

Which physicians are providing care in outpatient settings in the last year of life? A population-based descriptive study

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ABSTRACT

Background: Patient experience and healthcare utilization end-of-life outcomes vary for different dying trajectories and physician care provided in outpatient settings can influence these outcomes. This study describes the volume and mix of outpatient physician care over the last year of life among decedents in Ontario, stratified by type of end-of-life trajectory.

Methods: We conducted a retrospective cohort study of people 18 years of age and older who died in Ontario between 2013 and 2016. Decedents were grouped into mutually exclusive end-of-life trajectories (terminal illness, organ failure, frailty, sudden death and other). Outpatient physician encounters (i.e. a billed visit with a physician outside hospital) were examined across trajectories and included the volume of encounters by setting and by specialty in the last 12 and 3 months of life.

Results: Decedents (n=374,388) were on average 77.1 years of age (interquartile range 68-88) and 49.8% were female. In the last 12 months of life, decedents had, on average, 16.2 outpatient physician encounters (standard deviation [SD] 15.3) across an average of 5.8 (SD 4.6) unique physicians. The mean number of encounters ranged from 9.9 (SD 11.3) in the frailty trajectory to 26.2 (SD 17.0) in the terminal illness trajectory across 3.8 (SD 3.7) to 8.7 (SD 4.7) unique physicians, respectively. In the last 3 months of life, the mean number of physician encounters was 6.1 (SD 6.9) across an average of 3.7 (SD 2.6) unique physicians.

Interpretation: Many physicians are involved in outpatient care in the last year of life and the volume and mix varies considerably by end-of-life trajectory. These results have implications for continuity of care and shared care near the end of life.

Keywords: Palliative care, Family Practice, Terminal care, Retrospective Studies, Ambulatory Care

BACKGROUND

Our population is aging, and increasing numbers of people will require health care for at least one progressive life-limiting illness, often for several years until the end of life.¹⁻³ While approximately half of people in Canada die in a hospital and many experience unplanned admissions in the last year of life, the majority of time is spent in the community.

Formal palliative care is typically initiated late in the illness trajectory of patients,⁴⁻⁷ even though for many patients, there is evidence of recognizable functional decline and poor prognosis at least a year before death.^{8,9} Patients dying of organ failure or dementia are less likely to receive palliative care services or they receive them closer to end-of-life, compared to those with cancer.^{7,10} Physicians working in the community provide care near the end of life either as specialists in palliative care or through a generalist palliative approach.^{5,11} To achieve sustainable and equitable access to end of life care, it is widely accepted that palliative care will need to be integrated into the work of many types of providers (e.g. family physicians, oncologists).¹¹⁻¹⁴

Medical specialists are often thought to provide care for the specific illness(es) that may be contributing to patients' decline (e.g., oncologist provides care for cancer or cardiologists for heart disease that may be life limiting), while family physicians may play the 'quarterback' role in organizing care between specialists.¹⁵ Medical specialists may step back as patients move closer to death and are transitioned to palliative and end-of-life care provided by family physicians or palliative care physicians. With the likelihood of multiple physician involvement near the end of life, coordinated, continuous care is possibly disrupted.^{16,17} Patients' needs for healthcare escalate in the last three months of life leading to a greater number of encounters with

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3 the system.^{6,18,19} Given the complex needs associated with many late stage illnesses, physician
4 care near the end of life is likely to be provided by a mix of different specialties who may not
5 necessarily communicate and care may not encompass a palliative approach.²⁰ Health care
6 provided by various physicians, with varying intents, may be experienced as burdensome to
7 individuals as they decline in health and function from life-limiting illnesses.^{21,22}
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16 We do not have a clear picture of outpatient physician care across different patient
17 populations in the last year of life, a time when end-of-life healthcare needs increase for most
18 patients. To address this knowledge gap, the objective of this study was to describe the volume
19 and mix of outpatient physician care over the last 12 and 3 months of life among patients dying
20 of different end-of-life trajectories, including with cancer, organ failure, frailty, and sudden
21 death.
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30 **METHODS**

31 **Study design and data sources**

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34 We conducted a retrospective study using linked population-based health administrative
35 databases in Ontario, Canada, held at ICES. ICES is an independent, non-profit research institute
36 whose legal status under Ontario's health information privacy law allows it to collect and
37 analyze health care and demographic data, without, consent for health system evaluation and
38 improvement. The holdings include a comprehensive set of healthcare sectors in Ontario, which
39 has a population of over 14 million residents with nearly universal health care coverage. These
40 datasets were linked using unique encoded identifiers and analyzed at ICES. The use of data in
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3 this project was authorized under section 45 of Ontario's Personal Health Information Protection
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5 Act, which does not require review by a Research Ethics Board.
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8 9 **Study Cohort**

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12 We created a cohort comprised of all adult decedents (18+ years) who died between
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14 January 1, 2013 and December 31, 2016. We excluded decedents who were older than 105 years
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16 at death (in case of administrative error), or were ineligible for insured health services through
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18 the Ontario Health Insurance Program (OHIP) at any point in the last year of life, who had an
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20 address outside Ontario at time of death, who had no healthcare encounters in the five years prior
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22 to death, or had no cause of death listed. Deaths were captured through the Registered Persons
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24 Database (RPDB) and cause of death through the Ontario Registrar General – Deaths (ORGD)
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26 database (see Supplementary File 1 for description of databases).
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32 We categorised decedents by the major trajectories of functional decline at end of life,
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34 defined by main cause of death as per prior research,^{1,10,23} a method that has been validated in
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36 Canada using the International Classification of Diseases 10th Revision codes from the death
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38 certificate.^{2,24} Decedents were classified into these trajectories: terminal illness (e.g., cancer),
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40 organ failure (e.g., chronic heart failure), frailty (e.g., Alzheimer's disease), sudden death (e.g.,
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42 accident) and other.
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47 **Decedent Characteristics**

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50 Demographic characteristics were determined using information in databases pertaining
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52 to the last year of life. Age at death and sex were obtained from the RPDB. Neighborhood level
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3 income quintile and rurality were estimated using the Postal Code Conversion File Plus (PCCF+)
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5 and patients' postal code from the RPDB.
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9 A history of any comorbidities was determined looking back from 2008 up to death via
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11 previously developed algorithms that use diagnosis codes and medication data to assign
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13 conditions.²⁵⁻³⁴
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16 17 **Outcomes of Interest** 18 19

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21 This study focused on physician encounters in the outpatient setting (as opposed to
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23 during a hospitalization) because we were interested in patterns of care in the community. These
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25 encounters were identified using physician claims to the Ontario Health Insurance Plan (OHIP)
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27 database. Multiple billings by the same physician on the same visit date were considered one
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29 encounter. Management fee codes, which are codes used for care over a period of time were not
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31 included, because the billing does not correspond one to one with an encounter.
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35 We categorized physician specialty and identified unique physicians through OHIP
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37 billings. Billing codes are specific to each specialty and billings also include a unique identifier
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39 for the submitting physician. In Ontario, any physician can bill the palliative care fee codes, and
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41 in Canada palliative care is not a designated specialty. Therefore, to determine which physicians
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43 had a focus of practice in palliative care, we used an existing algorithm that was validated in
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45 family physicians which considered physicians of any specialty who billed 10% or more of
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47 encounters using palliative care billing codes. The algorithm was developed based on three years
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49 of data (2008-2011) to all physicians.³⁵ We applied the same billing codes over the period of
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51 January 1, 2012 to December 31st, 2016 to the physicians providing care to decedents in the
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3 cohort. The physicians identified with this billing pattern (10% or more) in our data comprised
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5 18.5% of physicians, and were grouped for analyses as palliative care focused physicians.
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9 Over the last 12 months and last 3 months of life, we examined the number and location
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11 of physician encounters (office, home, telephone), number of unique physician specialties
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13 involved per patient and specialty of physician, number of unique physicians involved per
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15 patient, and the five most frequent types of specialties involved. These patterns were described
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17 across the five mutually exclusive illness trajectories. The top causes of death included cancers
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19 in the terminal illness trajectory, chronic respiratory and cardiovascular related causes in the
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21 organ failure trajectory, cardiovascular, infection and dementia-related causes in the frailty
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23 trajectory, accident and injury-related causes for the sudden death trajectory and infections, falls
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25 and ill-defined unspecified causes in the other trajectory. Additional causes of death in each
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27 trajectory can be found in Supplementary File 2. The decision to look at different time horizons
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29 recognizes that palliative needs are more apparent and care patterns may change closer to end of
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31 life.
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36 37 **Analyses**

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41 Descriptive results are presented as proportions for categorical variables, and as mean
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43 and standard deviation (SD), or median (with interquartile range for variables with skewed
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45 distribution) for continuous variables. Results are presented by end-of-life trajectory. All
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47 analyses were completed using SAS Enterprise Guide v. 7.15.
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51 **RESULTS**

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3 From January 1, 2013 to December 31, 2016, there were 374,388 deaths among
4 individuals aged 18 years and older. The average age of decedents was 77.1 years (SD 14.8),
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6 49.8% were female, 13.9% resided in rural regions (Table 1). The distribution of illness
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8 trajectories was 28.5% terminal illness, 33.8% organ failure, 27.0% frailty, 4.7% sudden death
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10 and 6.0% other causes.
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16 In the last 12 months of life, 92.4% of decedents had at least one outpatient physician
17 encounter, 78.5% had at least one family physician encounter and 59.9% at least one palliative
18 care physician encounter. In the last 3 months of life, these proportions were 83.8%, 57.5% and
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20 50.3%, respectively. The mean number of physician encounters in outpatient settings was 16.2
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22 (SD 15.3) over the last 12 months of life, involving a mean of 3.6 (SD 2.4) unique specialties and
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24 5.8 (SD 4.6) unique physicians (Table 2). In the last 12 months and three months of life,
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26 decedents in the terminal illness trajectory experienced the highest mean number of outpatient
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28 physician encounters and also had the highest mean number of unique specialties and unique
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30 physicians, while decedents in the frailty trajectory had the least. In the last 12 months of life, the
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32 mean number of palliative care physician encounters was also highest for decedents in the
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34 terminal illness trajectory (mean 10.6, SD 12.7), compared to all other trajectories where there
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36 were fewer than three encounters on average. The numbers of encounters, unique specialties and
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38 unique physicians for decedents in the organ failure and the 'other' trajectories fell between the
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40 terminal illness trajectory and the frailty trajectory. For the sudden death trajectory, the mean
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42 number of encounters in the last 12 months of life was 11.8 (SD 14.4), however this trajectory
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44 had the lowest number of encounters with a palliative care physician (mean 1.4, SD 4.0). The
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46 findings that the highest mean number of encounters were provided for the terminal illness
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48 trajectory and the lowest mean number for the frailty trajectory persisted in the last three months
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3 of life. In the last 12 months and last three months of life, family physicians provided a higher
4 mean number of encounters than palliative care physicians for all trajectories except terminal
5 illness, where palliative care physicians provided a higher mean number of encounters.
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11 Figure 1 shows the five physician specialties with the highest number of outpatient
12 encounters across each trajectory in the last 12 and three months of life. Family physicians and
13 palliative care physicians were the two specialties with the highest encounter volumes for all
14 trajectories in both time periods. Family physicians provided the highest volume of encounters
15 (>30%) for all trajectories in the last 12 and three months of life, except for individuals dying
16 with a terminal illness, where palliative care physicians provided the highest volume (40.6% in
17 last 12 months and 56.3% in last three months). Therapeutic radiology (predominantly radiation
18 oncology), medical oncology and internal medicine comprised the remaining top five specialties
19 for the terminal illness trajectory over the last 12 and three months. Internal medicine,
20 psychiatry, cardiology, ophthalmology, respirology, and orthopedic surgery comprised the
21 remaining top five specialties for the other trajectories.
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38 **DISCUSSION**

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41 In this retrospective study of Ontarians in the last year of life, we found that decedents
42 had numerous outpatient physician encounters with multiple physicians. Decedents in the
43 terminal illness trajectory experienced the highest number of outpatient physician encounters
44 overall and the highest number of different physicians providing care. Overall, family physicians
45 and palliative care physicians provided approximately three-quarters of the outpatient encounters
46 in the last 12 and three months of life. Palliative care physicians provided the highest volume of
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3 outpatient encounters only for the decedents in the terminal illness trajectory and family
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5 physicians provided the highest volume of care for all other trajectories.
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9 The finding that palliative care is more likely to be provided to patients with cancer
10 versus other end-of-life trajectories is not new.^{7,36,37} The variability in the rapidity and
11 consistency of decline in non-cancer compared to cancer end-of-life trajectories suggest that
12 models of care need to be adaptable to accommodate different trajectories.³⁸ Our results for non-
13 cancer trajectories, where family physicians provided the highest volume of encounters may
14 reflect the fluctuating declines in health for organ diseases and frailty that limit accurate
15 prognostication of the timing of end of life and the less identifiable start of the terminal phase
16 compared to cancer.^{9,23,39} In addition, many palliative care clinics in Ontario provide care only to
17 cancer patients because they are funded by cancer centres; therefore, increasing the onus of
18 providing end-of-life care onto family physicians for non-cancer patients.
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33 Decedents in the organ failure trajectory had fewer outpatient physician encounters than
34 the terminal illness trajectory, but more encounters than the frailty trajectory. This finding may
35 reflect an ongoing involvement of specialists focused on disease management, for example in
36 cardiovascular and respiratory conditions. A previous study of the same illness trajectories found
37 that initiation of palliative care was less frequent and later for decedents in the organ failure and
38 frailty trajectories compared to the terminal illness trajectory.⁷ It was interesting that the lowest
39 mean number of palliative care physician encounters occurred for decedents in the sudden death
40 trajectory, however, 33% of people in sudden death had at least one palliative care physician
41 encounter. It may be that some decedents who were receiving palliative care for a short time died
42 of a sudden cause or an unexpected complication.
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3 The average number of outpatient specialties involved in care in the last year of life was
4 nearly four, with an average of six different physicians involved. With multiple physicians
5 involved in care, it is possible that continuity of care in the relational sense, could be disrupted.
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7 Continuity of care with the same physician has been shown to be beneficial for patients near the
8 end of life and is associated with reduced likelihood of intensive care use⁴⁰, emergency
9 department use and hospital death.⁴¹⁻⁴⁴ Our findings have implications for operationalizing
10 Canada's national palliative care framework that has called for models of care led by primary
11 care providers in a shared-care approach.^{45,46}
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23 The study has some limitations. The health administrative data does not directly allow for
24 assessment of the appropriateness or quality of care associated with outpatient physician
25 encounters in the last year of life and whether patients' needs are met. This study is based on one
26 province of Canada (representing approximately 40% of the population) and health care systems
27 are organized provincially. Therefore, the results may not be entirely generalizable to other
28 jurisdictions.
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38 The proportion of patients in our study who received care from a palliative care focused
39 physician was higher than in previous studies that used the same method to identify such
40 physicians in administrative data. The study that validated the identification method used all
41 physicians rather than a sub-set providing care to people in the last year of life as we did.
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48 In the last year of life, patients have many encounters with various physicians in
49 outpatient settings and the volume and mix varies by end-of-life trajectory. For people with non-
50 cancer trajectories, family physicians provide the majority of outpatient physician care and for
51 people dying of cancer, palliative care physicians provide most of the care. These results have
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implications for continuity of care and shared care near the end of life. To design systems that will meet population needs for care at the end of life, further research is needed on the best models to optimize the complementary roles of different physicians while maintaining adequate continuity.

Confidential

DECLARATIONS

Authorship

MH, SI, PT, AH conceived the study. All authors designed the study and interpreted the results. MH wrote the manuscript. All authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Research ethics

The use of data in this project was authorized under section 45 of Ontario's *Personal Health Information Protection Act*, which does not require review by a Research Ethics Board.

Data management and sharing

The data set from this study is held securely in coded form at ICES. While data sharing agreements prohibit ICES from making the data set publicly available, access may be granted to those who meet pre-specified criteria for confidential access, available at www.ices.on.ca/DAS. The full data set creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification.

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Table 1: Profile of decedents aged 18 years or older who died between January 1, 2013 and December 31, 2016, in Ontario, Canada.

Variable	End-of-life Trajectory					Total Cohort (n= 374,388)
	Terminal Illness (n= 106,866)	Organ Failure (n= 126,534)	Frailty (n= 100,917)	Sudden Death (n= 17,761)	Other (n= 22,310)	
Age at death in years, n (%)						
18-44	2,477(2.3%)	2,745 (2.2%)	764 (0.8%)	5,025 (28.3%)	886 (4.0%)	11,897 (3.2%)
45-54	6,716 (6.3%)	5,338 (4.2%)	2,461 (2.4%)	2,905 (16.4%)	966 (4.3%)	18,386 (4.9%)
55-64	17,040 (15.9%)	12,430 (9.8%)	6,652 (6.6%)	2,729 (15.4%)	1,776 (8.0%)	40,627 (10.9%)
65-74	26,874 (25.1%)	20,350 (16.1%)	12,165 (12.1%)	1,967 (11.1%)	2,751 (12.3%)	64,107 (17.1%)
75-84	30,860 (28.9%)	34,532 (27.3%)	25,731 (25.5%)	2,231 (12.6%)	5,632 (25.2%)	98,986 (26.4%)
85-94	20,748 (19.4%)	42,650 (33.7%)	42,181 (41.8%)	2,434 (13.7%)	8,275 (37.1%)	116,288 (31.1%)
95+	2,151 (2.0%)	8,489 (6.7%)	10,963 (10.9%)	470 (2.6%)	2,024 (9.1%)	24,097 (6.4%)
Mean (SD)	73.3 (13.1)	78.4 (13.8)	82.3 (12.1)	58.7 (21.8)	79.1 (15.4)	77.1 (14.8)
Median (IQR)	75 (65-83)	82 (70-89)	85 (76-91)	58 (42-78)	83 (72-90)	80 (68-88)
Female, n (%)	51,414 (48.1%)	64,318 (50.8%)	52,611 (52.1%)	6,371 (35.9%)	11,809 (52.9%)	186,523 (49.8%)
Rural residence, n (%)	15,143 (14.2%)	18,586 (14.7%)	13,251 (13.1%)	2,518 (14.2%)	2,564 (11.5%)	52,062 (13.9%)
Neighborhood Income Quintile, n (%)						
1 (lowest)	24,494 (22.9%)	33,525 (26.5%)	26,608 (26.4%)	5,153 (29.0%)	5,834 (26.2%)	95,614 (25.5%)
2	23,230 (21.7%)	27,880 (22.0%)	21,948 (21.8%)	3,777 (21.3%)	4,896 (22.0%)	81,731 (21.8%)
3	21,009 (19.7%)	23,889 (18.9%)	18,925 (18.8%)	3,215 (18.1%)	4,252 (19.1%)	71,290 (19.0%)
4	19,128 (17.9%)	21,444 (17.0%)	17,024 (16.9%)	2,858 (16.1%)	3,719 (16.7%)	64,173 (17.1%)
5 (highest)	18,750 (17.6%)	19,341 (15.3%)	16,024 (15.9%)	2,678 (15.1%)	3,536 (15.9%)	60,329 (16.1%)
Illness History, n (%)						
Cancer	98,681 (92.3%)	28,121 (22.2%)	16,565 (16.4%)	2,371 (13.4%)	5,285 (23.7%)	151,023 (40.3%)
CHF	20,809 (19.5%)	56,184 (44.4%)	39,093 (38.7%)	2,538 (14.3%)	8,196 (36.7%)	126,820 (33.9%)
COPD	22,532 (21.1%)	40,380 (31.9%)	23,087 (22.9%)	2,212 (12.5%)	5,304 (23.8%)	93,515 (25.0%)
Renal Disease	23,488 (22.0%)	41,654 (32.9%)	26,817 (26.6%)	2,401 (13.5%)	6,922 (31.0%)	101,282 (27.1%)

Table 2: Outpatient physician encounters in last 12 months and last 3 months of life among decedents who died in Ontario, Canada from 2013 to 2016, by end-of-life trajectory

Time Frame	Outcome of Interest	End-of-Life Trajectory										Total Cohort (n= 374,388)		
		Terminal Illness (n= 106,866)		Organ Failure (n= 126,534)		Frailty (n= 100,917)		Sudden Death (n= 17,761)		Other (n= 22,310)				
		Mean (SD)	N (%), any encounters	Mean (SD)	N (%), any encounters	Mean (SD)	N (%), any encounters	Mean (SD)	N (%), any encounters	Mean (SD)	N (%), any encounters	Mean (SD)	Median (IQR)	N (%), any encounters
Last 12 months of life	No. encounters with all physicians	26.2 (17.0)	105,650 (98.9%)	13.7 (12.9)	117,596 (92.9%)	9.9 (11.3)	86,031 (85.3%)	11.8 (14.4)	15,823 (89.1%)	13.5 (12.8)	20,776 (93.1%)	16.2 (15.3)	12 (4, 24)	345,876 (92.4%)
	No. encounters with a family physician	6.7 (6.6)	93,655 (87.6%)	5.8 (7.3)	99,226 (78.4%)	4.5 (6.5)	69,893 (69.3%)	6.5 (11.1)	13,734 (77.3%)	5.6 (7.3)	17,260 (77.4%)	5.7 (7.2)	4 (1, 8)	293,768 (78.5%)
	No. encounters with a palliative care specialist	10.6 (12.7)	92,744 (86.8%)	2.9 (6.0)	68,980 (54.5%)	2.1 (5.1)	44,268 (43.9%)	1.4 (4.0)	5,885 (33.1%)	2.9 (5.8)	12,426 (55.7%)	4.8 (9.0)	1 (0, 6)	224,303 (59.9%)
	No. unique specialties involved	4.9 (2.3)	-	3.4 (2.3)	-	2.6 (2.2)	-	2.7 (2.1)	-	3.5 (2.4)	-	3.6 (2.4)	3 (2, 5)	-
	No. unique physicians involved	8.7 (4.7)	-	5.2 (4.2)	-	3.8 (3.7)	-	4.1 (3.9)	-	5.3 (4.3)	-	5.8 (4.6)	5 (2, 8)	-
Last 3 months of life	No. encounters with all physicians	10.9 (8.6)	102,852 (96.2%)	4.8 (5.2)	105,937 (83.7%)	3.4 (4.3)	73,025 (72.4%)	3.7 (4.7)	13,116 (73.9%)	4.9 (5.0)	18,861 (84.5%)	6.1 (6.9)	4 (1, 9)	313,791 (83.8%)
	No. encounters with a family physician	2.1 (2.9)	69,114 (64.7%)	1.6 (2.3)	73,546 (58.1%)	1.3 (2.1)	50,439 (50.0%)	1.7 (3.1)	9,497 (53.5%)	1.5 (2.3)	12,531 (56.2%)	1.7 (2.5)	1 (0, 2)	215,127 (57.5%)
	No. encounters with a palliative care specialist	6.1 (7.8)	85,647 (80.1%)	1.6 (3.5)	54,794 (43.3%)	1.1 (2.7)	33,450 (33.2%)	0.7 (2.2)	4,225 (23.8%)	1.5 (3.1)	10,179 (45.6%)	2.7 (5.4)	1 (0, 3)	188,295 (50.3%)
	No. unique specialties involved	3.1 (1.6)	-	2.4 (1.5)	-	2.1 (1.3)	-	2.1 (1.4)	-	2.6 (1.5)	-	2.6 (1.5)	2 (1, 3)	-
	No. unique physicians involved	5.0 (2.9)	-	3.3 (2.4)	-	2.8 (2.1)	-	2.8 (2.2)	-	3.5 (2.5)	-	3.7 (2.6)	3 (1, 5)	-

Figure 1a: Top 5 physician specialties by volume of outpatient physician encounters and average number of encounters per specialty in last 12 months, among decedents who died in Ontario, Canada from 2013 to 2016, per end-of-life trajectory. Page 20 of 26

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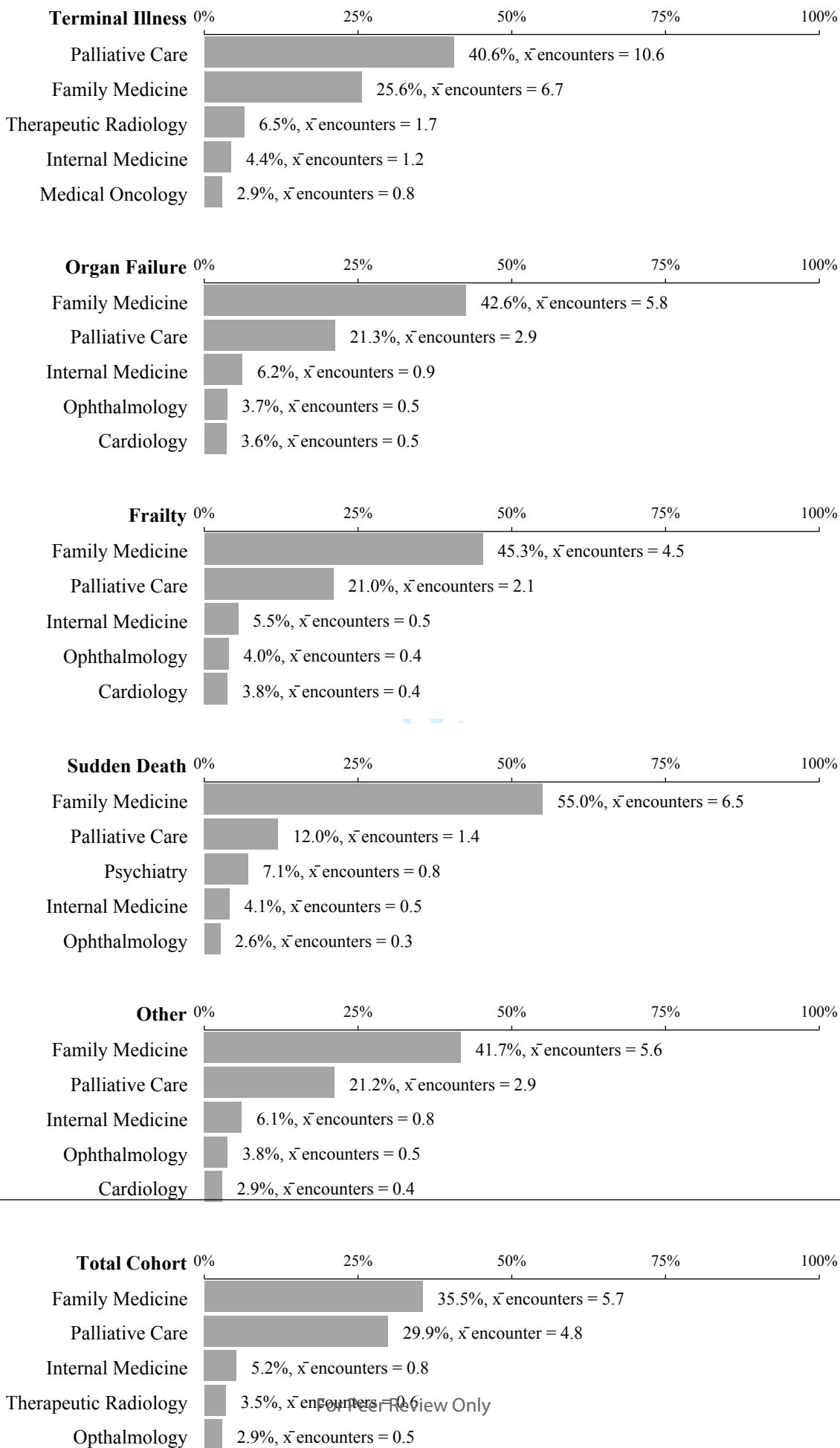
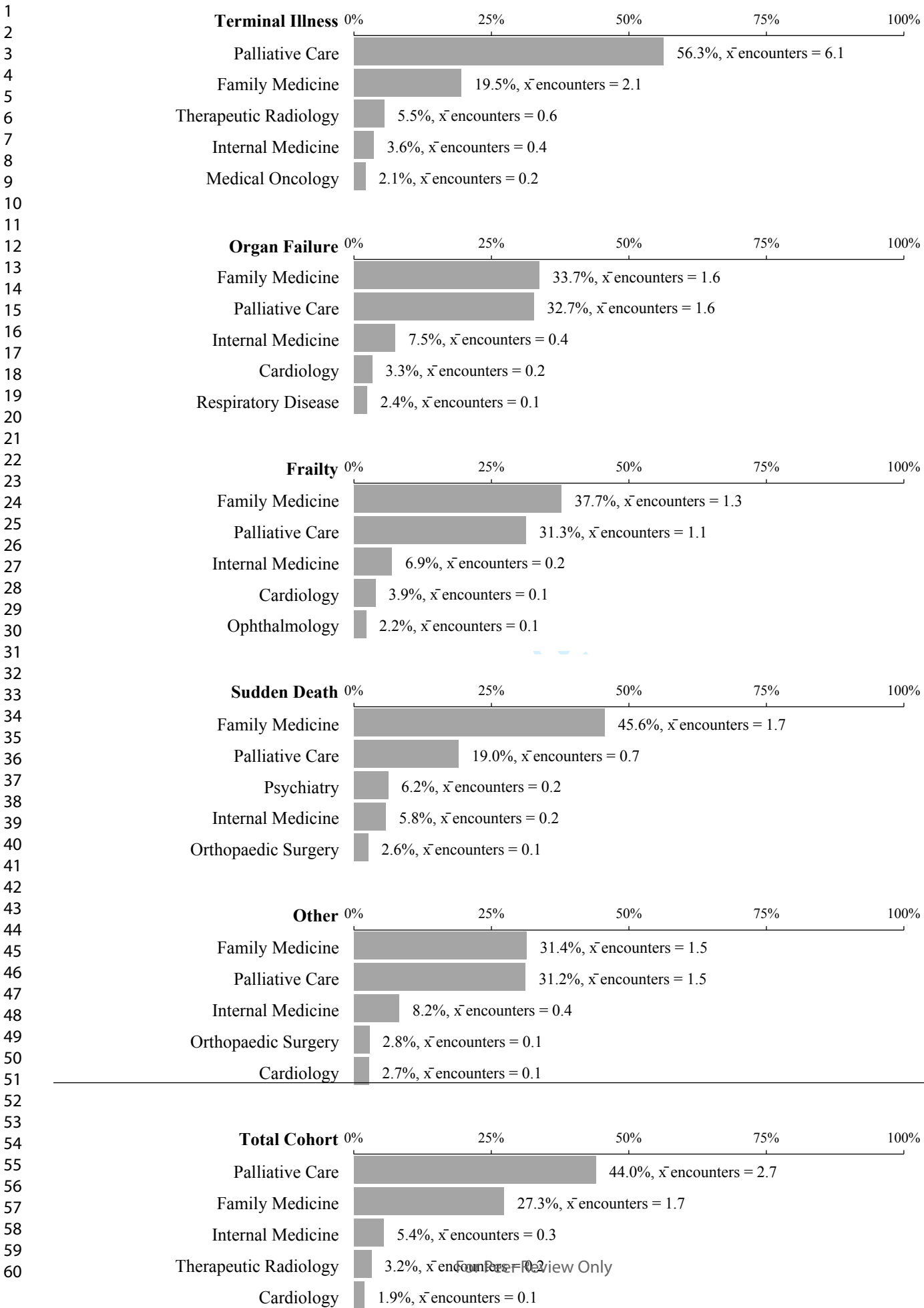


Figure 1b: Top 5 physician specialties by volume of outpatient physician encounters and average number of encounters per specialty in last 3 months, among decedents who died in Ontario, Canada from 2013 to 2016, per end-of-life trajectory.



Supplementary File 1: Description of health administrative databases held at ICES used in study

NAME OF DATABASE	DATABASE CONTENT
ICES-derived cohorts	Validated cohorts of individuals with specific diseases and conditions. These include: Ontario Asthma Dataset (ASTHMA); Congestive Heart Failure (CHF) database; Chronic Obstructive Pulmonary Disease (COPD) database; Ontario Dementia Dataset (DEMENTIA); Ontario Hypertension Dataset (HYPER); Ontario Crohn's and Colitis Cohort Dataset (OCCC); Ontario Diabetes Dataset (ODD); Ontario Myocardial Infarction Dataset (OMID); and the Ontario Rheumatoid Arthritis Dataset (ORAD).
Ontario Health Insurance Plan database (OHIP)	These data record all claims by Ontario physicians for inpatient and ambulatory visits, consultations and procedures. The data also include claims from optometrists for publicly-funded reimbursement and from laboratories for all diagnostic tests performed.
Ontario Registered Persons Database (RPDB)	Demographic, place of residence and vital status information for all persons eligible to receive insured health services in the province, including date of birth, sex, home address.
Ontario Registrar General – Deaths (ORGD) database	This database contains information (demographic, place of death, cause of death) for all decedents in Ontario.
Home Care Database (HCD)	This dataset contains clinical information for home care recipients. Information includes assessments, program admission dates, and service records.
Ontario Drug Benefit Claims (ODB)	This database contains information (recipients, payments, claims, practitioners) for the Ontario Drug Benefit Program.
Discharge Abstract Database (DAD)	This data captures patient-level information (administrative, clinical, and demographic) on hospital discharges. Discharges include deaths, sign-outs, and transfers to other healthcare settings.

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Supplementary File 2: Top 15 causes of death, per end-of-life trajectory

		End-of-life Trajectory									
		Terminal Illness		Organ Failure		Frailty		Sudden Death		Other	
	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	
1	C349, Malignant neoplasm of bronchus and lung (C34)*	20,262 (19.0%)	J449, Chronic obstructive pulmonary disease, unspecified	10,578 (8.3%)	I251, Atherosclerotic heart disease	25,425 (25.2%)	R97, Abnormal tumour markers	2,045 (11.5%)	A419, Sepsis, unspecified	3,510 (15.7%)	
2	C799, Secondary malignant neoplasm, unspecified site	18,098 (16.9%)	I10, Essential (primary) hypertension	9,486 (7.5%)	F03, Unspecified dementia	19,971 (19.8%)	W76, Other accidental hanging and strangulation	1,710 (9.6%)	W18, Other fall on same level	2,453 (11.0%)	
3	C800, Malignant neoplasm, primary site unknown, so stated	7,164 (6.7%)	I6409, Stroke, not specified as Haemorrhage or infarction (I64)*	8,352 (6.6%)	J189, Pneumonia, unspecified	15,546 (15.4%)	X42, Accidental poisoning by and exposure to narcotics and psychodysleptics [hallucinogens], not elsewhere classified	1,231 (6.9%)	W19, Unspecified fall	2,362 (10.6%)	
4	C61, Malignant neoplasm of prostate	4,653 (4.4%)	I5009, Heart failure (I50)*	7,888 (6.2%)	I2199, Acute myocardial infarction (I21)*	8,576 (8.5%)	X590, Exposure to unspecified factor causing fracture	1,095 (6.2%)	R53, Malaise and fatigue	1,161 (5.2%)	
5	C259, Malignant neoplasm pancreas part unspecified	4,255 (4.0%)	I489, Atrial fibrillation and flutter (I48)*	4,920 (3.9%)	G309, Alzheimer's disease, unspecified	3,909 (3.9%)	W80, Inhalation and ingestion of other objects causing obstruction of respiratory tract	1,011 (5.7%)	R999, Other ill-defined and unspecified causes of mortality (R99)*	1,107 (5.0%)	

Terminal Illness		Organ Failure		Frailty		Sudden Death		Other		
ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	
6	C189, Malignant neoplasm colon, unspecified	3,513 (3.3%)	E149, Unspecified diabetes mellitus without (mention of) complication	4,232 (3.3%)	I259, Chronic ischaemic heart disease, unspecified	3239 (3.2)	X41, Accidental poisoning by and exposure to antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs, not elsewhere classified	704 (4.0%)	R688, Other specified general symptoms and signs	789 (3.5%)
7	C509, Malignant neoplasm of breast (C50)*	3,132 (2.9%)	N390, Urinary tract infection, site not specified	3,657 (2.9%)	J690, Pneumonitis due to food and vomit	3230 (3.2)	X45, Accidental poisoning by and exposure to alcohol	677 (3.8%)	W10, Fall on and from stairs and steps	640 (2.9%)
8	N189, Chronic kidney disease, unspecified	2,647 (2.5%)	I709, Generalized and unspecified atherosclerosis	3,177 (2.5%)	G301, Alzheimer's disease with late onset	2494 (2.5)	X44, Accidental poisoning by and exposure to other and unspecified drugs, medicaments and biological substances	594 (3.3%)	R13, Dysphagia	579 (2.6%)
9	C859, Non-Hodgkin's lymphoma, unspecified type	1,838 (1.7%)	J841, Other interstitial pulmonary diseases with fibrosis	2,568 (2.0%)	G2009, Parkinson's disease (G20)*	2302 (2.3)	X599, Exposure to unspecified factor causing other and unspecified injury	492 (2.8%)	W01, Fall on same level from slipping, tripping and stumbling	522 (2.3%)
10	C900, Multiple myeloma	1,789 (1.7%)	N19, Unspecified kidney failure	2,466 (2.0%)	R54, Senility	2139 (2.1)	V892, Person injured in unspecified	417 (2.3%)	F329, Depressive	514 (2.3%)

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Terminal Illness		Organ Failure		End-of-life Trajectory		Sudden Death		Other		
				Frailty						
ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	
								traffic motor-vehicle accident	episode, unspecified	
11	C679, Malignant neoplasm of bladder, unspecified	1,749 (1.6%)	F179, Mental and behavioural disorders due to use of tobacco, unspecified mental and behavioural disorder	2,355 (1.9%)	I255, Ischaemic cardiomyopathy	1072 (1.1)	W34, Accidental discharge and malfunction from other and unspecified firearms and guns	404 (2.3%)	W06, Fall involving bed	369 (1.7%)
12	C159, Malignant lesion oesophagus unspecified	1,744 (1.6%)	I469, Cardiac arrest, unspecified	2,191 (1.7%)	A047, Enterocolitis due to Clostridium difficile	937 (0.9)	W79, Inhalation and ingestion of food causing obstruction of respiratory tract	246 (1.4%)	R568, Other and unspecified convulsions	358 (1.6%)
13	C439, Malignant melanoma of skin, unspecified	1,601 (1.5%)	E119, Type 2 diabetes mellitus without (mention of) complications	2,111 (1.7%)	F019, Vascular dementia, unspecified	833 (0.8)	X80, Intentional self-harm by jumping from a high place	244 (1.4%)	R64, Cachexia	347 (1.6%)
14	C787, Secondary malignant neoplasm of liver and intrahepatic bile duct	1,594 (1.5%)	K746, Other and unspecified cirrhosis of liver	2,061 (1.6%)	I6949, Sequelae of cerebrovascular disease (I69)*	702 (0.7)	X47, Accidental poisoning by and exposure to other gases and vapours	231 (1.3%)	R092, Respiratory arrest	323 (1.4%)
15	C169, Malignant neoplasm stomach unspecified	1,464 (1.4%)	K922, Gastrointestinal haemorrhage, unspecified	1,998 (1.6%)	E86, Volume depletion	689 (0.7)	V877, Person injured in collision between other	218 (1.2%)	F059, Delirium, unspecified	244 (1.1%)

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Terminal Illness		Organ Failure		<u>End-of-life Trajectory</u>		Sudden Death		Other	
ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)	ICD-10 Code, Description	Frequency (%)

specified motor vehicle (traffic)

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