated from these health administrative datasets using an established
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15 approach for person-level costing.^{13, 14} The algorithm summarizes costs attributed to
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17 a number of health sectors, for example, inpatient acute care, emergency room
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19 visits, complex continuing care and physician services (see Supplemental Appendix
20
21 for details). Briefly, costs for institutional care (for example hospital and rehabilitation
22
23 admissions) were derived by applying resource intensity weights for the specific care
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25 sector to the cost per weighted case determined from amounts paid by the
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27 MOHLTC. Costs for health services associated with specific fees (for example
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29 physician visits, diagnostic tests, drug costs) were based directly on the fee paid per
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31 use of these services.¹³ All costs were adjusted to 2014 Canadian dollars. These
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33 datasets were linked using unique encoded identifiers and analyzed at the Institute
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35 for Clinical Evaluative Sciences (ICES).
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44 *Variables*

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46 We examined health services use during the 6-months prior to death, including the
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48 number of acute care hospitalizations, emergency department admissions, receipt of
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50 mechanical ventilation, and number of physician visits. For decedents who were
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52 admitted to hospital within the 6-months prior to death, we identified the number of
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3 admissions to an intensive care unit (ICU) using special care unit codes in the
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5 DAD.^{15, 16} We also measured the total inpatient and ICU days for these individuals.
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7 Place of death was classified as occurring in a hospital, at home, in a long-term care
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9 facility, or in another location. This classification was performed using information
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11 contained in the vital status (RPDB), hospital (DAD) and emergency department
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13 (NACRS) databases. Deaths in hospital were further classified according to whether
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15 they occurred in an ICU.
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22 Receipt of palliative care was identified by codes contained in the home care (HCD),
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24 hospital (DAD), emergency department (NACRS), long-term care and complex
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26 continuing care (CCRS) and physician billing (OHIP) databases for palliative care
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28 services, consistent with a prior study.¹⁷ Decedents' demographics, including age,
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30 sex, income, location of residence, and cause of death were measured at the time of
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32 death. Income (ascribed as neighbourhood income quintile) and urban or rural
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34 residence was determined by linking each decedent's residential postal code at the
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36 time of death to the Statistics Canada 2006 census. Cause of death was determined
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38 from the ORGD database and classified based on the International Classification of
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40 Diseases 10th Revision (ICD-10). A primary chronic condition was defined as a nine-
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42 level variable indicating the presence of cancer, chronic obstructive pulmonary
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44 disease (COPD), coronary artery disease (CAD), congestive heart failure (CHF),
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46 peripheral vascular disease (PVD), severe liver disease, diabetes with end organ
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48 failure, renal failure or dementia.¹⁸ Decedents were assigned to one of these
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50 conditions based on the ICD-10 diagnostic codes during his/or her last
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3 hospitalization, which was available for over 90% of decedents. When multiple
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5 chronic conditions were identified the following hierarchy was applied: most
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7 responsible diagnosis, then co-morbid diagnoses, then minor diagnoses. For each
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9 LHIN, we determined the number of acute care beds per 100,000 population and
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11 calculated the median bed capacity for the province over the study period. We
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13 classified LHINs falling below and above the provincial median acute care beds as
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15 “low acute care bed capacity” and “high acute care bed capacity”, respectively, and
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17 categorized decedents according to the acute care bed capacity of their LHIN.
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24 *Statistical Analyses*

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26 We used descriptive statistics to characterize health services use and location of
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28 death for all decedents and according to groups defined by age, chronic condition,
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30 and year of death. Categorical and continuous variables were summarized as
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32 proportions and means (standard deviation, SD) or medians (interquartile range,
33
34 IQR), respectively. Student’s t-test was used to compare continuous data and the
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36 Chi-square test was used for comparison of categorical data. We used the Cochran-
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38 Armitage trend test and linear regression, as appropriate, to examine changes over
39
40 time in location of death and costs. Multilevel logistic regression, accounting for the
41
42 clustering of decedents within LHINs, was used to identify factors associated with
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44 dying in hospital. Putative factors were considered based on their clinical relevance
45
46 and availability in the dataset. At the patient-level this included age, sex, Charlson
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48 comorbidity score, rural residence, income, year and cause of death. LHIN acute
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50 care bed capacity was included as a cluster-level factor.
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Ethics

This study was approved by the institutional review board at Sunnybrook Health Sciences Centre, Toronto, Canada.

Results

Patterns and Temporal Trends in Place of Death and Palliative care Use

There were 962,462 decedents in Ontario between fiscal 2004 and 2014. Mean (SD) age at death was 76.3 (14.8) years and 50.1% were women (Table 1). Overall, 45% of decedents died in hospital. Fewer individuals died in hospital over time, (45.9% in 2004 to 43.2% in 2014; absolute difference (95% confidence interval) 2.7% (2.3%, 3.2%), test for trend $p < 0.001$, Figure 1), with a corresponding increase in deaths at home (37.9% to 43.2%; absolute difference 5.3% (4.9%, 5.8%), test for trend $p < 0.001$, Figure 1). Patterns in place of death varied based on primary chronic condition, with those with liver disease (73.3%), peripheral vascular disease (67.5%), congestive heart failure (61.1%), COPD (60.8%), coronary artery disease (57.7%), and cancer (54%) more likely to die in hospital than those with dementia (34.2%) (Supplemental Figure 1, $\chi^2 p < 0.001$).

There was a two-fold increase in the proportion of decedents who received palliative care during the terminal hospital admission; from 14.0% in 2004 to 29.3% in 2014 (absolute difference 15.3% (14.9%, 15.7%), $p < 0.001$, Figure 1). Decedents with cancer had the highest rates of palliative care during the terminal hospitalization

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3 throughout the study (37.9% in 2004 to 44% in 2014, (absolute difference 6.1%
4 (5.2%, 7.1%), $p < 0.001$), but increased uptake of palliative care was observed for all
5 conditions, including patients with dementia (7.9% in 2004 to 23.7% in 2014,
6 absolute difference 15.8% (14.7%, 16.8), $p < 0.001$), coronary artery disease (7.6%
7 in 2004 to 25.6% in 2014, absolute difference 18.0% (16.4%, 19.6%), $p < 0.001$), and
8 congestive heart failure (10.3% in 2004 to 35.3% in 2014, absolute difference 25.0%
9 (24.0%, 26.2%), $p < 0.001$) (Supplemental Figure 1). Restricting to decedents dying
10 in hospital, receipt of palliative care during the terminal hospital admission increased
11 significantly, from 30.5% in 2004 to 67.9% in 2014, (absolute difference 37.4%
12 (36.8%, 38.1%), $p < 0.001$). Similar increases were observed among chronic
13 conditions, with decedents with cancer having amongst the highest rates of palliative
14 care during the terminal hospital admission (Supplemental Figure 2).

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33 In the adjusted analysis, men and older decedents were more likely to die in hospital
34 than out of hospital (Table 2), with the association between age and death in hospital
35 attenuating among those 85 years and older. In addition, those residing in more rural
36 areas (OR 1.12, 95% CI 1.11 to 1.13) and neighbourhoods with the lowest
37 (compared to the highest) income quintile (OR 1.13, 95% CI 1.12 to 1.14) had higher
38 odds of dying in hospital. There was a trend towards increased odds of in-hospital
39 deaths amongst decedents living in a high acute bed capacity LHIN; however, this
40 was not statistically significant (Table 2).
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Decedents' Use of Health Resources – Last 6-months of Life

The majority of decedents visited the emergency department (77.3%) and saw ten or more physicians (52.6%) during the last 6-months of life (Table 3). In the same period, 68.4% were hospitalized one or more times (median hospitalizations (interquartile range (IQR)) 1(0, 2)) and approximately one in every five decedents were admitted to an ICU and 13.9% received mechanical ventilation. Decedents spent a median of 6 (0, 19) days in hospital during the last 6-months of life. Over the 11-year period, there was no substantial change in proportion of decedents being admitted to hospital, ICU or using emergency department services in the last six months of life. There was, however, an increasing trend in the proportions of decedents seeing 10 or more physicians and in receiving mechanical ventilation in the 6-months prior to death (Table 3). Rates of health services use during the last 6-months of life were highest amongst decedents who died in hospital, including a higher proportion of admissions to ICU (36.2% vs 5.6%, $p < 0.001$) and receipt of mechanical ventilation (27.7% vs 2.6%, $p < 0.001$). Among individuals who died in hospital, rates of use of these high intensity resources (ICU and mechanical ventilation) were lower among those who received palliative care within the last 6-months of life (Table 4). Compared to decedents with a chronic organ failure-related condition (for example COPD, CHF) those with cancer and dementia were less likely to be admitted to ICU and less likely to receive mechanical ventilation (Supplemental Table 1). Approximately 1 in every 2 decedents received palliative care services during the last six months of life, with use of these services increasing significantly over the study period (from 28.1% in 2004 to 57.7% in 2014, absolute difference

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3 29.6% (29.2%, 30.1%), $p < 0.001$) (Figure 2). Receipt of palliative care during the last
4
5 6-months of life was highest amongst decedents dying in a long-term care facility
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7 across all years, ranging from 61.9% in 2004 to 88.3% in 2014, absolute difference
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9 26.4% (25.1%, 27.8%), $p < 0.001$ (Figure 2).
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14 *Healthcare Costs in the last 6 months of life*

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17 The median (IQR) total health care costs in the last 6-months of life were highest
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19 amongst decedents who died in hospital (\$32,291 (\$18,245, \$55,308)) compared to
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21 those who did not (\$22,895 (\$7,636, \$36,931)) (Supplemental Table 2). Overall, the
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23 majority of non-patient borne healthcare costs were attributed to inpatient costs,
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25 which ranged from a median of \$0 (\$0, \$11,060) amongst decedents who died in
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27 settings other than a hospital to \$16,284 (\$7,290, \$33,216) amongst those dying in
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29 hospital.
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35 **Interpretation**

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37 In this population-based study, we found substantial healthcare utilization among
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39 decedents in the 6-months prior to death. We found that three in every four
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41 decedents were admitted to a hospital or emergency department; nearly one-half of
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43 all deaths occurred in hospital; and one-quarter of these deaths occurred in the ICU.
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45 Between 2004 and 2014, deaths in hospital decreased, with concomitant increases
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47 in the proportion of terminal hospitalizations involving palliative care and deaths at
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49 home; however, other markers of acute care and hospital-based healthcare resource
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51 use have not changed.
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5 Similar to others,^{1-3, 19, 20} we have demonstrated considerable acute care healthcare
6 resource use at or near the time of death. Overall, these findings suggest a
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8 continued reliance on hospitals to provide end-of-life care services, and underscore
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10 the gaps in options for palliative, hospice or home-based care at the end of life within
11
12 the Canadian health system.^{7, 8, 21} A lack of outpatient structures and processes for
13
14 delivering end-of-life services may therefore be an explanation for the observed
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16 utilization patterns, especially so in more rural and remote areas. For example,
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18 compared to the United States, which has more available hospice services,²² Ontario
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20 has over twice as many deaths occurring in hospital.¹ The observed trend towards
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22 increased in-hospital deaths among individuals living in LHINs with a higher number
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24 of acute care beds, support a role for differential availability of institutional services in
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26 the delivery of end-of-life care. Future studies that clarify the contributions of
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28 system-level factors, such as availability of institutional- and community- based
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30 resources (including in-home palliative care services) on where individuals die are
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32 warranted.
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42 Our study did find modest changes in end-of-life care practices over time, notably
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44 decreasing rates of hospital deaths. From 1980 to 1997, over 66% of Ontarians died
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46 in hospital, with relatively stable rates over this time.²³ However, between 1997 and
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48 2004, there was a substantial drop in deaths occurring in hospital - from 66% to
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50 45%. This may have been related to significant health restructuring efforts that
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52 occurred in Ontario that resulted in the closure of thousands of hospital beds and the
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3 creation of new long-term care beds.²⁴ While we cannot confirm the number of
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5 deaths in hospital-based hospice or palliative care units in the present study, a
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7 substantial proportion of decedents dying in an acute care institution still do not
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9 receive palliative care, suggesting additional avenues are required to improve
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11 access to less aggressive end-of-life care. In particular, future studies to understand
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13 the determinants of the observed lower rates of in-hospital deaths amongst
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15 individuals with dementia, compared to other chronic conditions, and the extent to
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17 which this may reflect improved care at the end of life for these individuals are
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19 warranted. Notwithstanding, our estimate that 46.1% of decedents received some
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21 form of palliative care in the last six months of life is generally similar to recent
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23 observations using comparable methods.^{17, 25} We extend these findings by providing
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25 evidence of increasing trends in the receipt of palliative care at the population level.
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28 Contributing factors to the observed rise in palliative care use among these
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30 decedents likely include the increasing recognition of the benefits of palliative care
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32 for improving care at the end of life and the growth of palliative care services in the
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34 last decade.²⁶⁻³⁰ It is also plausible that shifting awareness regarding palliative care
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36 services among dying individuals and their caregivers might have influenced end-of-
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38 life care decisions. With population aging and increasing number of older adults
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40 living with chronic and terminal diseases, understanding the drivers of the observed
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42 increase will be informative to efforts targeted at meeting the palliative care needs of
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44 these individuals.
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3 Receipt of in-patient and technology laden end-of-life care may not align with
4 patients' preferences,^{4, 31, 32} and is costly.^{20, 33} Our finding that individuals dying in
5 hospital had higher costs of care in the last 6-months of life and that approximately
6 50% of these were attributable to inpatient costs align with previous data from
7 Ontario,³³ and suggest that there may be opportunities to improve end-of-life care
8 that is better aligned with patient wishes. In particular, the observed higher risk of
9 dying in hospital among individuals from rural residences and lower income
10 neighbourhoods may be indicative of disparities in access to end-of-life care
11 services, including availability of home-, palliative-, and hospice- care. Further,
12 although our data is unable to provide insights regarding the appropriateness of
13 care, the observation that a large proportion of decedents received care from
14 multiple physicians within the last 6-months of life, is suggestive of fragmented care.
15 This has important implications not only for the quality of care provided to these
16 individuals but may also adversely impact healthcare costs.³⁴ Investigations
17 delineating the reasons for these observations may be instructive to health policies
18 and efforts to organize and deliver end-of-life care that meet the needs of these
19 individuals, including improving access to services that support individuals dying at
20 home.

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47 While ascribing cause of death and associating this cause of death with specific end-
48 of-life preferences is challenging,³⁵ our findings suggest important differences in care
49 based upon predominant terminal clinical diagnoses. There were higher rates of ICU
50 admission, receipt of mechanical ventilation in the period before death, and hospital-
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3 based deaths among those with organ failure (e.g. congestive heart failure, chronic
4 obstructive pulmonary disease, coronary artery disease, liver failure, renal failure) as
5 compared to patients with cancer or dementia. This finding has implication for
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8 planning health services, supporting individuals dying from these conditions, and
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10 potentially supporting sub-specialist clinicians treating those conditions. Having
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12 greater options for end-of-life and palliative care at home or in hospice may increase
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15 quality-adjusted-life-days, and reduce both hospitalization rates and overall costs.^{19,}
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20 21 22 23 24 **Limitations**

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26 Our population-based observational study describes associations but cannot explain
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28 the causes for high rates of healthcare utilization near the end-of-life. In particular,
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30 we lacked information on several factors previously shown to be associated with use
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32 of healthcare services, for example patient and family preferences, provider decision
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34 making, and potentially, differential availability of hospice and palliative care services
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36 across various patient populations and geographies.^{19, 39-41} Our cost analyses does
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38 not include all single public payer health system costs, including for example health
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40 services provided at the community level. These may have important influences on
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42 decisions with respect to location of death. Further, we report costs from the health
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44 system payer perspective and therefore not all societal costs, including out-of-pocket
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46 expenses and informal care costs, are considered. These costs may vary by chronic
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48 condition⁴² and can be a substantial burden on patients and informal care
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54 providers.^{42, 43} It is also plausible that changes in coding practices over time might
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3 have impacted our report estimates. However, given the relatively short duration of
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5 our study and the lack of sharp spikes in year-to-year trends, we believe this would
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7 have minimal impact on our results and the conclusions drawn. Additionally, our
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9 population-based focus, inclusion of a wide range of health sectors and emphasis on
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11 temporal trends in estimates of health services use by decedents are key strengths
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13 of our study.
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19 **Conclusion**

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21 In this population-based study, while there are slightly decreasing rates of deaths in-
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23 hospital, and a corresponding increase in the provision of palliative care, the
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25 Canadian health system remains reliant on hospitals to provide end-of-life care.
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27 Approximately three-quarters of decedents were admitted to hospital and one in five
28
29 were admitted to ICU during the last 6-months of life, with rates remaining stable
30
31 over time. Rates of hospitalization prior to death were higher for those living in more
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33 rural and economically disadvantaged neighbourhoods. Care in hospital appears to
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35 be more costly than home-based alternatives. Increased capacity for palliative,
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37 hospice and home care at the end-of-life may help to better align health system
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39 resources with patient preferences.
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Author Contribution

All authors contributed to the conceptualization of this manuscript, including the design or analysis and interpretation of the data, drafting the article, and revising the manuscript for important intellectual content. All authors gave final approval of the version to be published, and agree to act as guarantors of the work.

Confidential

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References

1. Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. *JAMA*. 2016;315(3):272-83.
2. Pivodic L, Pardon K, Morin L, Addington-Hall J, Miccinesi G, Cardenas-Turanzas M, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *J Epidemiol Community Health*. 2016;70(1):17-24.
3. Cohen J, Pivodic L, Miccinesi G, Onwuteaka-Philipsen BD, Naylor WA, Wilson DM, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. *Br J Cancer*. 2015;113(9):1397-404.
4. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*. 2013;12:7.
5. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Ann Oncol*. 2012;23(8):2006-15.
6. Heyland DK, Barwich D, Pichora D, Dodek P, Lamontagne F, You JJ, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med*. 2013;173(9):778-87.
7. Carstairs S, Beaudoin G. Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology. Quality end-of-life care: the right of every Canadian. Final report 2000 [Available from: <https://sencanada.ca/content/sen/committee/362/upda/rep/repfinjun00-e.htm>].
8. Schuklenk U, van Delden JJ, Downie J, McLean SA, Upshur R, Weinstock D. End-of-life decision-making in Canada: the report by the Royal Society of Canada expert panel on end-of-life decision-making. *Bioethics*. 2011;25 Suppl 1:1-73.
9. Wilson DM, Truman CD, Thomas R, Fainsinger R, Kovacs-Burns K, Froggatt K, et al. The rapidly changing location of death in Canada, 1994-2004. *Soc Sci Med*. 2009;68(10):1752-8.
10. Gomes B, Calanzani N, Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med*. 2012;26(2):102-7.
11. Mai TTX, Lee E, Cho H, Chang YJ. Increasing Trend in Hospital Deaths Consistent among Older Decedents in Korea: A Population-based Study Using Death Registration Database, 2001-2014. *BMC Palliat Care*. 2018;17(1):16.
12. Sarmiento VP, Higginson IJ, Ferreira PL, Gomes B. Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliat Med*. 2016;30(4):363-73.
13. Wodchis WP, Bushmenev K, Nikitovic M, McKillop I. Guidelines on Person-Level Costing Using Administrative Databases in Ontario [Internet]. 2013 [cited May 23, 2018]. Available from: http://www.hsprn.ca/uploads/files/Guidelines_on_PersonLevel_Costing_May_2013.pdf.

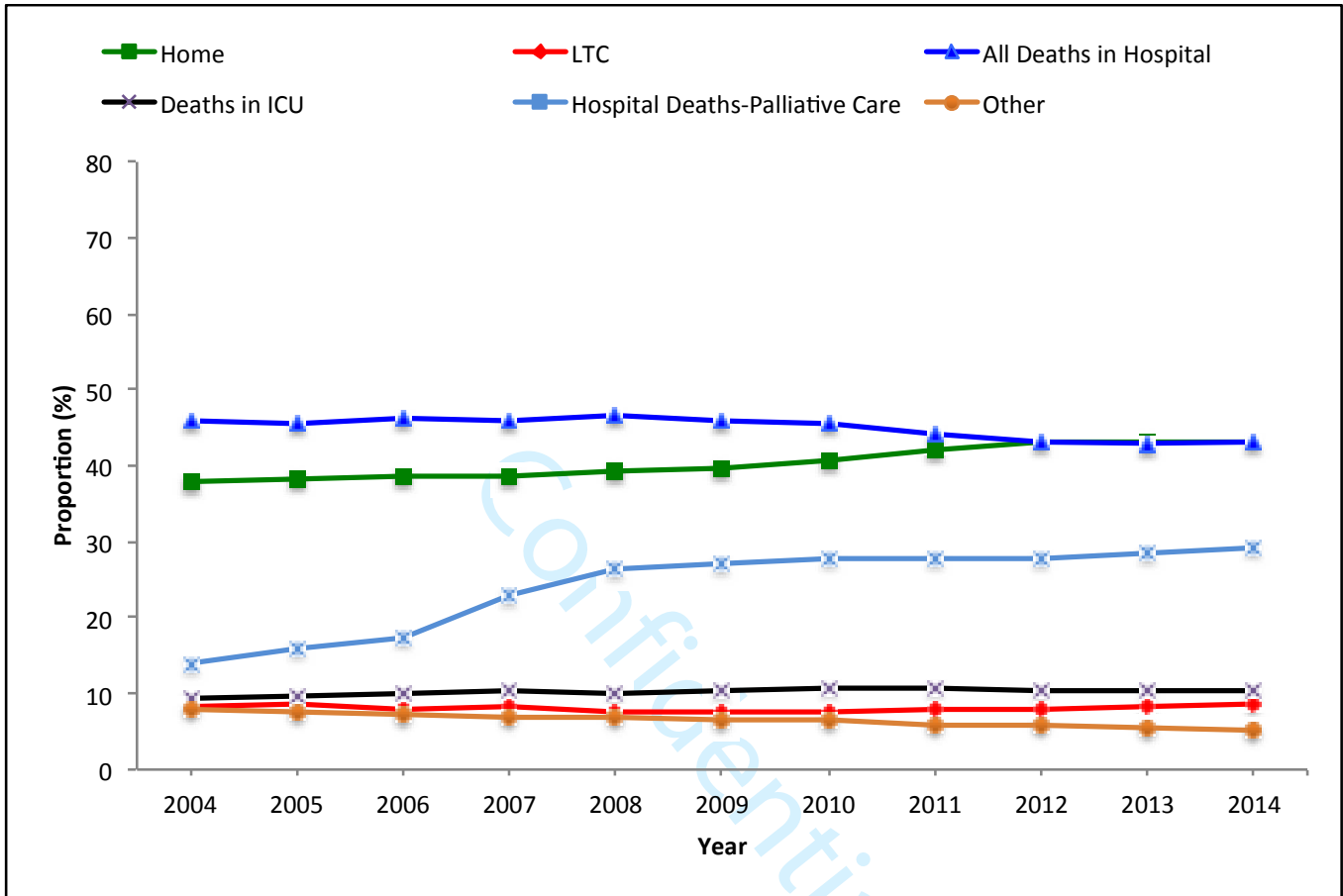
14. Wodchis WP, Austin PC, Henry DA. A 3-year study of high-cost users of health care. *Cmaj*. 2016;188(3):182-8.
15. Garland A, Yogendran M, Olafson K, Scales DC, McGowan KL, Fransoo R. The accuracy of administrative data for identifying the presence and timing of admission to intensive care units in a Canadian province. *Med Care*. 2012;50(3):e1-6.
16. Scales DC, Guan J, Martin CM, Redelmeier DA. Administrative data accurately identified intensive care unit admissions in Ontario. *J Clin Epidemiol*. 2006;59(8):802-7.
17. Tanuseputro P, Budhwani S, Bai YQ, Wodchis WP. Palliative care delivery across health sectors: A population-level observational study. *Palliat Med*. 2017;31(3):247-57.
18. Iezzoni LI, Heeren T, Foley SM, Daley J, Hughes J, Coffman GA. Chronic conditions and risk of in-hospital death. *Health Serv Res*. 1994;29(4):435-60.
19. Seow H, Sutradhar R, McGrail K, Fassbender K, Pataky R, Lawson B, et al. End-of-Life Cancer Care: Temporal Association between Homecare Nursing and Hospitalizations. *J Palliat Med*. 2016;19(3):263-70.
20. Fassbender K, Fainsinger RL, Carson M, Finegan BA. Cost trajectories at the end of life: the Canadian experience. *J Pain Symptom Manage*. 2009;38(1):75-80.
21. Office of the Auditor General of Ontario. Annual Report (2016): Volume 2. Chapter 1: Follow-Up Reports on 2014 Annual Report Value-for-Money Audits: Palliative Care. Page 98 -108 [Available from: http://www.auditor.on.ca/en/content/annualreports/arreports/en16/v2_108en16.pdf].
22. Medicare Payment Advisory Commission (MedPAC). Report to the congress. Medicare payment policy 2016 [Available from: <http://medpac.gov/docs/default-source/reports/march-2016-report-to-the-congress-medicare-payment-policy.pdf?sfvrsn=0>].
23. Heyland DK, Lavery JV, Tranmer JE, Shortt SED. The final days: An analysis of the dying experience in Ontario. *Ann R Coll Phys Surg Can*. 2000;33(6):356-61.
24. Sinclair D, Rochon M, Leatt P. Riding the Third Rail. The Story of Ontario's Health Services Restructuring Commission, 1996-2000. [Internet]. 2005 [cited February 27, 2017]. Available from: <http://irpp.org/research-studies/book-2005-08-15/>.
25. Seow H, O'Leary E, Perez R, Tanuseputro P. Access to palliative care by disease trajectory: a population-based cohort of Ontario decedents. *BMJ Open*. 2018;8(4):e021147.
26. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. *J Pain Symptom Manage*. 2013;45(6):1094-106.
27. Advancing high quality, high value palliative care in Ontario: a declaration of partnership and commitment to action. [Internet]. 2011 [cited November 1, 2017]. Available from: http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf.
28. Sutradhar R, Barbera L, Seow HY. Palliative homecare is associated with reduced high- and low-acuity emergency department visits at the end of life: A population-based cohort study of cancer decedents. *Palliat Med*. 2017;31(5):448-55.

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29. Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC, et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *Bmj*. 2014;348:g3496.
 30. Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The Growth of Palliative Care in U.S. Hospitals: A Status Report. *J Palliat Med*. 2016;19(1):8-15.
 31. Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med*. 2000;3(3):287-300.
 32. Shih CY, Hu WY, Cheng SY, Yao CA, Chen CY, Lin YC, et al. Patient Preferences versus Family Physicians' Perceptions Regarding the Place of End-of-Life Care and Death: A Nationwide Study in Taiwan. *J Palliat Med*. 2015;18(7):625-30.
 33. Tanuseputro P, Wodchis WP, Fowler R, Walker P, Bai YQ, Bronskill SE, et al. The health care cost of dying: a population-based retrospective cohort study of the last year of life in Ontario, Canada. *PLoS One*. 2015;10(3):e0121759.
 34. Wodchis WP, Arthurs E, Khan AI, Gandhi S, MacKinnon M, Sussman J. Cost trajectories for cancer patients. *Curr Oncol*. 2016;23(Suppl 1):S64-75.
 35. Bach PB, Schrag D, Begg CB. Resurrecting treatment histories of dead patients: a study design that should be laid to rest. *JAMA*. 2004;292(22):2765-70.
 36. Phan Pham B, Krahn M. End-of-life care interventions: an economic analysis. 2014 [14(8):1-70]. Available from: <http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ontario-health-technology-assessment-series/eol-econ-interventions>.
 37. Seow H, Pataky R, Lawson B, O'Leary EM, Sutradhar R, Fassbender K, et al. Temporal association between home nursing and hospital costs at end of life in three provinces. *Curr Oncol*. 2016;23(Suppl 1):S42-51.
 38. Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leigh N, Oza A, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet*. 2014;383(9930):1721-30.
 39. Hart JL, Harhay MO, Gabler NB, Ratcliffe SJ, Quill CM, Halpern SD. Variability Among US Intensive Care Units in Managing the Care of Patients Admitted With Preexisting Limits on Life-Sustaining Therapies. *JAMA Intern Med*. 2015;175(6):1019-26.
 40. Obermeyer Z, Powers BW, Makar M, Keating NL, Cutler DM. Physician Characteristics Strongly Predict Patient Enrollment In Hospice. *Health Aff (Millwood)*. 2015;34(6):993-1000.
 41. Kelley AS, Ettner SL, Morrison RS, Du Q, Wenger NS, Sarkisian CA. Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med*. 2011;154(4):235-42.
 42. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med*. 2015;163(10):729-36.
 43. Chai H, Guerriere DN, Zagorski B, Coyte PC. The magnitude, share and determinants of unpaid care costs for home-based palliative care service provision in Toronto, Canada. *Health Soc Care Community*. 2014;22(1):30-9.

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Figure 1: Temporal trends in location of death: Ontario 2004 – 2014



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Figure 2: Trends in proportion of patients receiving palliative care in the last six months of life: overall and by location of death

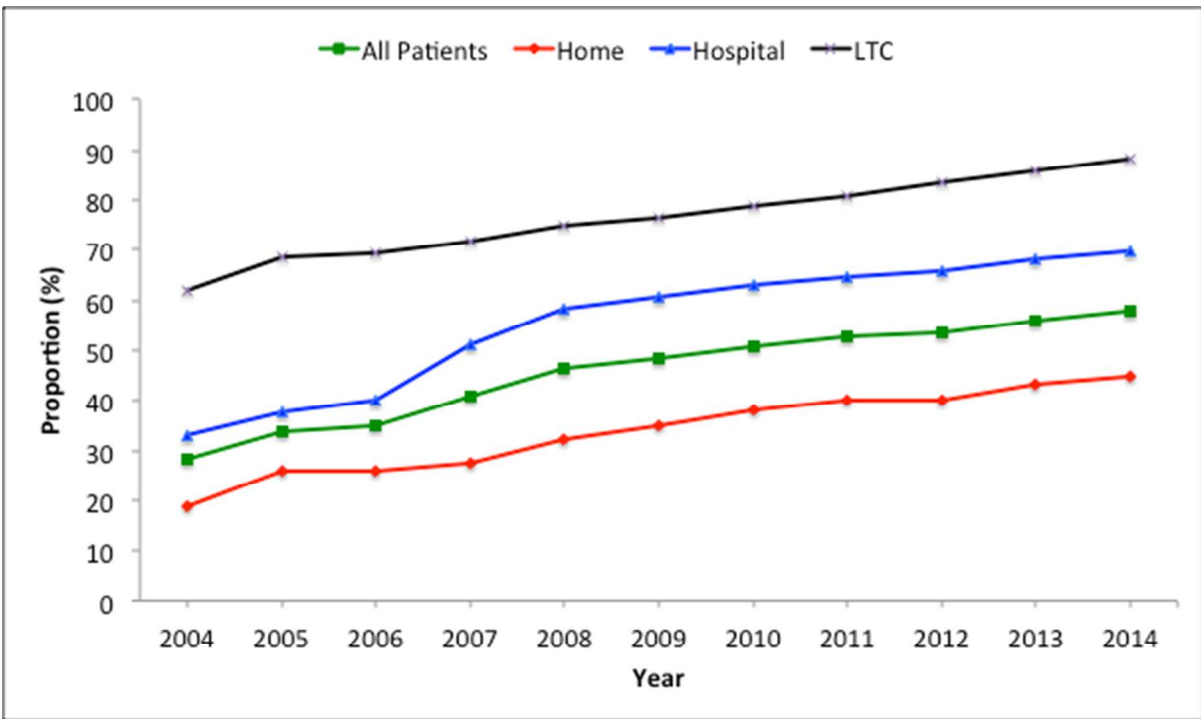


Table 1: Demographics of Ontario Decedents, 2004 – 2014*

	All Decedents (N=962,462)	Death in Hospital (N=433,074)	Death Out of Hospital (N=529,388)
Age at death (Mean, SD)	76.3 (14.8)	75.8 (13.5)	76.6 (15.8)
Age category (%)			
18 - 49 years	5.8	4.6	6.8
50 - 54 years	3.4	3.3	3.5
55 - 59 years	4.7	4.7	4.6
60 - 64 years	6.0	6.4	5.6
65 - 69 years	7.4	8.3	6.6
70 -74 years	9.5	11.0	8.3
75 - 79 years	12.8	14.7	11.4
80 - 84 years	16.6	17.9	15.6
≥85 years	33.7	28.9	37.6
Female (%)	50.1	48.0	51.9
Charlson comorbidity index score (%)			
0	14.1	6.5	20.4
1	13.9	14.3	13.5
≥ 2	61.7	79.2	47.3
Missing	10.3	–	18.7
Income quintile** (%)			
1 (Lowest)	23.5	23.8	23.3
2	21.1	21.9	20.4
3	19.1	19.2	19.0
4	18.5	18.2	18.8
5 (Highest)	17.8	16.9	18.5
Location of residence** (%)			
Rural	14.8	15.3	14.5
Chronic conditions (%)			
Cancer	20.3	24.4	17.0
Congestive heart failure	11.5	15.6	8.1
Dementia	9.0	6.9	10.8
Chronic obstructive pulmonary disease	5.1	6.9	3.6
Coronary artery disease	4.7	6.1	3.6
Renal failure	3.0	4.1	2.1
Severe liver disease	1.5	2.5	0.7
Peripheral vascular disease	1.0	1.5	0.6
Diabetes with end organ damage	0.1	0.1	0.1
None	43.8	32.1	53.3

Table 1 (cont'd): Demographics of Ontario Decedents, 2004 – 2014*

	All Decedents (N=962,426)	Death in Hospital (N=433,090)	Death Out of Hospital# (N=529,336)
Cause of death (top 20)			
Ischemic heart disease	13.6	9.9	16.7
Cancer			
Lung	6.2	7.1	5.5
Colorectal	3.0	3.0	2.9
Hematological	2.5	3.5	1.6
Breast	1.8	1.8	1.8
Prostate	1.4	1.2	1.5
Pancreas	1.4	1.4	1.4
Dementia and Alzheimer's disease	5.9	2.5	8.7
Cerebrovascular diseases	5.1	6.0	4.3
Chronic lower respiratory diseases	3.5	4.1	3.0
Diabetes	2.8	2.2	3.4
Influenza and pneumonia	2.2	3.0	1.5
Diseases of the urinary system	2.0	2.8	1.3
Falls	1.6	2.4	1.0
Heart failure and complications	1.6	1.7	1.5
Cirrhosis and other liver diseases	1.2	1.9	0.7
Hypertensive disease	1.0	0.6	1.4
Intentional self harm	1.0	0.2	1.6
Cardiac arrhythmias	1.0	1.2	0.8
Sepsis	0.9	1.6	0.3

*P < 0.05 for all comparisons by location of death

** 0.5% (5,213) and 0.1% (617) of decedents had missing information on income and location of residence, respectively.

Out of hospital deaths include dying at home (n=389,235); long-term care facility (n=77,228); and other (n=62,873).

Table 2: Multi-level model of factors associated with dying in hospital versus all other locations*

	Odds Ratio and 95% Confidence Limit
Patient Factors	
Age category (%)	
18 - 50 years	Reference
50 - 54 years	1.34 (1.30, 1.38)
55 - 59 years	1.47 (1.43, 1.51)
60 - 64 years	1.63 (1.59, 1.67)
65 - 69 years	1.80 (1.76, 1.84)
70 - 74 years	1.91 (1.86, 1.95)
75 - 79 years	1.89 (1.85, 1.93)
80 - 84 years	1.74 (1.70, 1.78)
≥85 years	1.22 (1.20, 1.25)
Sex (reference men)	0.88 (0.87, 0.89)
Income quintile	
1 (Lowest)	Reference
2	1.02 (1.01, 1.04)
3	0.96 (0.94, 0.97)
4	0.92 (0.91, 0.93)
5 (Highest)	0.88 (0.88, 0.89)
Rural residence (reference no)	1.12 (1.11, 1.13)
Cause of death	
Ischemic heart disease	Reference
Cancers	
Lung	2.00 (1.96, 2.04)
Colorectal	1.71 (1.66, 1.75)
Hematological	3.51 (3.41, 3.61)
Breast	1.79 (1.73, 1.85)
Prostate	1.31 (1.26, 1.36)
Pancreas	1.60 (1.54, 1.66)
Dementia and Alzheimer's disease	0.55 (0.54, 0.56)
Cerebrovascular diseases	2.48 (2.43, 2.53)
Chronic lower respiratory diseases	2.28 (2.22, 2.34)
Diabetes	1.06 (1.03, 1.09)
Influenza and pneumonia	3.72 (3.61, 3.83)
Diseases of the urinary system	3.84 (3.72, 3.97)
Falls	4.67 (4.50, 4.84)
Heart failure	2.09 (2.02, 2.17)
Cirrhosis and other liver diseases	4.64 (4.45, 4.83)
Hypertensive disease	0.82 (0.79, 0.86)
Intentional self harm	0.19 (0.18, 0.21)
Cardiac arrhythmias	2.94 (2.82, 3.07)
Sepsis	9.29 (8.78, 9.82)
Year**	0.81 (0.79, 0.82)
LHIN Factors	
Acute care bed capacity (reference low)	1.02 (1.00, 1.05)

*Out of hospital deaths include dying at home (n=389,235); long-term care facility (n=77,228); and other (n=62,873); Dying in hospital n=433,090. Odds ratios for fiscal year reflect per 10-year unit change.

** Per 10 year increase

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Table 3: Healthcare utilization in the last 6-months of life among all decedents

Year	Hospital Admission	Hospital Days	ICU Admission	ICU Days*	ED Visits	Saw ≥10 Different Physicians	Mechanically Ventilated
	(%)	Median (IQR)	(%)	Mean (SD)	(%)	%	%
All	68.4	6 (0, 19)	19.4	1.7 (6.5)	77.3	52.6	13.9
2004	68.7	6 (0, 20)	19.1	1.5 (6.1)	76.4	44.8	12.3
2005	68.8	6 (0, 20)	19.2	1.6 (6.5)	77.1	45.9	12.6
2006	68.2	6 (0, 20)	19.1	1.6 (6.2)	77.1	48.7	13.2
2007	68.4	6 (0, 20)	19.3	1.6 (6.3)	77.2	51.3	13.6
2008	68.2	6 (0, 20)	18.6	1.6 (6.4)	77.0	52.2	13.5
2009	68.6	6 (0, 19)	19.5	1.7 (6.9)	77.2	53.8	14.3
2010	68.5	6 (0, 19)	19.2	1.7 (6.4)	77.6	54.8	14.3
2011	68.5	6 (0, 19)	19.5	1.8 (6.9)	77.7	55.7	14.3
2012	67.9	6 (0, 19)	19.7	1.7 (6.6)	77.2	55.1	14.5
2013	68.5	6 (0, 19)	20.1	1.8 (6.8)	77.7	57.1	15.1
2014	68.6	6 (0, 18)	19.9	1.8 (6.7)	77.9	57.5	15.1

* Median ICU days is 0 for all years.

IQR – interquartile range; SD – standard deviation; ICU – Intensive Care Unit; ED – Emergency Department

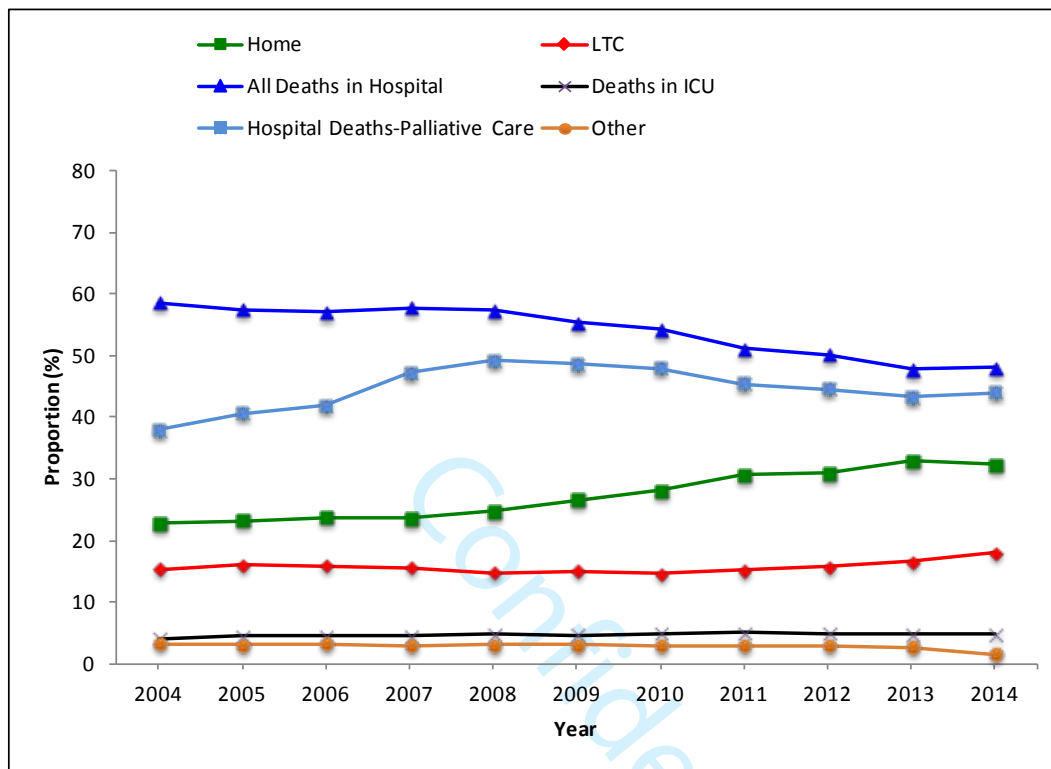
Table 4: Healthcare utilization in the last 6-months of among individuals dying in hospital (n=433,074)

Fiscal Year	Hospital Admission (%)		ED Visits (%)		Saw \geq 10 Different Physicians (%)		ICU Admission (%)		Mechanical Ventilation (%)	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
	Receipt of Palliative Care in the Last Six Months of Life									
2004-2014	99.8	99.5	96.2	96.0	76.9	66.7	26.6	48.6	18.9	38.9
2004	99.9	99.9	93.2	95.6	69.3	58.4	16.5	44.5	8.2	31.9
2005	99.9	99.8	94.0	95.9	69.9	59.0	18.5	45.9	10.2	33.8
2006	99.9	99.8	94.8	96.1	72.9	64.5	19.7	45.6	11.2	35.5
2007	99.9	99.6	95.4	96.1	75.2	67.5	24.0	47.4	16.0	37.5
2008	99.8	99.4	95.9	95.9	75.8	68.0	25.0	46.8	18.1	37.5
2009	99.8	99.2	96.1	95.6	77.0	69.1	27.0	49.7	19.6	41.1
2010	99.8	99.1	96.6	95.7	77.7	70.7	27.1	50.6	19.9	42.7
2011	99.8	99.3	96.8	96.3	78.7	72.0	28.6	52.1	20.8	43.6
2012	99.8	99.3	97.2	96.2	78.9	71.6	30.2	52.5	21.9	44.7
2013	99.8	99.2	97.2	96.1	80.5	73.2	31.4	54.6	23.6	46.9
2014	99.8	99.2	97.3	96.4	80.6	73.3	31.5	53.8	24.2	46.5

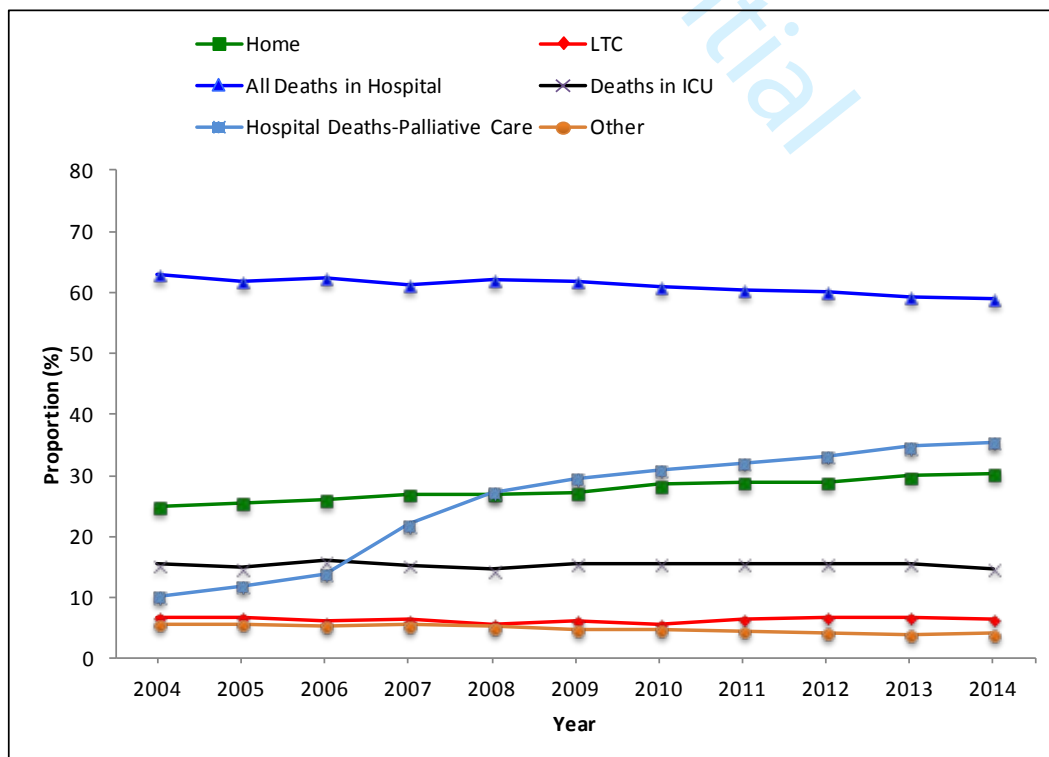
ICU – Intensive Care Unit; ED – Emergency Department

Supplemental Figure 1: Temporal trends in location of death stratified by chronic condition: Ontario 2004 –2014*

Cancer

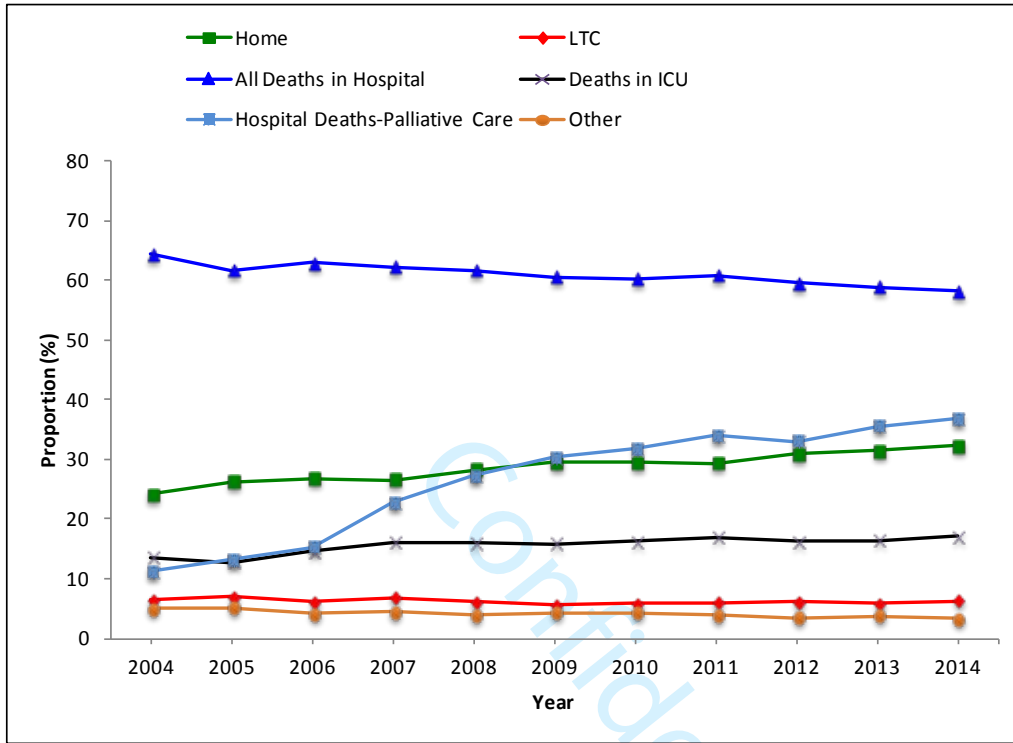


Congestive Heart Failure

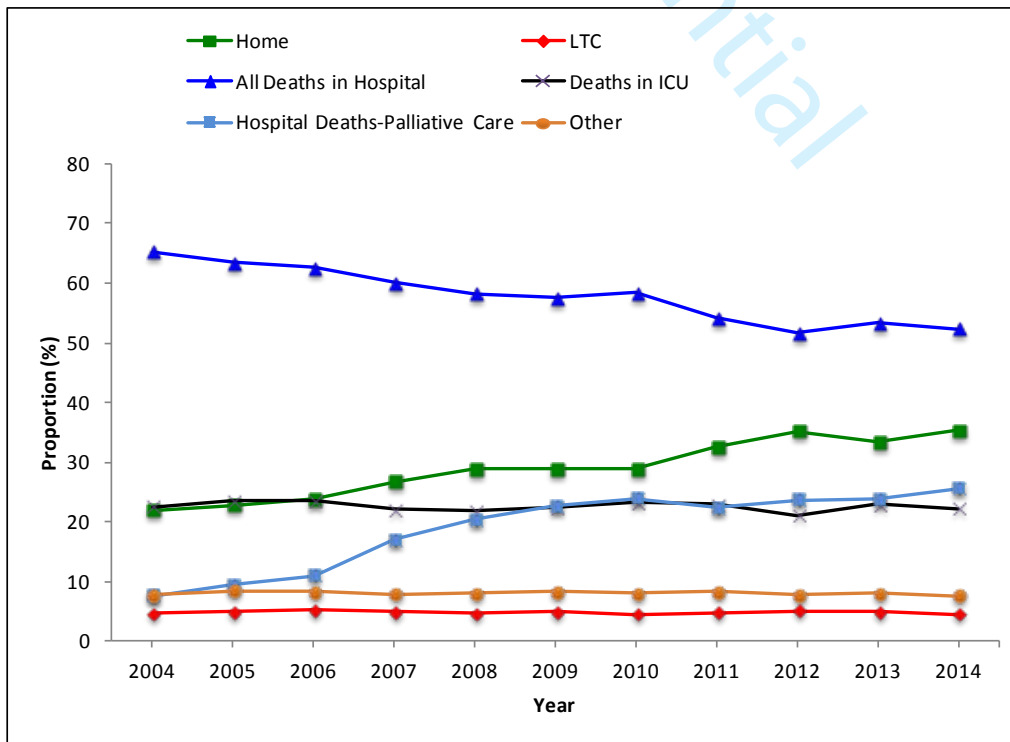


Supplemental Figure 1: Temporal trends in location of death stratified by chronic condition: Ontario 2004 –2014 (cont'd)*

COPD



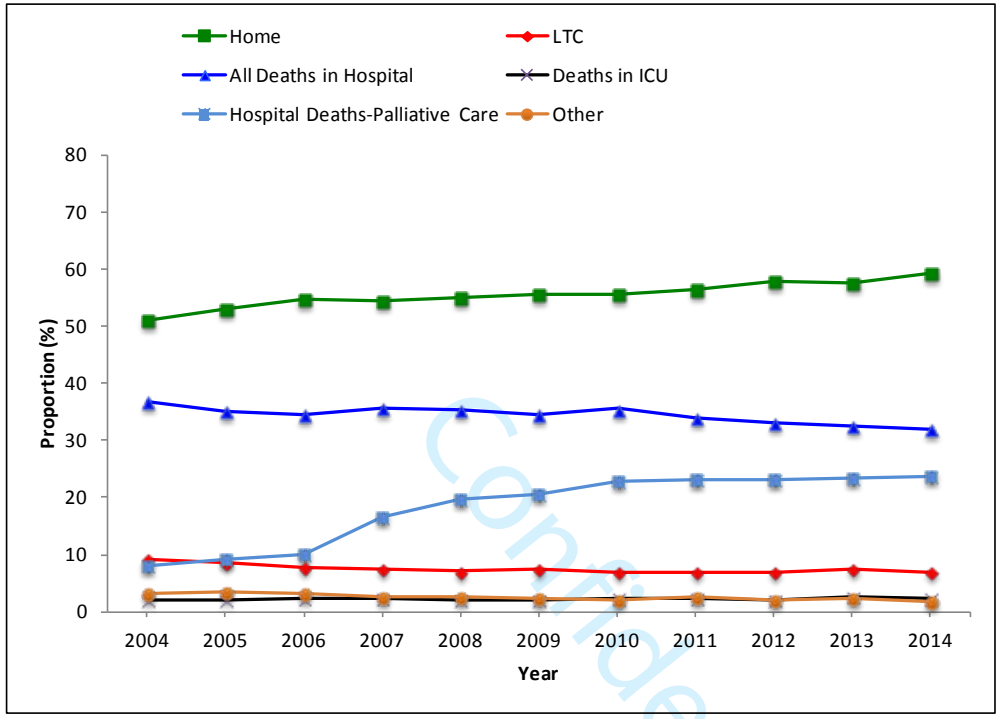
Coronary Artery Disease



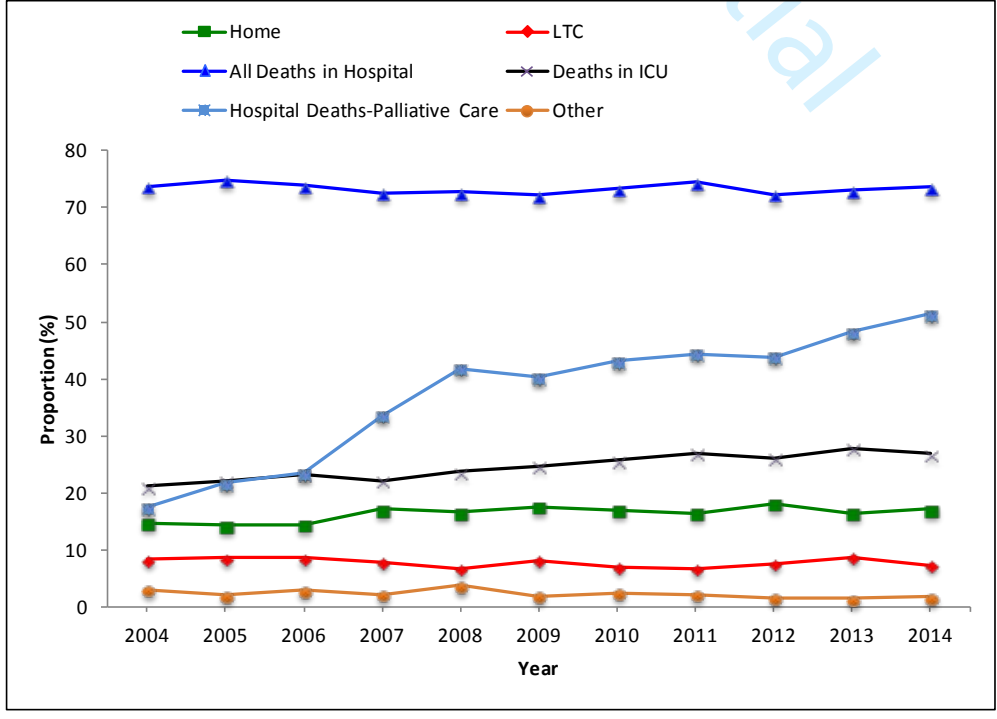
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Supplemental Figure 1: Temporal trends in location of death stratified by chronic condition: Ontario 2004 –2014 (cont'd)*

Dementia

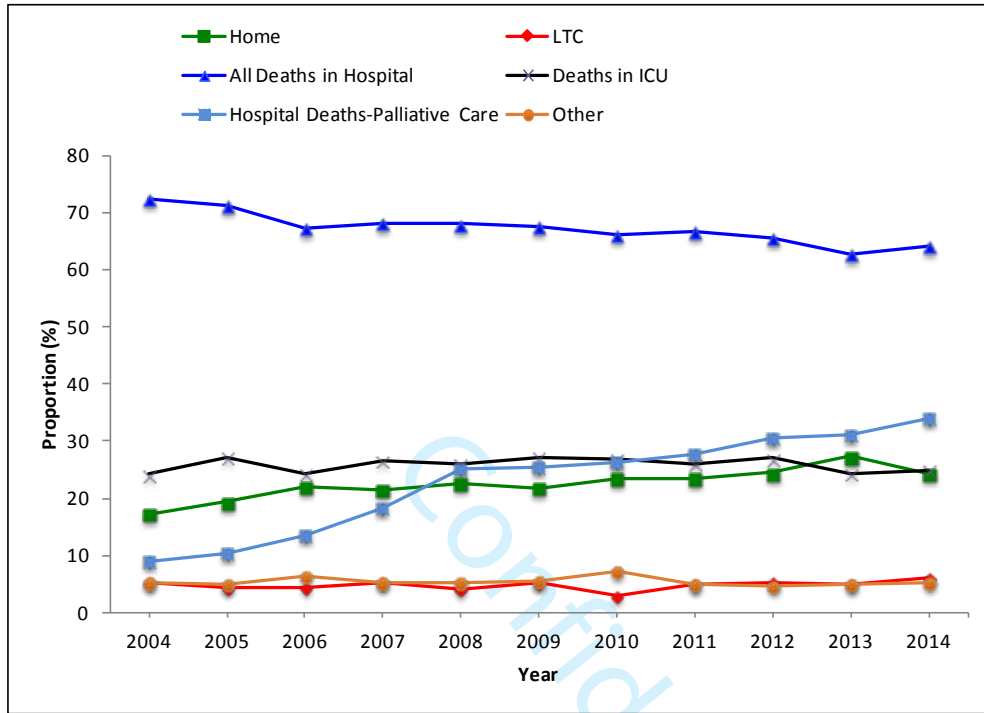


Severe Liver Disease

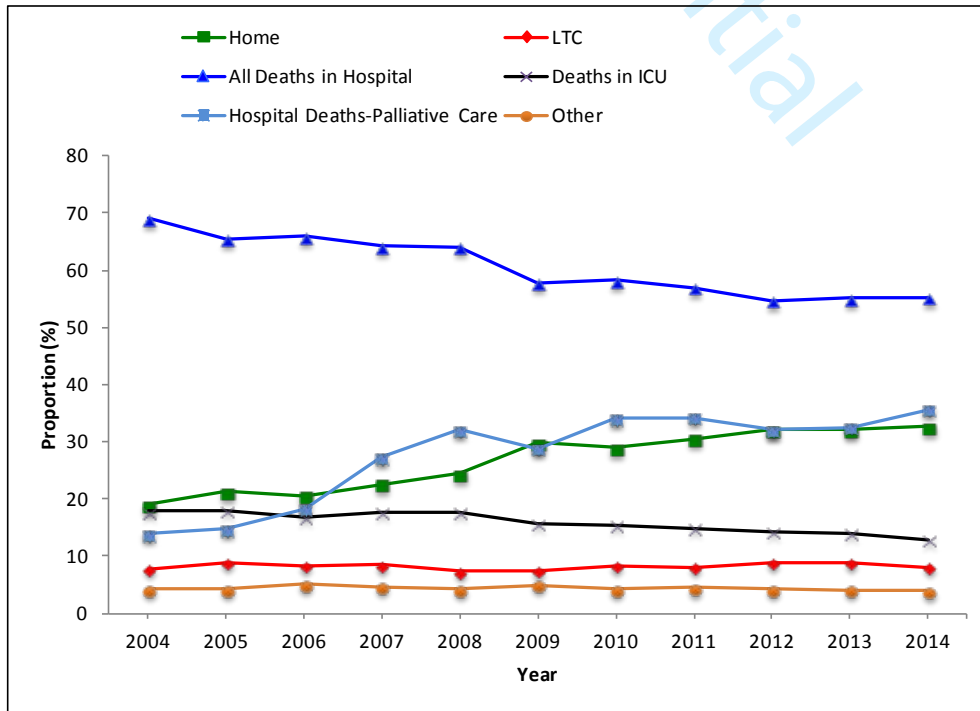


Supplemental Figure 1: Temporal trends in location of death stratified by chronic condition: Ontario 2004 –2014 (cont'd)*

Peripheral Vasular Disease

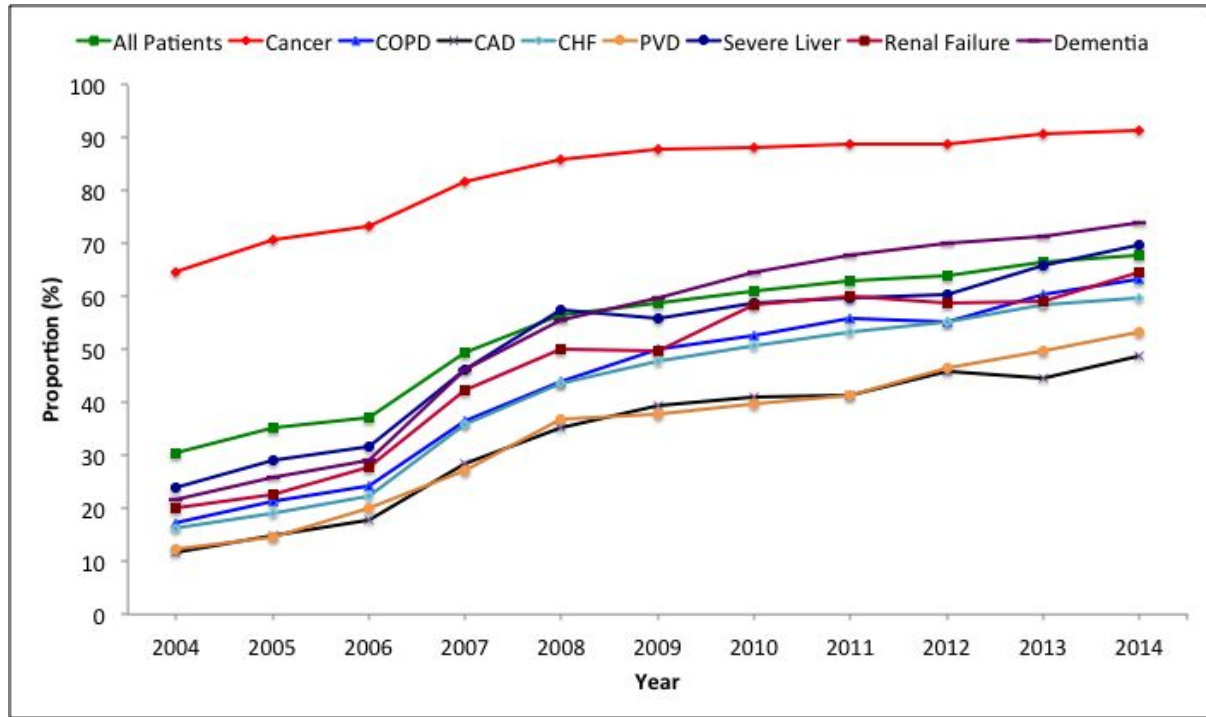


Renal Failure



* Diabetes with end-organ failure not included in trend analysis due to small numbers (≤ 5) in some categories

Supplemental Figure 2: Receipt of palliative care during the terminal hospitalization among decedents dying in hospital: overall and by chronic condition



Confidential

Supplemental Table 1: Healthcare utilization in the last 6-months of life stratified by chronic condition

Decedents	Fiscal Year	Hospital Admission %	ICU Admission %	ED Visits %	Saw ≥ 10 Different Physicians %	Mechanical Ventilation %
Cancer (n=195,560)	All	91.9	13.6	89.7	76.6	8.0
	2004	93.2	13.3	88.0	68.7	7.1
	2005	92.7	13.4	88.1	69.2	7.6
	2006	92.3	13.2	88.8	72.1	7.3
	2007	92.2	13.4	89.2	74.9	7.8
	2008	91.8	13.1	89.4	76.4	7.9
	2009	92.1	13.2	89.5	77.3	8.0
	2010	91.7	13.6	90.1	79.0	8.0
	2011	91.5	13.8	90.2	79.4	8.3
	2012	91.2	14.4	90.8	79.8	8.7
	2013	91.1	14.5	91.4	81.4	8.5
	2014	91.1	13.6	91.2	82.3	8.5
	COPD (n=48,755)	All	83.2	29.9	87.9	59.6
2004		87.3	29.6	89.7	51.2	21.5
2005		85.9	28.9	89.3	51.4	21.0
2006		84.8	29.1	88.9	57.0	23.8
2007		83.7	29.7	88.3	59.6	24.6
2008		82.7	28.4	87.2	58.1	24.5
2009		81.9	29.1	87.3	59.3	23.9
2010		82.3	30.2	87.6	62.2	24.6
2011		82.8	30.3	87.9	62.7	25.5
2012		82.0	29.7	87.6	62.3	24.7
2013		82.3	31.7	87.1	64.0	26.8
2014		81.5	31.1	87.1	63.2	27.5
CAD (n=45,400)		All	75.1	38.2	82.1	58.6
	2004	83.2	42.8	86.5	54.3	25.4
	2005	81.7	40.6	86.0	54.6	27.0
	2006	79.5	39.0	85.2	57.7	26.8
	2007	78.5	38.1	84.6	59.8	27.4
	2008	75.5	36.3	83.1	59.7	25.5
	2009	74.8	38.6	82.3	60.2	27.1
	2010	74.1	36.7	82.1	60.1	27.7
	2011	72.6	36.5	81.4	60.3	26.9
	2012	70.1	35.9	78.5	57.8	26.7
	2013	70.3	39.0	78.6	59.2	29.1
	2014	68.5	38.1	77.1	59.2	29.0

Decedents	Fiscal Year	Hospital admission	ICU admission	ED visits	Saw \geq 10 different physicians	Mechanical ventilation	
		%	%	%	%	%	
CHF (n=110,337)	All	84.8	32.2	88.8	66.3	20.5	
	2004	88.2	34.3	90.5	56.8	18.4	
	2005	86.3	34.0	89.9	57.1	18.6	
	2006	85.4	32.7	89.3	61.2	19.6	
	2007	84.4	32.7	88.4	64.9	19.5	
	2008	83.7	30.7	88.4	64.8	19.1	
	2009	84.5	31.9	88.2	67.4	20.6	
	2010	83.8	30.9	88.0	68.7	21.0	
	2011	84.1	31.9	88.5	70.4	21.3	
	2012	83.8	32.7	88.4	70.1	21.7	
	2013	84.2	31.9	88.8	72.1	22.5	
	2014	84.6	30.9	88.8	72.9	22.3	
	PVD (n=9,701)	All	81.8	39.6	82.5	58.4	31.7
		2004	89.0	43.7	84.8	54.1	30.2
2005		87.0	42.9	85.8	57.0	30.5	
2006		82.0	37.3	82.0	56.6	30.0	
2007		80.3	40.1	81.7	55.1	31.3	
2008		81.4	40.6	82.5	61.9	33.1	
2009		81.0	38.9	81.8	60.1	33.1	
2010		77.6	36.6	81.2	57.4	31.3	
2011		80.4	36.7	82.8	60.2	31.1	
2012		80.0	40.9	82.1	62.2	35.6	
2013		78.3	38.0	79.1	59.6	32.1	
2014		78.7	38.1	82.8	60.9	31.6	
Severe Liver Disease (n=14,643)		All	93.4	41.0	94.5	77.6	30.5
		2004	94.1	34.7	94.2	66.8	25.3
	2005	94.2	38.9	94.0	67.5	27.7	
	2006	94.5	40.1	94.7	73.3	28.9	
	2007	93.2	36.9	93.3	76.0	27.2	
	2008	92.1	37.2	94.1	76.4	27.7	
	2009	91.9	38.9	93.8	76.3	29.8	
	2010	93.8	39.9	95.2	79.2	30.2	
	2011	94.0	42.0	95.8	81.3	33.4	
	2012	92.4	43.5	93.8	80.9	31.9	
	2013	94.0	47.1	95.0	84.4	34.7	
	2014	93.9	47.6	95.6	85.1	35.5	

Decedents	Fiscal Year	Hospital admission	ICU admission	ED visits	Saw ≥ 10 different physicians	Mechanical ventilation
		%	%	%	%	%
Diabetes (with end-organ failure (n=745))	All	72.6	27.7	81.8	66.5	22.4
	2004	100.0	32.1	85.7	67.9	25.0
	2005	76.7	30.0	93.3	53.3	13.3
	2006	76.9	36.9	80.0	63.1	24.6
	2007	74.0	20.6	82.2	63.0	13.7
	2008	71.2	17.8	82.2	76.7	16.4
	2009	73.5	33.8	80.9	67.7	27.9
	2010	64.5	25.8	74.2	59.7	25.8
	2011	71.1	24.1	75.9	63.9	20.5
	2012	71.6	31.1	85.1	66.2	32.4
	2013	69.6	28.3	79.4	67.4	23.9
	2014	70.4	29.6	82.7	72.5	23.5
Renal Failure (n=29,199)	All	85.3	30.3	87.8	72.3	20.3
	2004	91.6	35.6	90.0	72.3	22.4
	2005	90.0	33.4	89.4	72.1	21.3
	2006	88.2	31.4	89.8	73.5	20.5
	2007	87.4	33.2	89.1	74.9	22.3
	2008	86.2	30.4	88.0	75.1	21.6
	2009	80.0	27.7	85.0	70.1	18.9
	2010	80.9	26.7	86.4	69.1	18.8
	2011	81.3	27.3	86.2	72.0	18.2
	2012	80.4	27.3	85.2	69.0	18.5
	2013	82.2	28.2	86.8	72.8	20.3
	2014	81.9	26.9	86.7	71.6	18.1
Dementia (n=86,778)	All	63.4	6.5	70.9	39.4	4.2
	2004	71.9	6.9	77.2	36.0	4.0
	2005	67.4	6.2	74.7	33.5	4.0
	2006	64.0	6.4	72.0	35.4	4.0
	2007	63.9	6.2	71.7	37.9	3.6
	2008	62.3	5.7	69.7	37.7	3.3
	2009	62.3	6.4	69.2	39.3	4.4
	2010	63.8	6.8	71.4	42.3	4.2
	2011	62.5	7.1	70.4	40.6	4.4
	2012	61.7	6.3	69.2	40.3	4.4
	2013	61.9	6.9	69.4	42.3	4.6
	2014	61.2	6.6	69.4	42.4	4.3

COPD- Chronic obstructive pulmonary disease; CAD – Coronary artery disease; CHF- Congestive heart failure; PVD – Peripheral vascular disease; ICU – Intensive Care Unit; ED – Emergency Department

Supplemental Table 2: Health care costs (adjusted to 2014 Canadian dollars) in the last 6-months of life stratified by site of death

	All patients N=962,462	Died in hospital N=433,074	Died out of hospital N=529,388
Cost Categories	Cost (\$)		
In-patient			
Mean (SD)	17,521 (32,456)	28,387 (41,727)	8,631 (17,753)
Median (IQR)	7,824 (0-21,426)	16,284 (7,290-33,216)	0 (0-11,060)
Hospital outpatient clinic			
Mean (SD)	1,294 (2,571)	1,841 (3,161)	847 (1,844)
Median (IQR)	359 (0-1,558)	779 (0-2,279)	0 (0-966)
Same day surgery*			
Mean (SD)	163 (691)	213 (806)	121 (576)
Emergency department			
Mean (SD)	936 (930)	1,291 (922)	646 (831)
Median (IQR)	754 (205-1,351)	1,061 (697-1,660)	412 (0-976)
Drug cost			
Mean (SD)			
Median (IQR)	980 (311-1,939)	896 (298-1,794)	1,058 (325-2,054)
Rehabilitation services*			
Mean (SD)	563 (4,807)	662 (5,122)	482 (4,532)
Complex continuing care*			
Mean (SD)	2,420 (11,575)	843 (6,923)	3,710 (14,166)
Long-term care *			
Mean (SD)	4,215 (8,072)	1,879 (5,577)	6,125 (9,215)
Home care services			
Mean (SD)	2,220 (4,828)	2,083 (4,103)	2,332 (5,346)
Median (IQR)	414 (0-2,334)	616 (0-2,382)	0 (0-2,275)
Physician (fee for service)			
Mean (SD)	3,296 (4,950)	4,556 (5,593)	2,265 (4,075)
Median (IQR)	2,108 (832-4,313)	3,172 (1,707-5,664)	1,233 (485-3,077)
Total cost			
Mean (SD)	36,335 (40,369)	45,621 (49,090)	28,739 (29,379)
Median (IQR)	26,329 (13,873-45,279)	32,291 (18,245-55,308)	22,895 (7,636-36,931)

* Median (IQR) costs are 0 for these health sectors

Appendix: Cost Estimation

Healthcare costs are derived from the perspective of Ontario's Ministry of Health and Long-Term Care. The costing methodology computes costs for services utilized during encounters with the publicly funded healthcare system, with the approach to costing differing based on the type of encounter.¹ Table 1, summarizes the databases used to identify healthcare utilization and the costing approach for each health sector. The databases and costing algorithm used in this study are held and maintained by ICES.

Table 1: Administrative databases to identify healthcare use and methods for cost estimation

Cost sector	Database Source	Description of database	Method of cost estimation
Hospital			
Inpatient acute care	CIHI Discharge Abstract Database (CIHI-DAD)	Demographic, administrative and clinical data on acute care hospital separations in Ontario.	Resource intensity weights (RIW) ² multiplied by cost per weighted case (CPWC)
Emergency room visits	National Ambulatory Care Reporting System (NACRS)	Captures administrative, demographic and clinical data for emergency department and ambulatory care visits in Ontario.	RIW x CPWC
Same day surgery	NACRS CIHI Same Day Surgery (CIHI-SDS)	Contains administrative and patient-level clinical and demographic data for day surgery hospitals in Ontario.	RIW x CPWC
Outpatient clinic visits	NACRS		RIW x CPWC
Physician services			
Fee for service claims and shadow-billed claims	Ontario Health Insurance Plan (OHIP)	Claims data for services provided by eligible providers (includes physicians, nurse practitioners, and laboratories).	Claims-based: billed costs per visit and services provided based on the province's approved rates.
Primary care capitation based models	Client Agency Program Enrolment	Contains information on individuals enrolled in a primary care model in Ontario	Capitation payments: base rate multiplied by age-sex multiplier, with adjustment for relevant premiums
Complex Continuing Care	Continuing Care Reporting System (CCRS)	Captures administrative, demographic, clinical and functional data on individuals receiving continuing care services in designated facilities (hospitals and long-term care homes) in Ontario.	Cost derived from case mix index, number of days in care and resource utilization groups: weighted length of stay (LOS) multiplied by cost per weighted day (CPWD).
Long-term Care	CCRS		Cost estimated from fixed per diem costs based on payment rates set by the province multiplied by LOS.
Rehabilitation	National Rehabilitation Reporting System (NRS)	Contains administrative, demographic and other client-level data from participating adult inpatient rehabilitation facilities and programs across Ontario	Rehabilitation cost weights (RCW) x rehabilitation CPWC

Cost sector	Database Source	Description of database	Method of cost estimation
Mental health care	Ontario mental health reporting system	Captures data on individuals receiving adult mental health services in designated inpatient facilities in Ontario.	Cost derived from case mix index, number of days in care and resource utilization groups: weighted length of stay (LOS) multiplied by cost per weighted day (CPWD).
Home Care	Home Care Database (HCD) Resident Assessment Instrument-Home Care (RAI-HC)	Contains administrative, demographic and other client-level data on provincially funded home care services.	Standard cost per service multiplied by the number of hours (or visits) of service.
Prescription drugs	Ontario Drug Benefit	Captures claims for prescriptions dispensed to Ontarians eligible for the Ontario Drug Benefit program (primarily individuals ≥ 65 years)	Total costs paid by the provincial health plan for eligible individuals.
Non-physician	OHIP		Billed costs per visit and services provided by eligible non-physician providers.
Laboratory	OHIP		Costs based on established diagnostic tests fees (technical and professional fees)
Assistive device	Assistive Devices Program (ADP)		Amount paid by the province to individuals for high-cost medical equipment.

*CIHI - Canadian Institute for Health Information

References

1. Wodchis WP, Bushmenev K, Nikitovic M, McKillop I. Guidelines on Person-Level Costing Using Administrative Databases in Ontario [Internet]. 2013: http://www.hsprn.ca/uploads/files/Guidelines_on_PersonLevel_Costing_May_2013.pdf Last Accessed: May 23, 2018
2. Canadian Institute for Health Information. Case Mix: <https://www.cihi.ca/en/submit-data-and-view-standards/methodologies-and-decision-support-tools/case-mix> Last Accessed: November 2, 2018