

# The Delivery of Palliative and End-of-Life Care in Ontario

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## Abstract

Healthcare use in the year prior to death represents a large portion of healthcare spending by older adults. While Canada is considered to have advanced integration of palliative care services within our healthcare system, much of this care is still delivered in hospitals and with varying levels of access according to cause of death trajectory and geography. Results presented in a series of studies from the Institute for Clinical Evaluative Sciences (ICES) unveil gaps in current palliative care delivery and offer directions for future research and policy development.

## The Issue

Utilization of health services in the last year of life represents a large portion of total healthcare spending by older adults (Hoover et al. 2002; Madsen et al. 2002; Menec et al. 2004). In Ontario, Canada, healthcare expenses in the year prior to death – incurred by just 0.7% of the population – accounted for nearly 10% of the province's healthcare budget (Tanuseputro et al. 2015). The high expenditure on healthcare prior to death is driven by the cost of care in hospitals. Dying in hospitals, however, does not align with the wishes of most terminally ill patients, who instead prefer to spend their end-of-life period in the community and their own homes (Gomes et al. 2013).

While Canada is considered to have advanced palliative care services at the health-system level (Connor and Bermedo 2014), much of this care is still being delivered in hospitals. In fact, among seven developed countries, Canada has the highest rate of hospital deaths and mean total costs for patients dying with cancer (Bekelman et al. 2016). Part of the issue may be a lack of consistent and equitable access to palliative and end-of-life care across Canadian provinces and territories, and a lack of recognition for palliative care needs, especially for those dying from chronic non-malignant diseases. A report by the Standing Senate Committee on Social Affairs, Science and Technology noted that only one in three Canadians have access to high-quality end-of-life care (Standing Senate Committee on Social Affairs, Science and Technology 2012). Integrated hospice and palliative care in the community setting would not only improve the dying experience of Canadians, by preventing unnecessary and costly transfers to acute care, but is also better

aligned with the desire of individuals who wish to spend their remaining days out of hospitals.

Still, even when integrated hospice and palliative care services are available, uncertainties around prognosis is a major challenge to palliative care delivery. Prognostication is often neglected and/or not communicated to patients, particularly in the inpatient care setting (Heyland et al. 2013; You et al. 2014). When prognostications are made based on clinical judgement, it is often imprecise because prior studies have found that physicians tend to overestimate the survival of patients (Glare et al. 2003). The inability to provide accurate prognoses makes care planning and delivery challenging.

Using routinely collected healthcare information at ICES, the series of studies presented in this paper aimed to answer the following questions: What palliative services were provided to Ontarians in the last year of life? Who received palliative care prior to death? How can linked administrative databases be used to prognosticate the need for palliative and end-of-life supports?

## The Study

From the Ontario Registered Persons Database – a registry of Ontarians who are eligible for the provincial health insurance program – we identified all Ontarians who had died between April 1, 2010, and March 31, 2012. For each decedent, we retrospectively examined the receipt of palliative healthcare services in the last year of life.

Healthcare data used to identify palliative care included physician services and billings to the Ontario Health Insurance Program; publicly funded home care captured in the Resident Assessment Instrument–Home Care (RAI–HC) database; care provided in long-term care facilities (otherwise known as nursing homes) and in complex continuing care settings captured in the Continuing Care Reporting System; visits to the emergency department captured by the National Ambulatory Care Reporting System and any inpatient hospital admissions recorded in the Discharge Abstract Database. Billing codes and detailed descriptions of each database are provided elsewhere (Tanuseputro et al. 2017). We used billing codes that indicate palliative care delivery, then examined the number of decedents who had at least one record of palliative care prior to death.

**Key Findings**

**Palliative care in the last year of life**

Across all health sectors, about half (51.9%) of all decedents ( $n = 177,817$ ) received at least one record of palliative care in the last year of life (Tanuseputro et al. 2017). Among decedents who had received palliative care 50.8% had their first palliative service encounter in the last two months of life. In terms of total days of palliative care provided across settings in the last year of life, home care and inpatient acute care contributed the largest number (44.2% and 37.5%, respectively). Physician-based outpatient palliative care was next at 17.1%. Physician services provided in the home setting (i.e., home visits) represented 2.3% of total palliative care days, while care provided in complex continuing care units, long-term care facilities and emergency departments combined formed an insignificant proportion (1.2%) of total days of care. The utilization of the four leading services rose exponentially in the 90 days prior to death (Figure 1), with the largest increase in the inpatient care setting. We also observed escalated expenditures for both palliative and non-palliative services in all health sectors in this period, with a steep rise in the costs associated with inpatient care which overall represented 42.9% of the total cost of care in the last year of life (Tanuseputro et al. 2015).

**Characteristics of decedents who received palliative care**

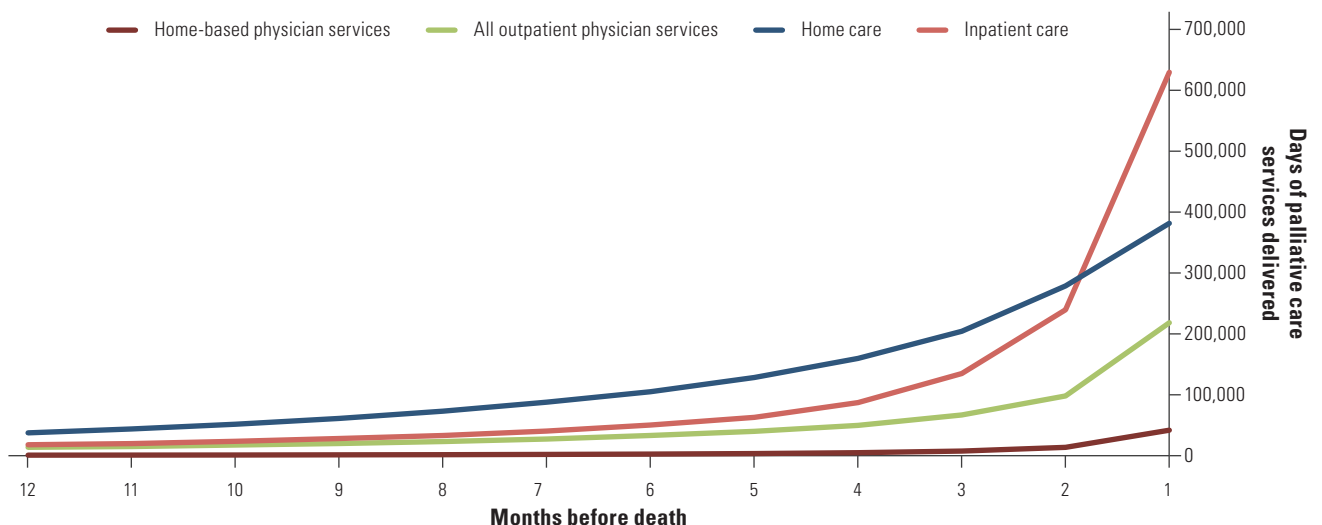
There is unequal delivery of palliative care in Ontario. For example, cancer patients were twice as likely as noncancer patients (odds ratio [OR] = 2.46;  $p < 0.0001$ ) to receive palliative care in their last year of life, after adjusting for age, sex, average neighbourhood income, rurality and number of chronic conditions (Tanuseputro et al. 2017).

Conversely, decedents with dementia were less likely to receive palliative services (adjusted OR = 0.60;  $p < 0.0001$ ) than those without dementia. Furthermore, there were geographic variations in the delivery of palliative and end-of-life care across Ontario’s 14 health regions, known as Local Health Integration Networks (LHINs). When we examined the four predominant health sectors in each LHIN, we found that the proportion of decedents who received a palliative physician home visit in their last year of life ranged from a low of 3.2% (North West LHIN) to a high of 14.5% (Champlain LHIN) — a four-fold difference (Figure 2). Less variation was found in the delivery of palliative outpatient physician service, home care and inpatient care; the relative difference in the proportion of these palliative services across LHINs ranged from 1.2 to 1.6 times. Decedents living in rural settings were overall 20% less likely to receive any palliative care (adjusted OR = 0.80;  $p < 0.0001$ ) than their urban counterparts (Tanuseputro et al. 2017).

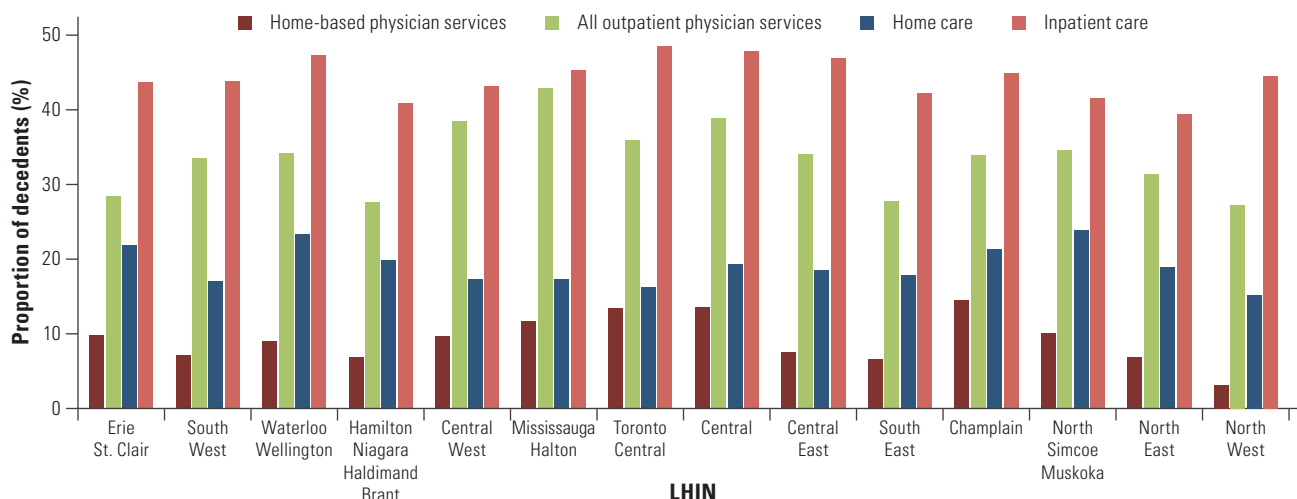
**Key Messages**

Most Ontarians received limited palliative and end-of-life care in the community, despite prior findings that many older adults with a terminal illness want to spend their last days at home. Overall, fewer than 1 in 5 received palliative home care and fewer than 1 in 10 received a palliative physician home visit in their last year of life. Rural and northern regions in Ontario have the lowest proportion of decedents who had received any palliative physician services, home care and inpatient care. Unfortunately, there is currently no central and systematic coordination of palliative care in the province, contributing to disproportionate delivery of services among Ontarians dying from different causes and across jurisdictions.

**Figure 1.** Total days of palliative physician encounters, palliative home care visits and palliative inpatient care admission days across the last 12 months of life for 177,817 decedents



**Figure 2.** Proportion of decedents ( $n = 177,817$ ) who received palliative services in different care settings across Ontario's LHINs



LHIN = Local Health Integration Network.

There are many reasons that contribute to the observed low levels of palliative care delivery. First, palliative care may not be provided because of the unexpected or rapid nature of some deaths, although sudden deaths have been estimated to represent only 5% of all deaths in Canada (Canadian Institute for Health Information 2007, 2011). Second, some healthcare practitioners, patients and caregivers may not recognize or accept that a patient is nearing the end of life early enough to initiate palliative care. Third, one of the main limitations of these studies is that some palliative supports may not be coded in the health administrative databases, even when practitioners recognize that their patient is at the end of life and are providing services that are palliative in nature. For example, because not all physicians are aware of palliative care billing codes, physicians providing palliative care in a clinic setting or in a nursing home may bill their services using a regular visit code. This may be especially true in nursing homes, where many residents are frail and approaching the end of life; palliative and end-of-life care in such places may be perceived as routine practice and not billed differently from general care. Furthermore, capturing the diversity in palliative care delivery models (e.g., variations in interdisciplinary palliative care) remains a challenge, and the true extent of palliative and end-of-life care delivery is difficult to define and capture using administrative data alone. Nevertheless, the extremely low levels of community care overall for decedents in their last year of life along with the large variation across regions suggest there is room for improvement.

The large, linked health administrative databases used to highlight these results could also be used to help increase access to palliative care. Such data can empower better prognostication through high-performance predictive algorithms and the integration of personalized mortality risks into care discussions (Hsu et al. 2016). For example, RESPECT (Risk Evaluation for Support: Predicting Elder-life in the Community Tool) is a mortality risk algorithm that is being developed with 1.3 million records in the RAI-HC database that were collected in Ontario over eight years (2007–2014). In addition to predicting outcomes that are more intuitive for care planning (such as median survival time), RESPECT will serve as a multilevel platform designed for use by both individuals (patients and their caregivers) and healthcare providers (nurses and clinical case managers who routinely collect and use home care data). For health system planners, RESPECT could inform resource allocation decisions across jurisdictions and populations. For clinicians and patients, personalized risk prediction may encourage patient engagement and promote patient-centred care.

Quality palliative and end-of-life care begins with recognizing the need for support and appropriately matching services to meet this need in the population. Administrative data present a unique opportunity to monitor and improve the delivery of palliative and end-of-life care at the population level. Results presented in this series of ICES studies unveil the gaps in current care delivery and offer directions for policy discussions and future research. **HQ**

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