

Person-Centred Perspective Indicators in Canada:

A REFERENCE REPORT

Palliative and End-of-Life Care

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Palliative and End-of-Life Care

Deaths of Cancer Patients in Acute-care Hospitals	3	Extent of Palliative Care in Acute-care Hospitals for Cancer Patients	25
Cumulative Length of Stay and Readmissions to Acute-care Hospitals	9	Access to Palliative Radiation for Prostate and Breast Cancer	35
Emergency Department Visits in the Last 28 Days of Life	15	Special Feature: Palliative Home Care	39
Intensive Care Use in the Last 7 and Last 14 Days of Life	18	References	42
Chemotherapy in the Last 14 and Last 30 Days of Life	21		

Palliative and End-of-Life Care

This section describes the current landscape of acute-care hospital use at the end of life and indirectly examines access to palliative care for cancer patients who died in a hospital in Canada. The World Health Organization (WHO) defines palliative care as “...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness...”¹ Early integration of palliative care can greatly reduce unplanned visits to the emergency department, multiple admissions to hospital, shorten hospital stays, and increase the number of home deaths for patients with advanced cancer. As well, palliative care has shown to significantly improve patient outcomes and quality of life in the domains of pain, anxiety and symptom control. This suggests that palliative care can optimize patient outcomes and can greatly impact health service utilization.

The Partnership is leading efforts to collect more pan Canadian data on palliative care and end-of-life care with the aim of developing a suite of palliative and end-of-life care measures that will lead to better understanding of the palliative and end-of-life experiences of Canadians with cancer and to identify opportunities for system improvement.

It is important to note that palliative care can be offered in a number of settings depending on where the patient is, including homes, acute-care hospitals, hospice and long-term care facilities. This report examined only inpatient palliative care in a single sector (acute-care institutions) in the Canadian context. Examination of system-wide palliative care practices was not possible because only limited data were available across all health sectors (data on community care, primary care services and ambulatory care were not available for this analysis). Hospital use indicators were restricted to cancer patients who died with a cancer diagnosis in acute-care hospitals.

Deaths of Cancer Patients in Acute-Care Hospitals

Depending on the province, anywhere from 37% to 70% of cancer patients who died of cancer died in an acute-care hospital (as opposed to at home or hospice).

Indicator definition: The ratio of the number of acute-care hospital deaths for patients diagnosed with cancer to the total number of cancer deaths. The number of acute-care hospital deaths is from April 2014 to March 2016. Total cancer deaths are based on projected cancer mortality cases for 2014 and 2015 and are reported by province and by patient characteristics (age, sex and disease site) nationally.

Why measure this?

Several Canadian surveys have shown that many cancer patients would prefer to spend their final days and die at home or in a hospice rather than in a hospital.³ However, a lack of awareness or availability of appropriate palliative care resources or services at home (e.g., to ensure effective symptom management) may make death at home or in a hospice less achievable.⁴

Knowing where cancer patients die is important because it enables better understanding of health system resource allocation. Enablers of dying at home could include provincial coverage of medication and equipment in the home setting, home care, caregiver benefits, respite care and access to 24/7 medical care. Preferably, this indicator would confirm whether patient preference and needs are met by community-based resources and supports for those who choose to die in their preferred setting. While small studies exist, as of 2016 there is no routinely collected national data source to identify a person's care needs or preferred location of death.

Provinces vary in how they categorize location of death and how they classify different settings (e.g., designation of hospital-based hospices or palliative care units). Manitoba, Nova Scotia and Prince Edward Island, for example, have palliative care units in some acute-care hospitals. Deaths in palliative care units are categorized as acute-care hospital

deaths and so the ratio of hospital deaths may appear higher relative to other provinces. In contrast, palliative care units in Ontario's acute-care hospitals are often classified as complex continuing care beds (which were excluded from this study). Palliative care units in acute-care hospitals may provide optimal end-of-life care even if they are not always the patient's preferred setting.

While the results presented here provide only a relatively crude measure of cancer deaths in hospital, the data may stimulate a focus on opportunities to begin conversations regarding advance care planning and goals of care as well as the need for palliative care indicators and data collection and analysis that will drive health system improvements.

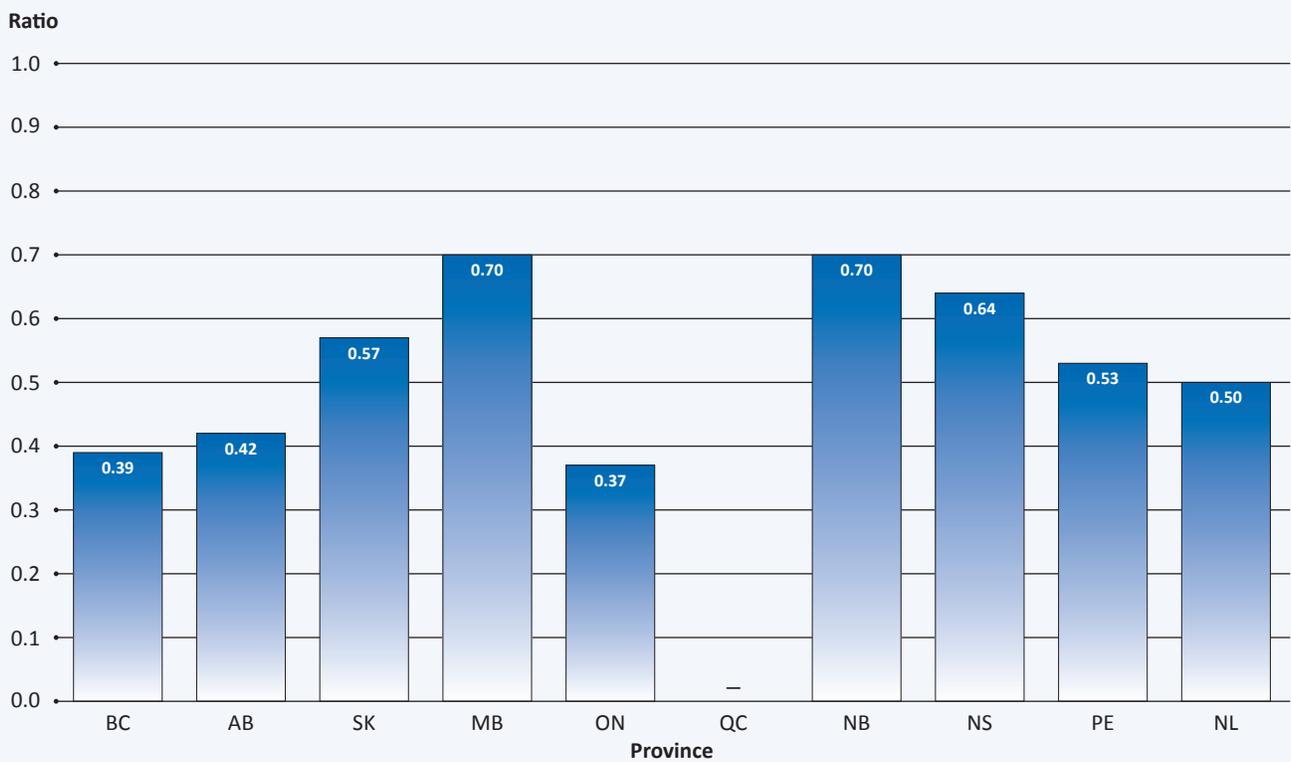
What are the key findings?

- Results below are presented as ratios, percentages are provided to aid in interpretation.
- Data suggest that in many reporting provinces, a majority of cancer deaths occurred in hospital. The ratio of cancer patients who died in hospitals ranged from 0.70 (70%) in Manitoba and New Brunswick to 0.37 (37%) in Ontario (Figure 1.1).
- Males are slightly more likely to die in hospital (3 percentage point difference) and young patients (aged 18–29) were much more likely to die in hospital than other age groups. Older cancer patients (aged 80+) had a lower ratio of deaths in hospital than other age groups (Figure 1.2). The following cancer sites had a higher number of deaths in hospital than others: lung, colorectal, pancreatic, leukemia and non-Hodgkin lymphoma (data not shown).

- Data suggest that the majority of cancer patients who died in acute-care hospitals were admitted to hospital directly from home (77.9%) (Figure 1.3). The remaining patients were transferred from another health care facility or were referred by home care or another level of care.
- 70.4% of cancer patients were admitted through the emergency department at their final acute-care admission (Figure 1.3).

FIGURE 1.1

Ratio of acute-care hospital deaths (with a cancer diagnosis) to cancer mortality cases,[†] by province, 2014/2015 – 2015/2016 fiscal years combined



“—” Data not available.

[†] Projected mortality cases included all cancer deaths aged 0+ in 2014 and 2015.

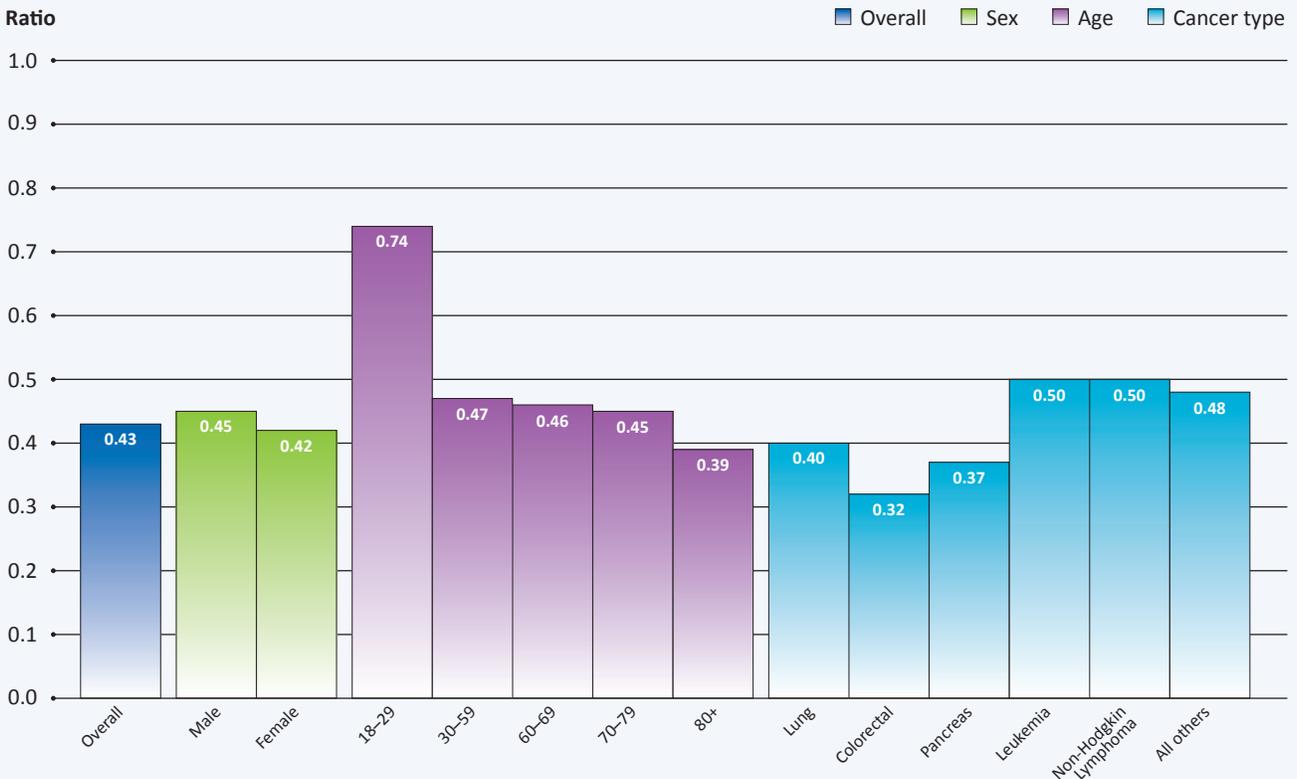
Number of cancer deaths in acute-care hospitals = 48,987.

Acute-care hospital deaths included adults 18+ discharged in fiscal years 2014/15 and 2015/16.

Data source: Canadian Institute for Health Information, Discharge Abstract Database; Canadian Cancer Society, Canadian Cancer Statistics.

FIGURE 1.2

Ratio of acute-care hospital deaths (with a cancer diagnosis) to cancer mortality cases,† Canada, 2014/15 – 2015/16 fiscal years combined



† Projected cancer mortality cases were for all ages except for the "Age" category. The estimated cancer mortality cases for age 0-17 were <1% of total death cases for all ages.

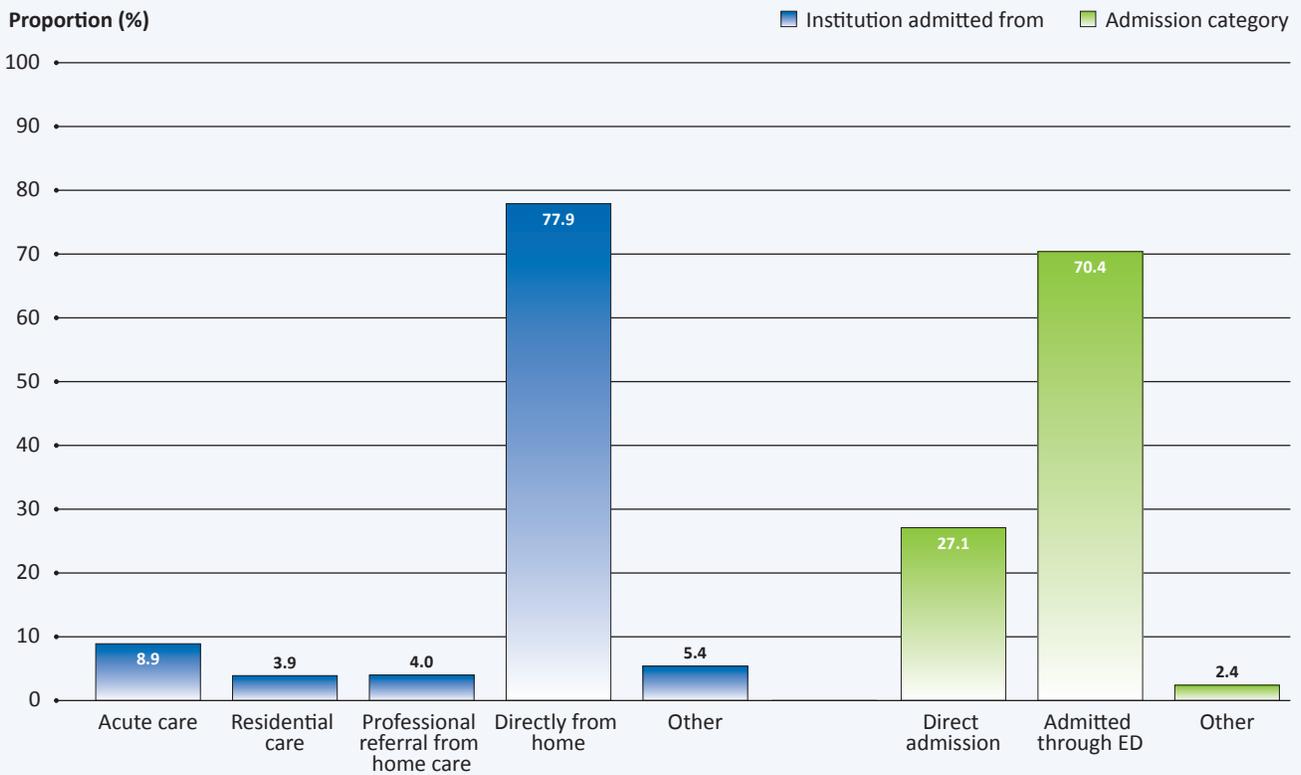
Data include all provinces and territories except QC. Cancer mortality cases in 2014 and 2015 were estimated based on the projected mortality cases from Canadian Cancer Statistics.

Acute-care hospital deaths include adults 18+ discharged in fiscal years 2014/15 and 2015/16.

Data source: Canadian Institute for Health Information, Discharge Abstract Database; Canadian Cancer Society, Canadian Cancer Statistics.

FIGURE 1.3

Distribution of deaths of cancer patients in acute-care hospitals by institution admitted from and by admission category, Canada, 2014/15 and 2015/16 fiscal years combined



Data include all provinces and territories except QC.

Acute-care hospital deaths include adults 18+ discharged in fiscal years 2014/15 and 2015/16.

Directly from home includes patients who had missing values in the “admitted from institution type” field in the Discharge Abstract Database.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

Why do these findings matter?

The health care system should, within reason, provide the necessary supports to make it possible for patients who so desire to die at home (or home-like setting) with appropriate supports. While patient surveys have indicated that the hospital is the least preferred setting for end-of-life care,⁵ other factors such as availability of health services and resources may influence what actually happens. In reality, symptom management resources, emotional support from caregivers or loved ones, and family caregiving and/or financial resources needed to support dying at home are not always available or realistically achievable at home. It is important to be aware that patient and caregiver preferences or needs may change over time as a result of clinical, psychological or practical challenges. For some people, the preferred end-of-life setting may eventually be the hospital or a hospital-like setting. Geography and access to care can also play a role.

Patients' province of residence is a key indicator of in-hospital deaths. The larger provinces (BC, Ontario and Alberta) report the lowest percentages of hospital deaths. Similar to results presented here, a systematic review examined cancer deaths by disease type and found that patients with hematological cancers (leukemias and non-Hodgkin lymphomas) were more likely to die in hospital.⁶ Cancer type can be a predictor of the aggressiveness of care, with some types resulting in more likelihood of being hospitalized at the end of life. This fact may be related to the complexity of symptoms (often related to cancer type). Complications of therapy may require a multidisciplinary team approach that makes a home death difficult.⁷ Also, it may be possible that certain cancer types are diagnosed at a later stage than others, possibly resulting in less time to prepare for a death at home. In some cases the focus may still be on curative treatment that ultimately is not successful.

The majority of cancer patients are admitted to the hospital through the emergency department in their final acute-care admission. These patients likely visited the emergency department because of an urgent crisis that required immediate attention, rather than to receive ambulatory services to meet their needs (e.g., pain and symptom management). This situation might signal that access to services such as nursing care, emergency/paramedic care,

respite care, physician home visits and required equipment are not available or that cancer patients and their caregivers have needs that are not being addressed by the resources. Another interpretation or factor to be addressed may be the lack of planning about impending death in cancer patients, with the need to increase community support or refer/transfer to non-acute-care facilities (e.g., hospice, nursing home). Future research should investigate types of services delivered in hospital or other settings required.

Findings that some provinces had a lower ratio of death in hospital may reflect the existence of more options for community-based care (e.g., home care, hospice) in those jurisdictions. It is possible that appropriate emergency department visits for urgent, unexpected symptoms occurred despite the presence of adequate support at home. These provinces may offer more resources that support home-based end-of-life care. As of February 2012, all provinces had some form of palliative drug coverage for home-based palliative care patients.⁸ Other areas of home-based palliative care, however, are inconsistently available across the country, such as 24/7 access to nursing, medical, paramedical, pharmacy and personal care services; and home-care wait time tracking.⁹ Some provinces have developed more strategic initiatives for advance care planning. See *Strategies for Palliative Care across Canada* on page 31.

In the United States, according to the *Dartmouth Atlas of Healthcare*, the average percentage of cancer deaths occurring in hospital was 15–33%, which is lower than the percentage reported for Canada.¹⁰ In Europe, the proportion of cancer deaths that occur in hospital ranges from 29.4% in the Netherlands to 51.2% in Belgium.¹¹

Data and measurement considerations

- These indicators are based only on cancer patients who die in an acute-care hospital. Hospital use by cancer patients who die elsewhere cannot currently be measured.
- Data and analysis for this indicator were provided by the Canadian Institute for Health Information (CIHI). Cancer death data came from the Canadian Cancer Society.
- Data on patients treated in Quebec facilities were excluded from the study. The Partnership did not receive permission from Quebec to include its data.
- A limitation of these indicators is that it measures only location of death and does not take into account where patients might have spent the majority of their days before death (see Cumulative Length of Stay Indicator on page 9). The indicator therefore does not fully reflect use of health system resources during the end of life.
- Cancer deaths were based on projections from the Canadian Cancer Society (CCS), which could result in an over- or under-estimation of the true percentages.
- “Directly from home” may include a situation where a family physician refers a patient to hospital or where a patient is admitted without a referral owing to a medical emergency. Other admitting institutions may include psychiatric, unclassified and day surgery.
- Data presented in previous System Performance reports based on vital statistics information (as opposed to the hospital abstract information used in this report) show that approximately 71% of Canadian cancer deaths occurred in hospital; this rate is markedly different from the results presented in this section (approximately 43% of cancer deaths occurring in hospitals). It is important to note that data reported here do not include Quebec, which had a higher proportion of in-hospital cancer deaths. Data presented here capture acute-care cancer death abstracts from the administrative Discharge Abstract Database (CIHI) and projected mortality cases from the Canadian Cancer Society, whereas previous System Performance reports used Statistics Canada’s Vital Statistics Death Database data.¹² The Vital Statistics Death Database use a broader definition of “hospital” that includes the emergency department and other institution types.¹³
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology are contained in the full Technical Appendix.

Hospital Use at the End of Life (for Those who Died in Hospital): Cumulative Length of Stay in an Acute-care Hospital in the Last Six Months of Life and Admissions to Acute Care in the Last 28 Days of Life

For cancer patients dying in hospital, the median number of days spent in acute-care hospitals in their last six months of life ranged from 17 to 25, depending on the province. Up to one-third of cancer patients (provincial proportions range from 18.1% to 32.8%) who were admitted to and subsequently died in an acute-care hospital had more than one admission in the last month of life. High admission rates may reflect problems requiring acute hospitalization but may also indicate inadequate community and home support.

Indicator definition: Cumulative length of stay for cancer patients measures the median, 25th and 75th percentile number of days spent in an acute-care hospital bed in the last six months of life of those with a cancer diagnosis who died in hospital. The frequency of multiple (two or more) inpatient acute-care admissions among cancer patients in the last 28 days who died with a cancer diagnosis in hospital was measured. The indicators measured acute-care admissions over two fiscal years (2014/15 and 2015/16) and are reported by province and by sex, age, place of residence and by disease site nationally.

Data on hospital admissions and length of stay include only cancer patients who died with a cancer diagnosis in an acute-care hospital; hence the results on hospital use at the end of life are based on only a portion of cancer patients.

Why measure this?

Admission to an acute-care hospital may be inevitable for some cancer patients because of the need for optimal management of treatment complications, progression of disease or the need for intensive supportive care. However, the duration of the stay and the frequency of hospital admissions are important to consider because the data may reveal that outpatient or community care available may not be addressing the patient's needs, signalling a gap in

palliative care services. Insufficient palliative home care could be one reason for hospital use at the end of life. The provision of palliative-focused home care reduces the relative risk of hospital stays at the end of life and is associated with a higher number of home deaths.¹⁴⁻¹⁶ A high number of transitions between care settings at the end of life has been shown to compromise a patient's quality of life and general well-being.^{17,18}

It is important to understand where cancer patients are cared for in the last months of life, what patient characteristics are associated with the care setting provided at the end of life and how often cancer patients are transferred between care settings in the last months of life. Measuring hospital use at the end of life is important to identify interprovincial variations that may signal what health care resources are being accessed at the end of life. Knowing this will help to advance jurisdictional initiatives targeted at improving palliative care services.

What are the key findings?

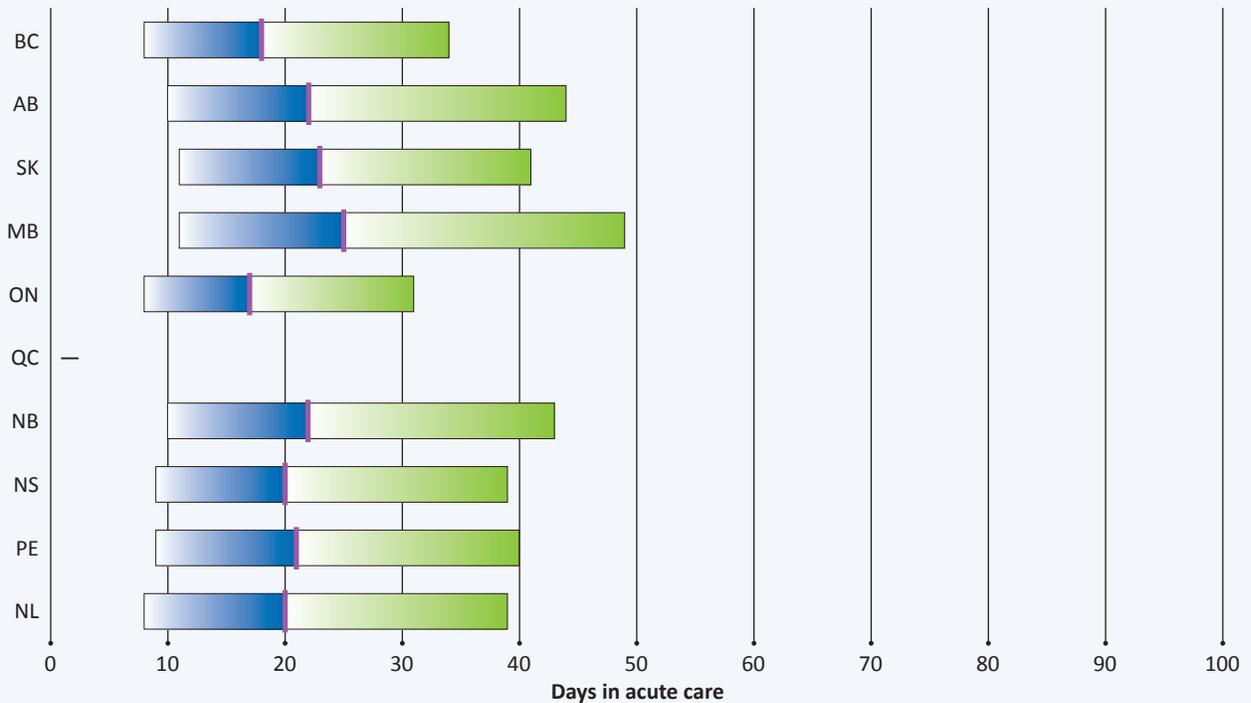
- In the last six months of life, 50% of cancer patients dying in hospital had a cumulative length of stay ranging from 17 days in Ontario to 25 days in Manitoba. The median length of stay (50th percentile) was not substantially different across provinces (Figure 2).

- There was interprovincial variation in the cumulative length of stay in hospital for 75% of these cancer patients, ranging from a low of 31 days in Ontario to a high of 49 days in Manitoba (Figure 2).
- Between 18.1% (in Manitoba) and 32.8% (in Saskatchewan) of patients experienced two or more admissions to hospital in the last month of life (Figure 3).
- A patient's place of residence (urban vs. rural) appeared to be related to the number of hospital admissions: rural patients (28.6%) were more likely to be admitted to the hospital two or more times in the last month of life than were urban residents (21.0%) (see Appendix C). While the frequency of admissions varied based on place of residence, the length of stay in hospital did not (see Appendix C).
- In general, results demonstrated that patients who were older at final hospital admission were admitted to the hospital less frequently (17.5% for those aged 80+, compared with 33.0% in those aged 18–29). Older cancer patients also had shorter lengths of stay than younger patients: older patients had a median stay of 18–21 days and patients aged 18–29 had a median stay of 37.5 days (see Appendix C).
- It appears that the majority of those diagnosed with leukemia and non-Hodgkin lymphoma were more likely to have a greater cumulative length of stay in hospital in the last six months of life and more frequent hospital admissions in the last month prior to death (see Appendix C).

FIGURE 2

Median, 25th and 75th percentile for cumulative length of stay in an acute-care hospital in the last six months of life for cancer patients dying in hospital – by province, 2014/15 and 2015/16 fiscal years combined

Province



“—” Data not available.

Acute-care hospital deaths included adults 18+ discharged in fiscal years 2014/15 and 2015/16.

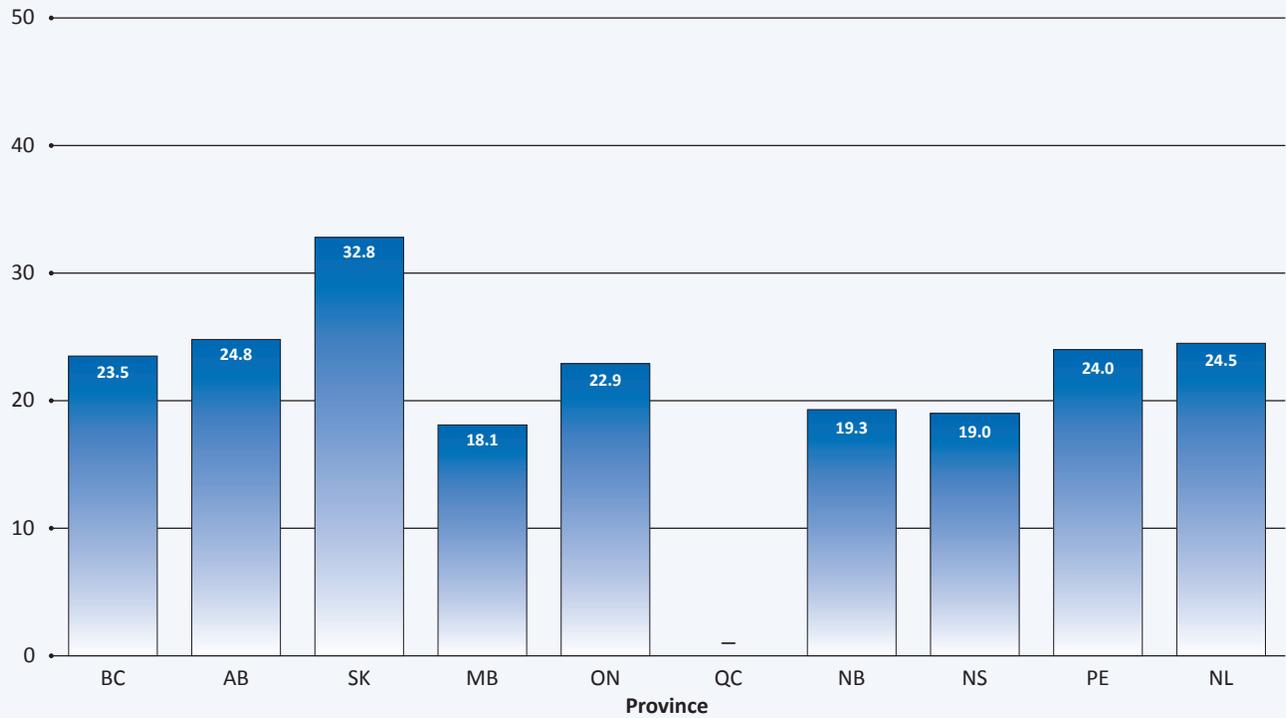
A box represents the range from the 25th and 75th percentiles with a short line as median (50th percentile).

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

FIGURE 3

Percentage of cancer patients dying in hospital with two or more acute-care inpatient admissions in the last 28 days of life, by province, 2014/15 – 2015/16 fiscal years combined

Percent (%)



“—” Data not available.

Acute-care hospital deaths included adults 18+ discharged in fiscal years 2014/15 and 2015/16.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

Why do these findings matter?

Admission to and a longer stay in an acute-care hospital may be warranted or desired for patients with complex medical needs. In these situations hospitals are the preferred setting to deliver the level of care required to support these patients, as home care services may not be able to provide all required care. Multiple transitions in care or hospital use at the end of life result in poorer quality of life and can worsen patient experience. Multiple admissions to hospital may signal that patients were not ready to go home when discharged and/or that community resources, caregiver burden and supports were inadequate, including availability of palliative care that can be provided in a home environment. Goals of care and needs of the patient are important in planning care delivery. Clarity about goals of care from the patient and good communication between patient/family and physicians are important to reduce unnecessary admissions and may help integrate palliative care earlier in the disease trajectory.

There may be a relationship between length of stay in acute-care hospitals and the frequency of admissions to acute-care hospitals. The possibility of such a relationship should be considered when interpreting these results. For example, patients in Manitoba had the longest stays in hospital in the last six months of life and reported the lowest admission rates to hospital in the last month of life. Likewise, while Ontario reported the shortest stays for patients, it reported in the mid-range for number of re-admissions to hospital in the last month of life. It is important to note that palliative care stays may be captured within acute-care stays for provinces that have palliative care units within acute-care hospitals.

Differences in hospital use at the end of life were examined and include patient age, place of residence and type of cancer. Results suggest that hospital use in general was higher in younger patients, who had longer stays and higher admission rates. Younger patients may undergo more aggressive treatment resulting in increased hospital use. While there was no apparent difference in length of stay between urban and rural residents, the frequency of admissions was higher in rural residents. Lack of access

to community-based services after clinic hours for these residents may increase the likelihood of admission to hospital.

Results suggest that patients with hematological cancers (e.g., leukemia and non-Hodgkin lymphoma) have longer hospital stays and more admissions than patients with other types of cancer. These results confirm previous studies that showed that certain cancer patients visit the hospital frequently and for the longest duration at the end of life.¹⁹ It is understood that these cancers result in higher rates of hospital use because of the complexities of the disease and the intensity of treatment (i.e., such as more intensive chemotherapy protocols at end of life than for patients with solid tumours).^{19,20} The medical and psychosocial needs of these patients may surpass what can be provided of care at home or in other settings. Discussions around the appropriate use of aggressive treatment at the end of life and about clarity of goals of care may prevent cancer patients from unnecessary admissions to hospital.

An international comparative study of hospital use during the last 30 days of life found that Canada falls in the middle range of seven countries in hospital use, including number of hospital days at the end of life for patients dying of cancer.¹¹ Patients spent 7.7 days in hospital at the end of their lives in Canada. Belgium had a higher number of hospital days (10.6 days) and Germany and England with fewer days in hospital (7.4 days). It is possible that the cost of a hospital stay influences the need to find alternatives to hospitalization, such as home or hospice. As reported in this study, the per diem hospital cost is relatively high in the United States, which may be one factor influencing hospital use.¹¹

Cancer patients who stayed in hospital for long periods may have received palliative care services in acute-care beds; but this is not evident from the data. Ideally, cancer patients at the end of life receive appropriate palliative care services in palliative care units, hospices or homes, rather than through acute-care hospitalization. Where appropriate, the system needs to encourage and promote the infrastructure to support more community-based end of life care. Multiple hospital admissions may be avoidable if home care supports are in place and if earlier referral to palliative care is

provided. A systematic review of the evidence for effective palliative care revealed that those with earlier palliative care intervention had higher hospice enrollment, fewer hospital admissions and fewer days spent in hospital near the end of their lives.²¹

Further study is required to examine other factors influencing hospital use, including social determinants of health (e.g., the patient's supportive care networks and ethnicity) and hospital-specific factors.

Data and measurement considerations

- These indicator results are based only on cancer patients who died in an acute-care hospital.
- Data and analysis for these indicators were provided by the Canadian Institute for Health Information (CIHI).
- Data on hospital admissions and length of stay include only patients who were admitted to an acute-care hospital so the results are based on only a portion of hospital admissions (i.e., community care hospitals are not included).
- The data include all acute-care hospital admissions (related or unrelated to the cancer diagnosis), as long as the final discharge abstract indicated cancer as the diagnosis.
- Provinces vary in how they categorize location of death and in how they classify different settings (e.g., designation of hospital-based hospices or palliative care units). Manitoba, Nova Scotia and Prince Edward Island, for example, have palliative care units within some acute-care hospitals. Deaths in the palliative care units are categorized as acute-care hospital deaths, so the ratio of hospital deaths may appear higher to other provinces. In addition to the data/coding issues, palliative care units in acute-care hospitals may provide optimal end-of-life care even if this is not always the patient's preferred setting.
- Data on patients treated in Quebec facilities were excluded from the study.
- Data tables for these indicators (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Emergency Department (ED) Visits in the Last 28 Days of Life

Up to a quarter of cancer patients who died with a cancer diagnosis in hospital visited the emergency department twice or more in the last 28 days of their lives. Emergency department over-utilization may be reflective of inadequate access to primary care and home/community care services.

Indicator definition: Measures the percentage of cancer patients who died with a cancer diagnosis in an acute-care hospital who visited the emergency department (ED) in the last 28 days of life. The data are for cancer patients who died in acute-care hospitals from April 2014 to March 2016. Characteristics of cancer patients in Ontario and Alberta (where comprehensive ED data are available) who visited the ED were examined using data from the National Ambulatory Care Reporting System, which tracks ED visits.

Why measure this?

It is widely accepted that a high frequency of visits to the emergency department by cancer patients near the end of life indicates inadequate palliative care.¹⁸ The goals of care at the end of life should include symptom management and supportive care in the patient's setting of choice. Multiple visits to an ED can be distressing and exhausting for cancer patients, family and caregivers, considering that wait times can be long and the environment can be stressful and overcrowded and can expose patients who may be immune-compromised to unnecessary infections.²²

A high number of ED visits by people with cancer across the country may signal inadequate access to both primary care and community-based services, including home care. Cancer patients may visit EDs as a result of acute symptom management crises or for non-urgent matters that could be better managed in the community. Studies have shown that provision of end-of-life care in the community, including earlier integration of comprehensive palliative care supports, can reduce visits to the ED.¹⁴⁻¹⁶

One example of the use of palliative home care, which is associated with fewer ED visits and a higher number of home deaths (a 50% reduction in the likelihood of dying in

hospital).¹⁴⁻¹⁶ Greater family supports and physician continuity of care (i.e., having a regular source of care) is associated with fewer ED visits.²³ Prince Edward Island, Nova Scotia and some areas of Alberta have paramedics supporting palliative home care programs to improve 24/7 access for patients at home.²⁴

Examining interprovincial variations in the use of EDs near death may point to opportunities to learn from other jurisdictions about strategies to minimize the need for an ED visit at the end of life for cancer patients (e.g., earlier discussions about goals of care with cancer patients, palliative care consultations, hospices). Comparing provincial variations will also help to identify gaps in cancer care (e.g., palliative care and community-based services) and thus help improve the delivery of quality cancer care.

What are the key findings (for Ontario and Alberta)?

- From April 2014 to March 2016 combined, 27.1% of cancer patients who died in hospital had no ED visits in the last 28 days of their lives (Figure 4).
- While the majority of patients visited the ED only once (48.4%), a significant portion visited twice or more in the last 28 days of life (24.5%) (Figure 4).
- Of those who visited the ED, 99.7% made unscheduled/unplanned visits compared with 0.3% who made scheduled/planned visits to the ED in the last 28 days of life (data not shown).
- Rural residents were more likely to visit the ED twice or more in the last 28 days of life (31.5% compared with 22.8% for urban residents). Males were slightly more

likely to visit the ED (3 percentage points higher). There is also some suggestion of a decrease in ED visits with increasing age (26.5% for those aged 18–29 compared with 22.9% for those 80+) (see Appendix C).

- Lung and pancreatic cancer patients had a higher risk of making two or more ED visits at the end of life (see Appendix C).

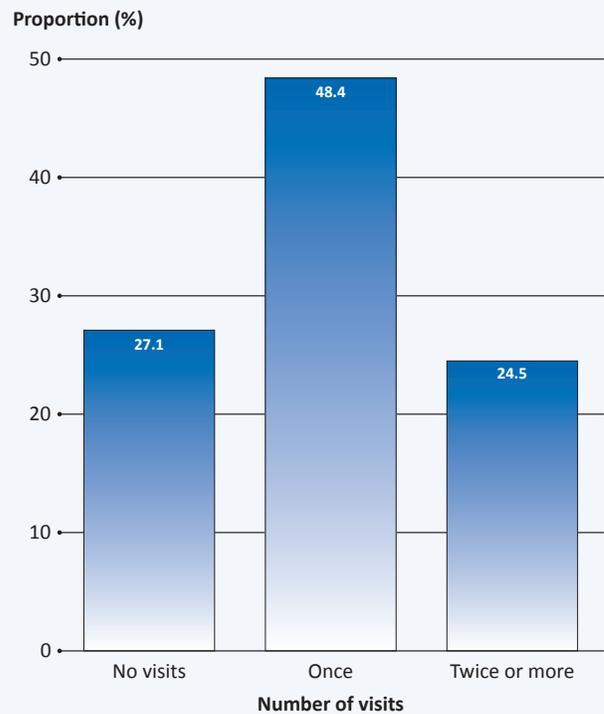
Why do these findings matter?

High-quality, available primary care and community-based services, including home care, have been shown to reduce multiple ED visits at the end of life.¹⁴⁻¹⁶ The goal of palliative community-based services is to optimize people’s quality of life, to reduce the time spent in hospital and to minimize the number of transitions between care locations and providers, enabling patients to spend as many of their final days at home as possible, if that is their preference. The results presented here for Ontario and Alberta show that as many as 24.5% of cancer patients who died in hospital visited an ED twice or more in the last month of life, which represents a marker of potentially poor access to high-quality care. ED visits may be preventable with earlier involvement and access to palliative care services in the community (including nurses, physicians or nurse practitioners and after-hours support).²³

Patient characteristics, including cancer type, were investigated. Patients with certain cancer types, such as lung and pancreatic cancer, had an increased risk of multiple ED visits. This finding is supported by numerous studies.²⁵ It is possible that lung cancer patients are more likely to visit an ED because of complications from aggressive therapy at the end of life (e.g., chemotherapy) and symptom control issues.²⁶ A systematic review supported the results presented here. The following patient factors influenced the use of the ED at the end of life: sex, place of residence and age.²⁵

FIGURE 4

Distribution of number of emergency department visits by cancer patients dying in hospital in the last 28 days of life, Ontario and Alberta combined, 2014/15 – 2015/16 fiscal years combined



Data include only Ontario and Alberta patients who died with a cancer diagnosis in acute-care hospitals.

“No visits” includes cancer patients already admitted to hospital 28 days before death.

Data source: Canadian Institute for Health Information, Discharge Abstract Database, 2014–15 and 2015–16; National Ambulatory Care Reporting System, 2013–14 to 2015–16.

There was an increased risk of ED use by:

- men
- younger patients
- patients with increased comorbidity
- those undergoing chemotherapy within two months of death
- patients with lower socioeconomic status
- patients who did not receive palliative care in the last month of life.²⁵

People living in rural areas may not have access to primary care (e.g., no walk-in clinics or a shortage of family physicians). Insight into patient factors that predict a high number of ED visits may inform policies for strategies and interventions.

Studies have signalled that a relatively high proportion of ED visits are potentially unnecessary, indicating there is an opportunity to reduce avoidable ED visits.^{27, 28} For this study the reason for ED visit was not available. However, an Ontario study showed that symptoms such as pain, dyspnea, malaise and fatigue were the main reasons for visiting the ED at the end of life.¹⁶ Symptom assessment tools could help to identify patient distress earlier and reduce unnecessary visits to the ED.

Single-institution studies in the United States set out to determine the frequency of avoidable and unavoidable ED visits for cancer patients.²⁷ They concluded that as many as 23% of ED visits were classified as potentially avoidable, with the main reason for the visit being cancer-related pain (36%). Other common presenting problems that can often be managed in other care settings included treatment-related complications, infections, neurological events and dyspnea.

It is important to consider that some ED visits may be required—for example, when the patient’s clinical needs and status of the patient are beyond the scope of home care services, and cancer clinic is at a great distance from home and other medical emergencies. Most of these situations are considered unplanned visits and may well be appropriate. Nevertheless, ongoing efforts are needed to reduce avoidable ED visits, including improving communication between patients, family/caregivers and physicians; increasing collaboration between palliative care, oncology teams and EDs; and increased community support between scheduled clinic appointments.²⁷

Data and measurement considerations

- Data on ED visits to facilities in Ontario and Alberta only were included.
- These indicator results are based only on cancer patients who died in an acute-care hospital. Hospital use of cancer patients who die elsewhere cannot currently be measured.
- Data and analysis for these indicators were provided by CIHI (National Ambulatory Care Reporting System).
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Intensive Care Use in the Last 7 and Last 14 Days of Life

Up to 11.5% of cancer patients who died with a cancer diagnosis in an acute-care hospital spent time in an ICU in their last 7 days of life — a setting that is not optimal for addressing the palliative care needs of patients near the end of life.

Indicator definition: Measures the percentage of cancer patients who died in an acute-care hospital and were admitted to an intensive care unit in the last seven and last 14 days of life. The data are for cancer patients who died in acute-care hospitals from April 2014 to March 2016 and are reported at the provincial level and by patient characteristics nationally.

Why measure this?

Over-use of ICUs during the last days of life may indicate inappropriate and overly aggressive care. People dying of cancer should receive care that alleviates physical symptoms and addresses their emotional and psychosocial needs and those of their families in a setting that is supportive, comfortable and minimally disruptive. While some cancer patients may have serious complications that require the life-sustaining therapies offered by critical care units, such units are not always the ideal setting for end-of-life care, which includes palliative care and symptom control.²⁹ Other patients may die unexpectedly in the ICU while being treated.

A Canadian study of patients with terminal cancer revealed that 16% of ICU visits during their last 30 days of life were futile and expensive and often led to unnecessary patient suffering.³⁰ This suggests that some ICU admissions at the end of life provide limited or no health benefit to patients and may even be harmful. It is important that the use of critical care units be reserved for patients who require life-sustaining medical care.

Examining interprovincial variations in the use of critical care in the last seven and last 14 days of life may point to opportunities for learning from other jurisdictions about strategies for optimizing the appropriate use of ICUs at the end of life for cancer patients (e.g., earlier discussions about goals of care, population awareness/use of health care directives, advance care planning and palliative care consultations).

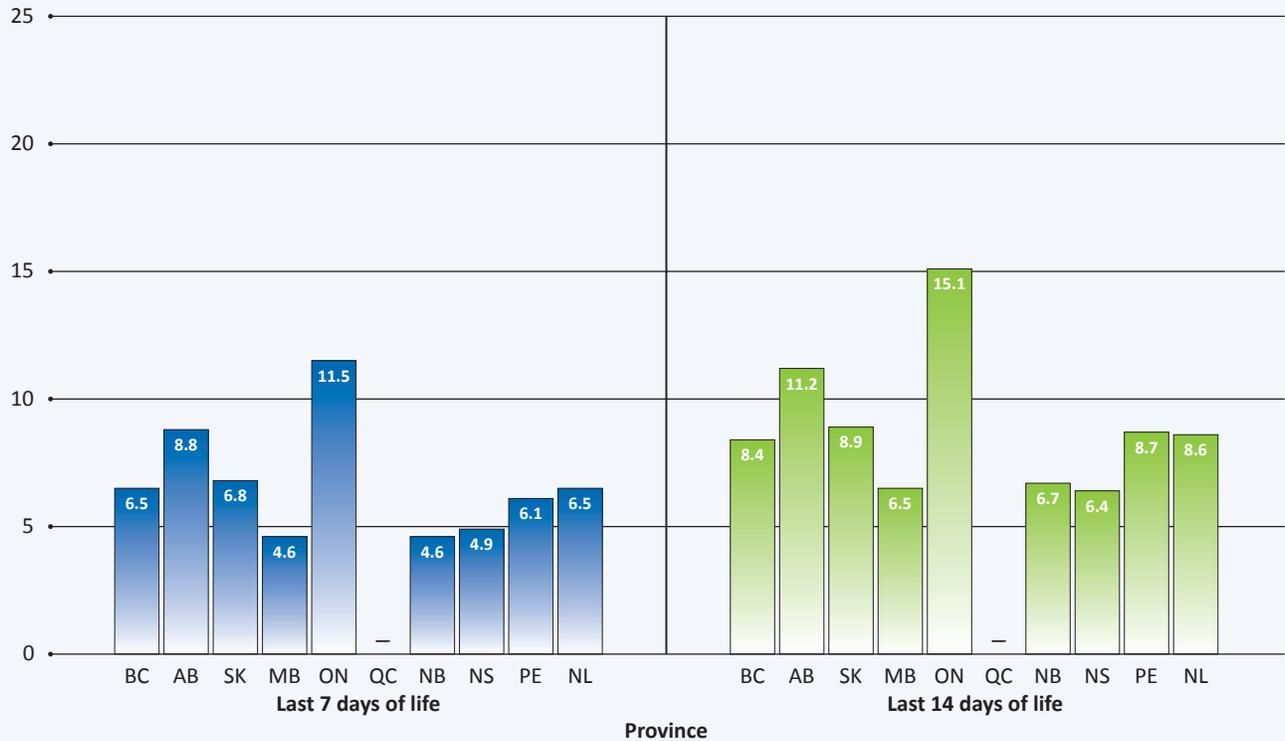
What are the key findings?

- A relatively small proportion of patients dying of cancer in acute-care hospitals received ICU care in the last 14 days of life—between 6.4% in Nova Scotia and 15.1% in Ontario, with the majority being admitted in the last seven days of life (Figure 5).
- There does not appear to be a correlation between ICU use and size of province—both small and large provinces appear at both ends of the range.
- Younger cancer patients, males and rural residents were more likely to be admitted to the ICU at the end of life (see Appendix C), as were those diagnosed with hematological cancers (leukemia and non-Hodgkin lymphoma) (see Appendix C).

FIGURE 5

Percentage of cancer patients dying in hospital who were admitted to an intensive care unit in the last 7 and last 14 days of life – by province, 2014/15 and 2015/16 fiscal years combined

Percent (%)



“—” Data not available.

Data on intensive care unit admissions include only facilities that report ICU data.

Acute-care hospital deaths include adults aged 18+ discharged in fiscal years 2014/15 and 2015/16.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

Why do these findings matter?

While the use of ICUs at the end of life for cancer patients is relatively low, provincial variations exist. Given the variation, it is likely that a portion of ICU visits are of limited value and that some patients may benefit more from less aggressive treatment. Interprovincial variation may be driven by local practice differences and or be a result of differences between academic and non-academic critical care centres.

A recent Canadian study examined regional variations in ICU admissions in the last 30 days of life.³¹ Regional variations were apparent across the four provinces examined. For example, in Nova Scotia hospitalization with ICU admission in the last 30 days of life ranged from a low of 2% to a high of 7%. Measuring regional differences will allow for evaluation of the function of health care in regions of varying sizes. A benchmark for ICU admissions at the end of life was set for this study at 2% based on the top-performing region. The United States has set a benchmark of 4%.^{32,33}

Patients who receive palliative care and advance care planning (i.e., discussions about the goals of and preferences for care) are less likely to be admitted to the ICU, undergo fewer invasive procedures and are less likely to die in hospital.³⁴⁻³⁶ Receiving palliative care in a non-acute setting is associated with a more positive patient experience and greater satisfaction with care as well as better use of system resources. In addition to intensive care settings being more costly than palliative care units, they do not usually provide comprehensive palliative care and may not be an appropriate setting to meet the patient's needs and preferences.

Further work is needed to better understand both the reasons for ICU use at the end of life and patient preferences for care. Future work could examine whether patients are transferred out of the ICU to another level of care. This may reveal whether patients have been transferred to another unit for end-of-life care. This information is particularly important given the growing older population and the consequent increasing costs of end-of-life care. Continued measurement of this indicator could identify opportunities for increasing the use of more suitable settings for end-of-life care delivery and thus improve quality of life for patients and their families.

Data and measurement considerations

- These indicator results are based only on cancer patients who died in an acute-care hospital. Hospital use by cancer patients who die elsewhere cannot currently be measured.
- Data and analysis for this indicator were provided by the Canadian Institute for Health Information (CIHI).
- Data on ICU admissions include only facilities that report ICU data.
- Data on ICU admissions include only patients who were admitted to an acute-care hospital, so the results are based on only a portion of hospital admissions (i.e., community care hospitals are not included).
- The DAD collects specific information on special care in acute-care hospitals. Special care is defined as the provision of services for seriously ill inpatients who require constant supervision and monitoring. It is quite possible that differences by province in ICU use at the end of life could be related to the types of special care units the provinces have and how they are reported to CIHI.
- Data on patients treated in Quebec facilities were excluded from the study.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Chemotherapy in the Last 14 and Last 30 Days of Life

The majority of patients with advanced cancer near end-of-life are not likely to benefit from chemotherapy. Only a small percentage of cancer patients are started on a new chemotherapy regimen within the last 14 or last 30 days of their lives, with younger cancer patients being the most likely to receive this treatment.

Indicator definition: Measures the percentage of all cancer patients who were started on a new chemotherapy regimen within the last 14 and last 30 days of their lives (measured by the first treatment date of a chemotherapy course). The data are adult patients (18 or older) who died of cancer in 2013 and 2014 (or the two most recent death reporting years) and are reported by province and age group. Chemotherapy was defined as traditional cytotoxic chemotherapy drugs, oral or intravenous, aimed at eliminating the growth of tumour cells.

Why measure this?

Avoiding chemotherapy near the end of life and focusing on symptom relief and palliative care in patients with advanced cancer unlikely to benefit from chemotherapy is a Choosing Wisely Canada recommendation.

In general, cancer-cure therapies are not likely to be helpful for patients with advanced metastatic tumours who are markedly debilitated by their cancer. Providing symptom control and palliative care aimed at improving quality of life should therefore be the priority.³⁷ Despite this, studies have found that many individuals with cancer continue to receive aggressive care near the end of life, which can have detrimental effects on quality of life.^{19,20,32,38} Specifically, chemotherapy use in the last weeks of life has been associated with less satisfaction with care, more frequent hospital visits, no or very short hospice involvement and death in an acute-care setting.²⁰

An effective, advance-care-planning and person-centred focus on palliative care can help patients with the treatment decision-making process, increasing the use of services that offer the most benefit to patients and improving quality of life.^{39,40} It is important to note that historically chemotherapy near the end of life may have been warranted in some cases. For example, some patients may have received chemotherapy appropriately in their last month of life and were expected to live longer, but died of complications (e.g., toxicity of chemotherapy).

Measuring variations across the country in the use of chemotherapy near the end of life could enhance alignment with evidence-based guidelines, thereby increasing the use of services that offer the most benefit to patients and improving quality of life.

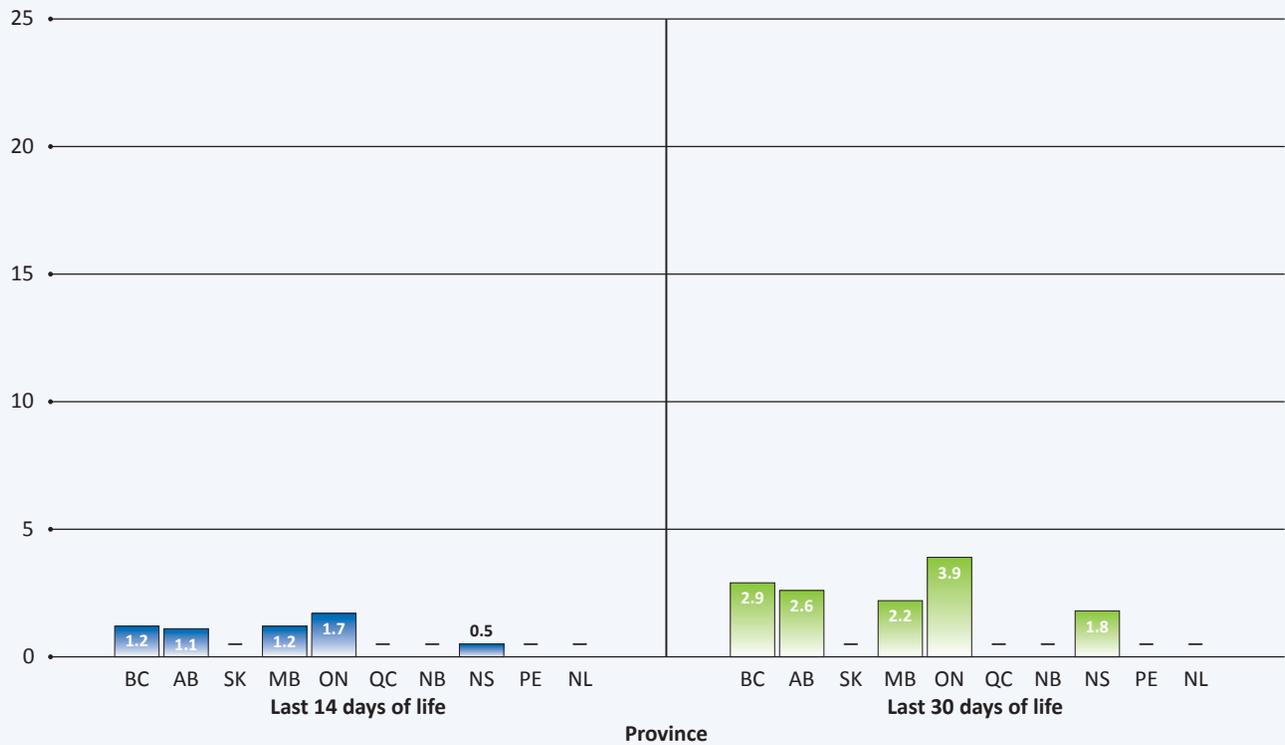
What are the key findings?

- For patients who died of cancer, between 1.8% (Nova Scotia) and 3.9% (Ontario) started a new chemotherapy regimen in their last 30 days of life (five provinces submitted data) (Figure 6.1). Between 0.5% (Nova Scotia) and 1.7% (Ontario) started chemotherapy in the last 14 days of life (Figure 6.1).
- Receiving chemotherapy at the end of life became progressively less likely as individuals got older: 5.1% of those aged 18–29 received chemotherapy in the last 14 days of life, compared with 0.3% of those 80 and older (Figure 6.2).

FIGURE 6.1

Percentage of cancer patients starting a new chemotherapy regimen[†] in the last 14 and last 30 days of life, by province – two most recent death years available

Percent (%)



“—” Data not available.

[†]AB, MB and ON included oral chemotherapy. In MB, data on oral chemotherapy were not complete in the cancer registry, but have been included if available.

NS estimate is conservative since oral chemotherapy data were not available and patients with haematological cancers were excluded from the analysis.

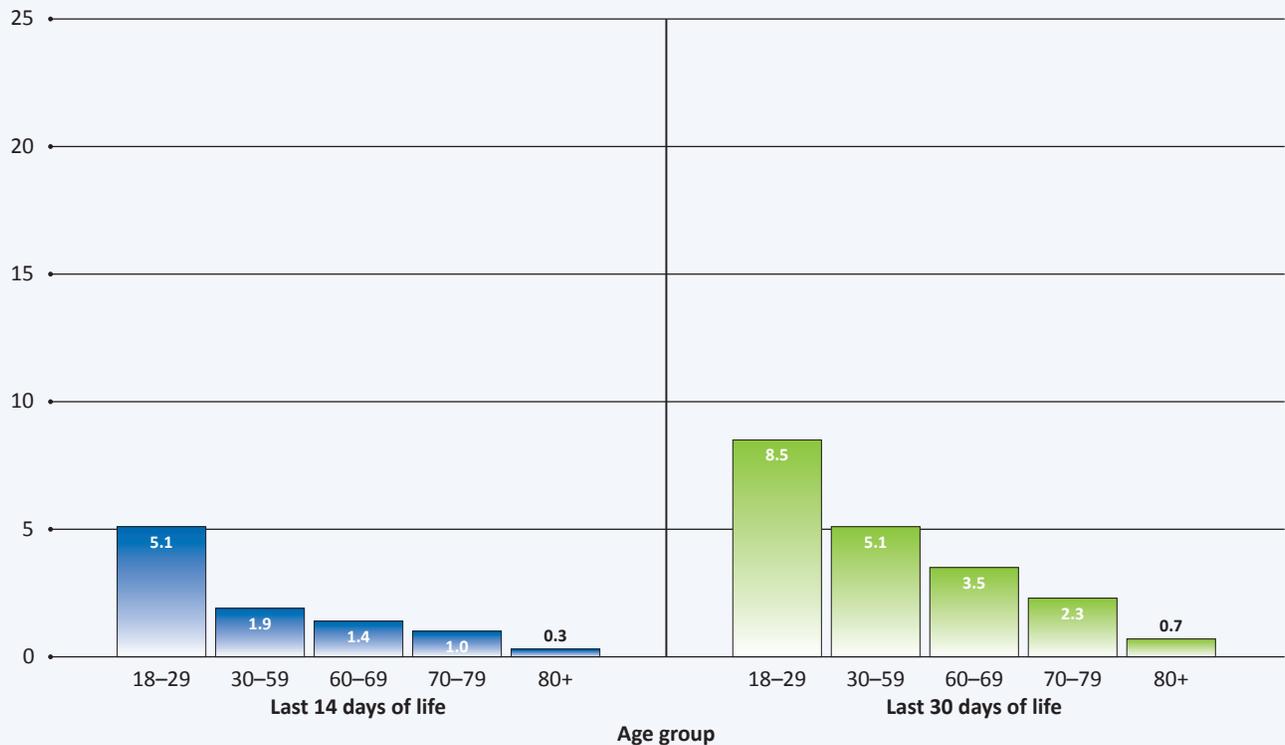
MB data include 2011–12 death years combined. ON: Data include 2012 death year only. Data for combined years cannot be calculated because of suppression. All other provinces include 2013–14 death years.

Data source: Provincial cancer agencies and programs.

FIGURE 6.2

Percentage of cancer patients starting a new chemotherapy regimen[†] in the last 14 and last 30 days of life, by age group, all provinces combined[‡] – two most recent death years available

Percent (%)



[†] AB and MB include oral chemotherapy. In MB, data on oral chemotherapy were not complete in the cancer registry, but have been included if available.

[‡] All provinces combined includes BC, AB, MB and NS.

NS estimate is conservative since oral chemotherapy data were not available and patients with hematological cancers were excluded from the analysis.

MB data include 2011–12 death years combined. All other provinces include 2013–14 death years.

Numbers in age group 18–29 were too low to report for one province. To avoid suppression, a number between 0 and 5 was randomly assigned. Age group 30–59 was adjusted accordingly to reflect the overall total.

Data source: Provincial cancer agencies and programs.

Why do these findings matter?

There were provincial and age-related variations in the use of chemotherapy in the last 14 and last 30 days of life. Data from five provinces suggest that less than 4% of cancer patients started a new chemotherapy regimen in their last month of life. These rates are much lower than those observed in other countries.⁴¹ For example, a population-based cohort study in Sweden found that a quarter of patients with terminal cancer received chemotherapy in the last month of their lives.⁴² The United States also reports a higher use of end-of-life chemotherapy, possibly driven by financial incentives (e.g., drug reimbursement) and cultural differences.²⁰

The data also suggest that younger patients are more likely to receive chemotherapy near the end of life. The literature supports the age-related variation in chemotherapy use.^{20, 32}

There may be more attempts to treat younger cancer patients aggressively, and they often present with fewer comorbidities than older patients. The most commonly diagnosed cancers in younger patients are often treated primarily with chemotherapy (e.g., hematological cancers), which may explain the increased rates in this age group.

Variations in chemotherapy use could be explained by differences in access to palliative care resources, differences in care protocols and patient-driven factors.^{32, 41} Evidence suggests that many individuals with advanced cancer do not clearly understand the intent of chemotherapy (i.e., they do not understand that it is unlikely to cure their cancer).⁴³ It is important for clinicians to introduce goals of care when making treatment decisions and to clearly explain the risks and benefits of treatments to patients so that they can make informed decisions that align with their preferences and personal considerations.

Data and measurement considerations

- One criterion of the Choosing Wisely Canada recommendation—a performance status of 3 or 4—was not captured owing to data limitations. The data may also include a subset of patients who may benefit from chemotherapy, such as those with specific disease types (e.g., germ cell cancer) or characteristics (e.g., mutations) that suggest a high likelihood of response to chemotherapy.
- Chemotherapy was defined as traditional cytotoxic chemotherapy drugs, oral or intravenous, aimed at eliminating the growth of tumour cells.
- Only five provinces were able to collect and submit the data required to calculate the indicator.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Extent of Palliative Care in Acute-care Hospitals for Cancer Patients

The vast majority (over 85%) of cancer patients who died with a cancer diagnosis in an acute-care hospital were identified as “palliative care” patients.

Indicator definition: Measures how early and how often inpatients who died in an acute-care hospital with a cancer diagnosis were identified as palliative care patients.

Assignment of the *palliative care code*

The designation of palliative care in an acute-care setting is based on the presence of the clinical code Z51.5 (palliative care) on a patient’s abstract. The palliative care code should be applied to abstracts whenever there is physician documentation of palliative care. Documentation that supports coding palliative care may include a palliative care consultation with initiation of a palliative care treatment plan; physician documentation such as “palliative patient,” “palliative situation,” “end-of-life care,” “comfort care,” “supportive care” or “compassionate care;” or use of specific palliative care services, treatment, advice and counselling were delivered.² Palliative care does not have to be provided in a designated palliative care bed or unit or be managed by a palliative care team for the palliative care code to be assigned on the abstract. Therefore, this code is not a measure of specialized palliative care services delivered.

One limitation of this analysis is that although there may be care provider documentation of the patient as palliative (i.e., to indicate that a physician identified a person as dying or the person is approaching the end of life), that designation may not reflect actual care. Another limitation is that the data do not capture patients who may have received ambulatory palliative care services.

This is a first look at inpatient palliative care across the country. The hope is to understand more about the engagement of palliative care in a hospital setting and at this time, the palliative care code is currently the only available tool to examine this.

The indicator includes information from all acute-care hospital admissions two years prior to death for patients with a cancer diagnosis who died in an acute-care hospital. The two measures are as follows:

- The *timing* of the first palliative care code being applied or initiated (i.e., first observed in the last two years of life) in one month increments to 24 months before death
- The *frequency* with which the code was applied two years before death (i.e., percentage of acute-care hospital admissions with a palliative care code)

Why measure this?

The World Health Organization (WHO) defines palliative care as “...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness...”.¹ It is important for palliative care to be integrated early in the course of disease, rather than being limited to end-of-life care, and that it can be concurrent with therapies aimed at prolonging life. End-of-life care is a component of palliative care that happens during the last days and hours of life.⁴⁴ Unlike end-of-life care, palliative care is not confined to a defined time frame.

Despite the WHO definition, societal understanding of the term *palliative* varies among physicians, patients and families. There is a misperception that palliative care is for patients who are dying. Palliative care should be extended

to patients, families and caregivers at any time in the disease course and should include the following:

- psychosocial and spiritual support
- supportive care
- pain and symptom relief
- bereavement counselling
- a multidisciplinary team approach (nurses, physicians, other allied health providers)

Studies demonstrate that provision of palliative care in the community, including earlier integration of comprehensive palliative care in oncology, can reduce unplanned visits to the ED, multiple admissions to hospital and deaths in hospital.¹⁴⁻¹⁶ The findings suggest that earlier assessment of palliative care needs and provision of required care can optimize patient outcomes and can greatly improve health service utilization.

Recently, the American Society of Clinical Oncology developed an update on the integration of palliative care into standard cancer care.⁴⁵ The new practice guideline states that palliative care should be integrated earlier in the disease course and provided alongside cancer treatment for both advanced and early-stage cancer patients.

It is important to highlight that palliative care can be offered wherever the patient is: home, acute-care hospital (inpatient and ambulatory), hospice or long-term care facility. For this study, only *inpatient* palliative care in a single sector (acute-care institutions) was examined in the Canadian context. A measure of the provision of palliative care system-wide was not possible because comprehensive national data on palliative care do not currently exist.

“With palliative care we seem to focus on end-of-life issues but we need to push for a palliative approach to care from the moment of diagnosis.”

– Penelope Hedges, family caregiver, Vancouver, BC

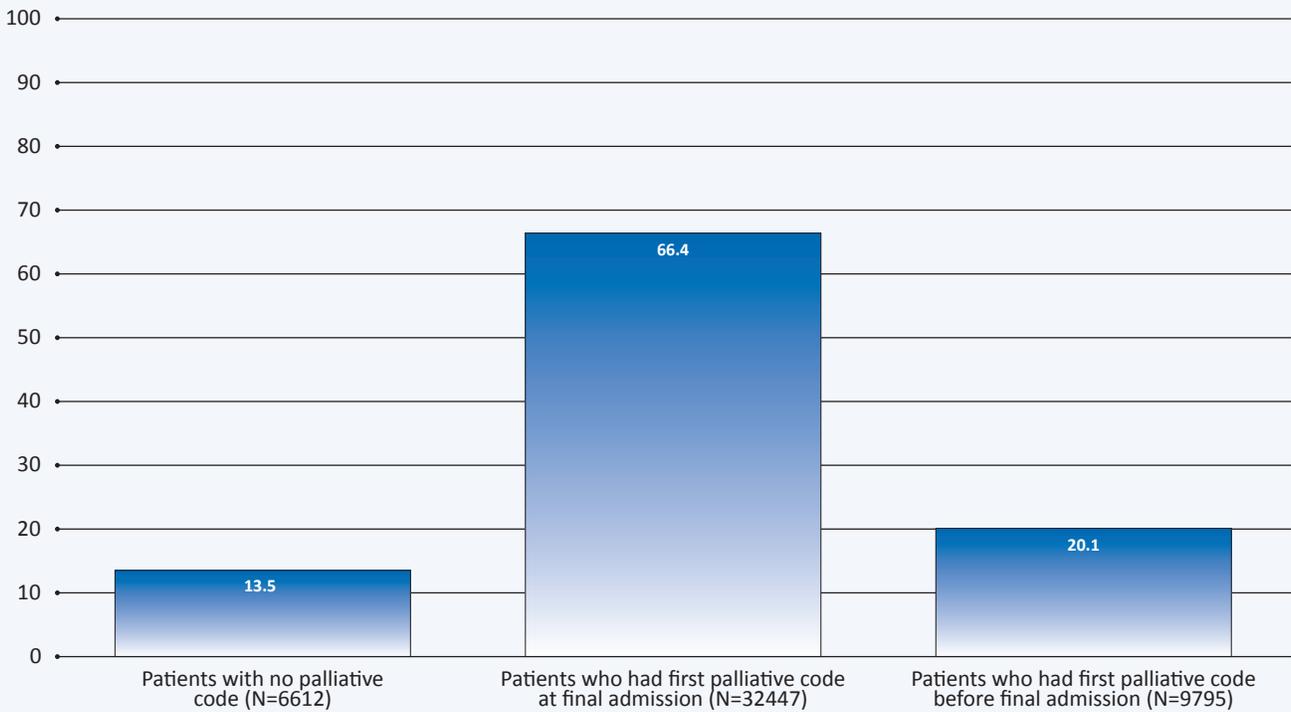
What are the key findings?

- The majority of cancer patients (66.4%) were first designated as palliative in an inpatient setting during the final acute-care admission (Figure 7.1). This finding was consistent across provinces and territories (data not shown). Twenty percent of patients received the palliative care designation from 1 through 24 months before death and 13.5% of patients did not receive a palliative designation before death.
- There was interprovincial variation in the percentage of patients who had no record of inpatient palliative care designation two years before death, ranging from 4.8% in Nova Scotia to 15.9% in Alberta (Figure 7.2).
- The percentage of acute-care admissions that included patients with a palliative care designation in the last two years of life ranged from 34.0% in the territories to 52.6% in Nova Scotia (Figure 7.3).

FIGURE 7.1

Timing of application of palliative care code (Z51.5) in the last two years of life for patients who died with a cancer diagnosis in an acute-care hospital – 2014/15 and 2015/16 fiscal years combined

Proportion (%)

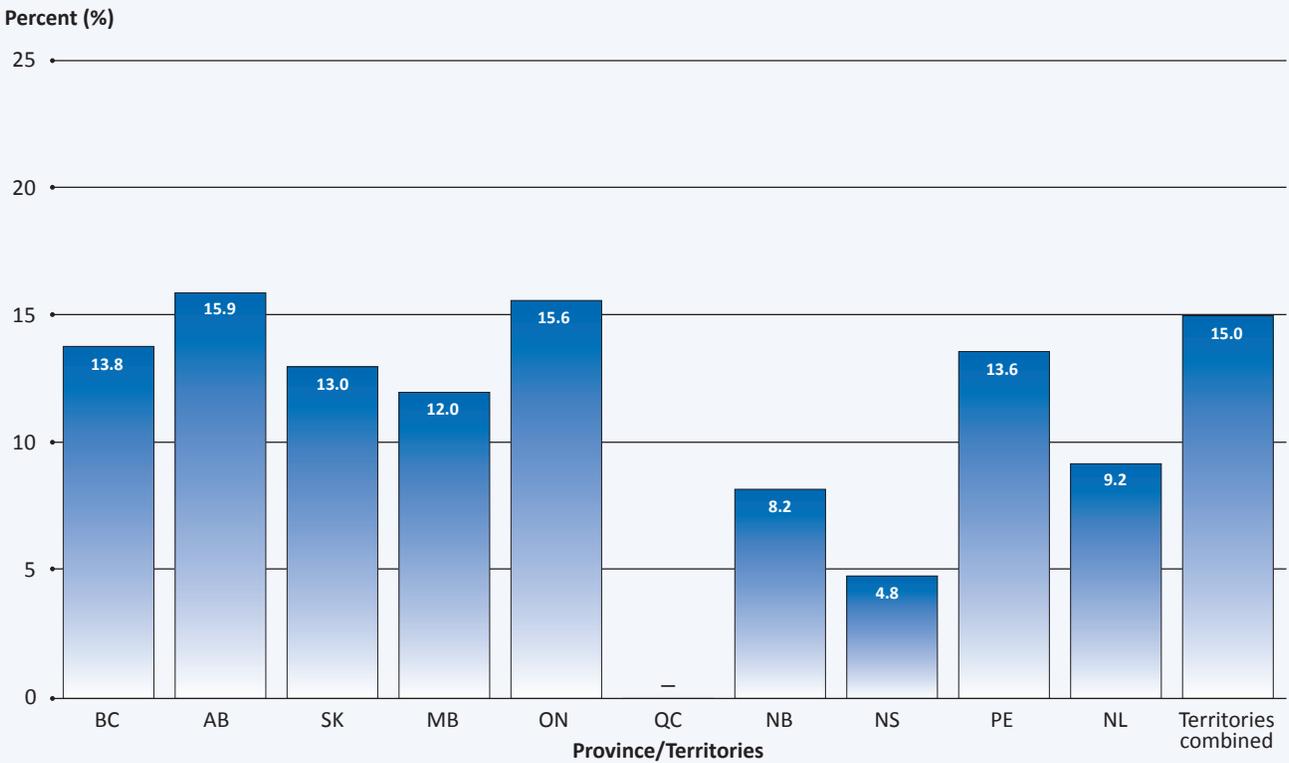


Data include all provinces and territories except QC.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

FIGURE 7.2

Percentage of cancer patients with no palliative care code (Z51.5) in the last two years of life among those who died with a cancer diagnosis in an acute-care hospital, by province/territories, 2014/15 and 2015/16 fiscal years combined

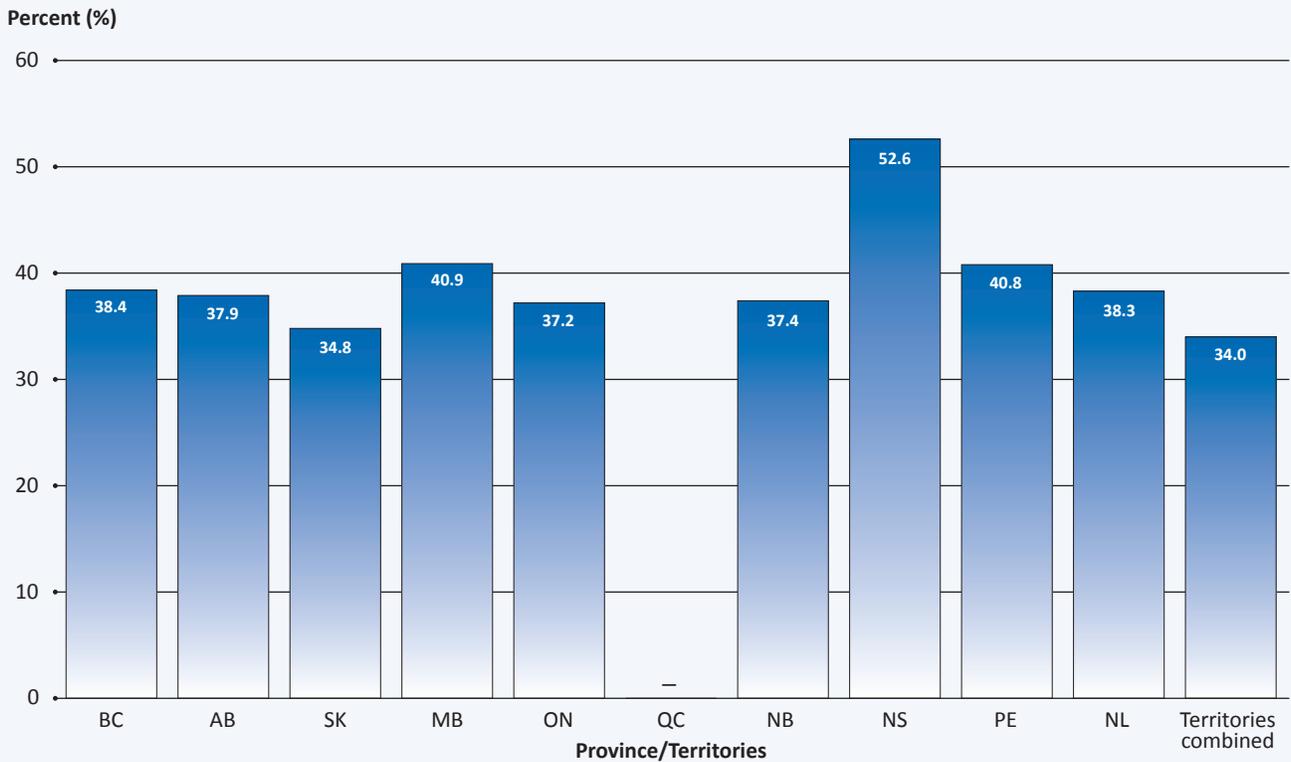


“—” Data not available.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

FIGURE 7.3

Percentage of admissions with a palliative care code (Z51.5) in the last two years of life for cancer patients who died with a cancer diagnosis in the acute-care hospital, by province/territories, 2014/15 and 2015/16 fiscal years combined



“—” Data not available.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

Why do these findings matter?

Numerous randomized controlled trials have provided evidence to support early involvement of specialized palliative care services for patients with cancer to increase patient quality of life.^{39,46} Based on the results of this analysis, 66.4% of patients received a palliative care designation for the first time at their final inpatient acute-care admission. Receipt of a palliative care designation near the time of death signals that the health care system has failed to identify the palliative care needs of patients earlier in the disease course. The data revealed that low use (34.0–52.6%) of hospital-based palliative care among cancer patients who were admitted to and died in acute-care hospitals (i.e., a low number of inpatient admissions are assigned to palliative care). Subgroups of patients (e.g., those who do not receive palliative radiotherapy, nursing home residents, those who die quickly after a cancer diagnosis) may not be experiencing equal access to palliative care.⁴⁷

It is important to note that assignment of a palliative care code to a cancer abstract does not give us information on the range and scope of palliative care services provided nor does it equate to optimal palliative care. The data do not capture patients who received palliative care in other settings (e.g., outpatient palliative care) nor do they capture patients' palliative care needs. The palliative care code may not be consistently applied—there are limitations to the use of this code (is dependent on the clinician or the abstractor applying the code).

One of the challenges is that the code does not identify all patients requiring a palliative approach to care. National data are needed about patient experiences with palliative care, palliative symptom management and care and when patients are identified as needing palliative care. The data presented here show that the majority of inpatients are designated as palliative near the end of life.

Earlier referral to palliative care is important; physicians have responsibility to initiate referrals to specialized palliative care (most often an oncologist).⁴⁸ A possible barrier to accessing palliative care may be the misconception that palliative care is only for end-of-life care

and the resulting concern that recommending palliative care could reduce hope for the patient and family.

“Don’t be afraid of palliative care. It means an approach to living the rest of your life the best way you can. It isn’t about stopping treatment. Holistic care should start at time of diagnosis and needs to include psychosocial care and support for both the patient and their primary caregiver. Patients need to have ongoing assessment of their needs throughout their journey; and it is essential that the primary caregiver be involved in the health care conversations along with the patient. We need to pay attention to the caregiver as well and offer them psychosocial support.”

– Penelope Hedges, family caregiver, Vancouver, BC

Education for oncologists may increase the use of palliative care for cancer patients, such as the EPEC™-Oncology Canada—Education in Palliative and End-of-Life Care for Oncology program or Learning Essential Approaches to Palliative Care (LEAP) by Pallium Canada, a federally funded program. These comprehensive curricula in palliative and end-of-life care help improve the level of skill of health care professionals and thus best practices on a pan-Canadian level.

To maintain palliative care as a profession, accreditation of this discipline is important. In Canada, palliative care medicine received sub-speciality status in 2016.⁴⁸ However, not everyone approaching the end of life needs specialist palliative care. Therefore, it is equally important that palliative care education be provided to primary care, continuing care and non-cancer specialists since many people with cancer die from non-cancer diseases, such as dementia, chronic obstructive pulmonary disease, congestive heart failure or renal failure.

Conversations about goals of and preferences for care and about prognosis and outcomes may not be occurring or may be occurring too late in the disease trajectory. To allow for more meaningful reporting on palliative care, improvements are needed in both the accuracy and consistency of palliative care coding by health records coders and in what physicians put in medical records to assist with accurate coding. The diversity of palliative care settings poses a data challenge. Ideally, it would be important to have improved

focus on the provision of palliative care across all health sectors, not only inpatient palliative care.

“Palliative care needs to be integrated into curriculum and be core content, not optional.”

- Bernard Lapointe, care provider, Eric M. Flanders Chair in Palliative Care, McGill University, Montreal

Strategies for palliative care across Canada

Strategies for palliative care vary across the country, as do policies and programs to support palliative care, including drug coverage, palliative home care and emergency community palliative support.

As of 2015, British Columbia, Alberta, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland and Labrador had palliative and/or end-of-life care either as part of the overall cancer strategy or as an independent strategy.²⁴

Provinces and territories provide broad drug plans that may or may not include drugs specifically for palliative care. British Columbia, Alberta, Saskatchewan, Manitoba, Prince Edward Island (Provincial Palliative Home Care Drug Program) and Nova Scotia provide drug plans that specifically cover palliative care. All provinces and territories have formal home care programs, but the extent and level of palliative care provision varies. PEI and Nova Scotia introduced paramedics supporting palliative home care programs to improve 24/7 access for patients at home.²⁴

British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Nova Scotia have policies on 24/7 access to nursing and personal care,⁴⁹ while only Ontario, New Brunswick, Yukon and Nunavut track wait times for palliative home care.⁴⁹

Palliative and end-of-life care integration

In 2014, the Partnership established a Palliative and End-of-Life Care (PEOLC) National Network to address national priorities to improve palliative and end-of-life care. This network is composed of appointees from the provincial and territorial ministries of health, representatives from provincial cancer agencies, program leaders from national organizations with vested interest in or responsibility for palliative care, and members of the public who are cancer patients or family members of patients.

The PEOLC National Network has identified palliative and end-of-life care integration as a key opportunity and need for Canadians. The goal of integrating palliative care and oncology care is to improve quality of and access to early palliative care and to meet the varied needs of cancer patients and their families. A working group was tasked with investigating and promoting best practices in palliative care integration. In August 2016, a survey was sent to 55 regional cancer clinics across Canada to gather information on their palliative care programs and services and to assess the current state of palliative and end-of-life care integration within the cancer centre.

By the end of 2016 survey responses had been received from 17 centres. Preliminary results show that the number of new cancer patients seen yearly in a cancer centre ranges between 700 and 10,000. The majority of respondents (14 of 17) indicated that they had dedicated outpatient specialist palliative care clinics (not counting subspecialized interventional clinics such as palliative radiotherapy access clinics). Respondents indicated that the eligibility criteria to be referred to or attend the palliative care clinics included, variously, less than one year prognosis, less than six months prognosis, metastatic disease, no further chemotherapy planned and unmanaged symptoms requiring specialist intervention. The majority of respondents indicated that patients access outpatient palliative care services through referral from a specialist, a family physician or any health professional.

The results to date provide preliminary insight into palliative care integration in cancer centres. Non-responders received a follow-up survey in January 2017. In addition, a survey is being developed to assess palliative care integration in the acute-care hospital sector. Findings from this survey should provide further information on palliative care integration across Canada.

A Pan-Canadian initiative: Palliative Care Matters

Covenant Health Palliative Institute collaborated with Canada's national health organizations, including the Partnership, on the Palliative Care Matters Initiative. The pan-Canadian initiative included a national public survey of 1,540 Canadians (aged 18+) to find out what Canadians think, the services and supports they value most and their views on access and approaches to palliative care.

The results of the survey show that Canada needs a vision for palliative care. Using the survey results, along with research by palliative care experts and a panel of lay members, who represented the broad groups of Canadians, Consensus Statements were developed and released. Further, the Conference Board of Canada is incorporating the findings into a national report that will be brought to the attention of policy makers, government and the public to change the way palliative care is delivered in Canada and to ensure all Canadians have access to quality palliative care.

Key findings from a national public survey: What are Canadians' view of palliative care?⁵⁰

- Only 58% of Canadians are aware of palliative care. A similar proportion is aware of end-of-life care, but less than half of Canadians are aware of residential hospice care (49%) or advance care planning (36%). Just under half of Canadians (46%) have had conversations about the type of care they would like to receive at the end of life, with only 11% reporting having written advance care plans for themselves.
- Half of Canadians (51%) have had someone important to them receive palliative care in Canada within the past 10 years, most commonly in hospital (36%), a long-term care facility (19%), at home (16%) or in a hospice (15%).
- Hospice care received the highest satisfaction score (93%), followed by home palliative care (86%), hospital setting (85%), and long-term care facility (82%).
- The vast majority of Canadians (90%) agree that patients should have the right to receive care in their home at the end of life and that the public health system should cover any related costs (85%).
- 85% agree that palliative care should be provided as frequently in rural locations as in urban centres.
- Over 79% of respondents agree that surveys should be conducted among family, caregivers and patients regarding the care received and to measure and track awareness of palliative care.

Recommendations

Twenty recommendations were made at the Palliative Care Matters Consensus Development Conference.⁵⁰ Below are just three:

- The *Canada Health Act* should include integrated palliative home care with universal access and support, customized to patients' needs
- The federal government should provide funding for the development of a national palliative care strategy
- All physicians in Canada should be trained with basic skills in palliative care

Data and measurement considerations

- These indicator results are based only on cancer patients who died with a cancer diagnosis in an acute-care hospital.
- Data and analysis for this indicator were provided by CIHI.
- Data on patients treated in Quebec facilities were excluded from the study because of differences in coding standards.
- The following is additional information on the palliative care code:
 - The palliative care code has been applied to patient abstracts in Canada since 2008–09, since standards came into effect in 2008. All reporting provinces follow the coding standards rules, and therefore coding practices should not differ among locations. A study was conducted to confirm adherence to national palliative care coding standards.⁵¹
 - The following are three scenarios in which the palliative care code would be documented in a patient's abstract:²
 - A patient is admitted to hospital with no intention of receiving palliative care, but after investigation a palliative care plan is put in place.
 - A patient is admitted to hospital with the sole purpose of receiving palliative care (the patient was known to be considered palliative before admission).
 - A patient is admitted to hospital for a “reversible” condition (e.g., pneumonia) and receives palliative care as part of their care plan (palliative care consumed the majority of the hospital stay).
 - The palliative care code can be assigned regardless of the availability of a designated palliative care bed or unit and care may not necessarily be provided by a team of palliative care experts.²
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Access to Palliative Radiation for Prostate and Breast Cancer

Palliative radiation is an effective symptom management option for cancer patients with advanced stage disease that is causing pain and other discomfort. There was relatively wide interprovincial variation in the percentage of prostate and breast cancer patients who received radiation therapy (to the primary or metastatic site) within one year prior to death.

Indicator definition: Measures the percentage of prostate and breast cancer patients who received radiation therapy in the last year of life. The data are for cancer patients who underwent therapy and died of prostate or breast cancer in 2012 and 2013 (or the two most recent death reporting years) and are reported by province.

Why measure this?

While radiation therapy plays an important role in the curative treatment of non-metastatic cancer, it is also used as an effective palliative therapy for patients with advanced disease that is causing pain and other discomfort—particularly for those whose cancer has metastasized to their bones, brain or spinal cord (causing spinal cord compression).⁵²⁻⁵⁴ Ensuring patients with end-stage prostate or breast cancer have access to palliative radiation therapy when needed is an important aspect of quality care.

Given the significant impact of debilitating pain on a person's quality of life, it is important to monitor access to treatments that can help manage distressing physical and emotional symptoms. It is also important to understand why these treatments may be used differently across jurisdictions.

Because reliable information on treatment intent is not routinely collected in provincial data sources, the use of radiation therapy as a palliative care treatment is examined indirectly. This has been achieved by measuring the percentage of patients receiving radiation therapy less than one year before death from prostate or breast cancer. Using this time frame increases the likelihood that the radiation therapy reported on in the indicator was delivered for palliative reasons, but some radiation therapy treatments with palliative intent will be missed.

Data (where available) were provided by the provincial cancer agencies and programs and include men and women who died of prostate and breast cancer, respectively, in 2012 and 2013 (or the two most recent death reporting years).

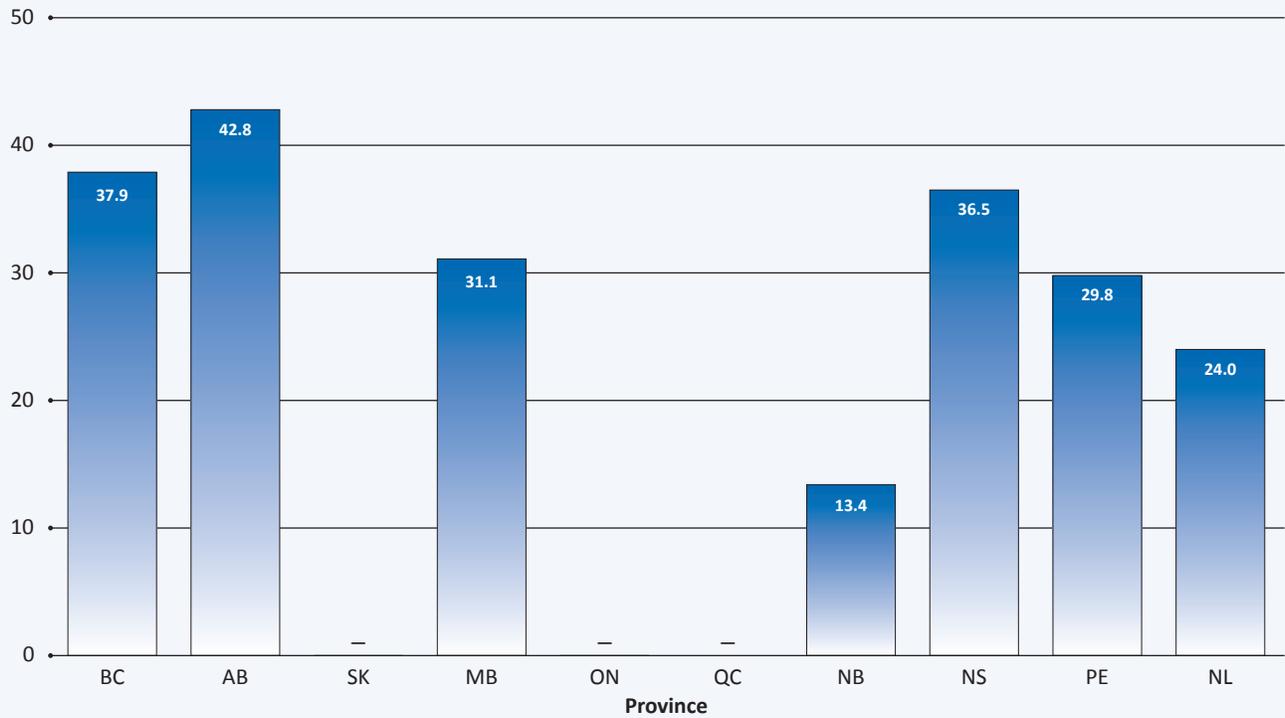
What are the key findings?

- There was relatively wide variation across reporting provinces in the use of radiation therapy in the last year of life among men who died of prostate cancer. Rates of use ranged from 14.3% in New Brunswick to 41.9% in Alberta (Figure 8.2). Similarly, for breast cancer, rates ranged from 13.4% in New Brunswick to 42.8% in Alberta (Figure 8.1).

FIGURE 8.1

Percentage of women with breast cancer receiving radiation therapy in the last year of life, by province – two most recent death years available

Percent (%)



“—” Data not available.

MB and NL: Data include 2011–12 death years combined. All other provinces include 2012–13 death years.

NB: 2011 and 2012 radiation therapy data may be incomplete.

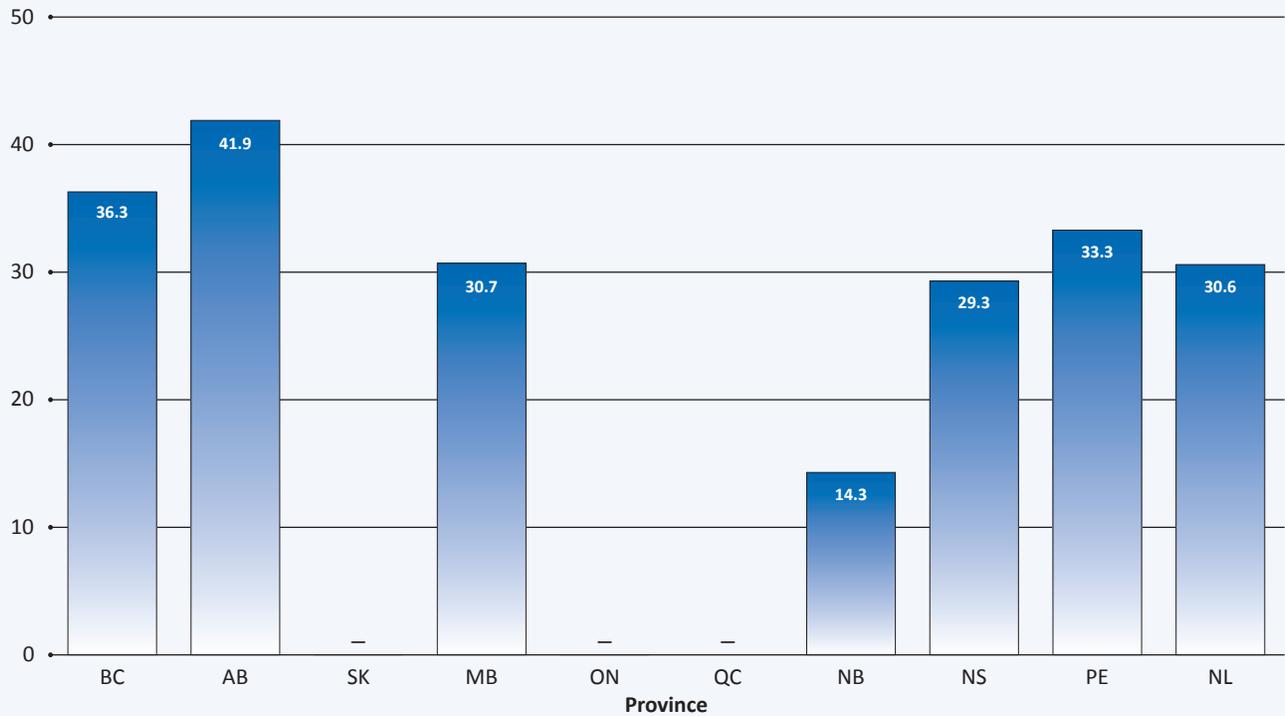
NL: 2011 radiation therapy data may be incomplete.

Data source: Provincial cancer agencies and programs.

FIGURE 8.2

Percentage of men with prostate cancer receiving radiation therapy in the last year of life, by province – two most recent death years available

Percent (%)



“—” Data not available.

MB and NL: Data include 2011–12 death years combined. All other provinces include 2012–13 death years.

NB: 2011 and 2012 radiation therapy data may be incomplete.

NL: 2011 radiation therapy data may be incomplete.

Data source: Provincial cancer agencies and programs.

Why do these findings matter?

The underuse of radiation therapy as a palliative care treatment is well-documented in the literature, despite the evidence of its effectiveness for managing pain.^{55, 56} The results shown here may support these findings.

Physician referral practices have been identified as one of the most influential drivers of palliative radiation therapy uptake. For example, for men with metastatic prostate cancer, the referring physician may be a radiation oncologist, palliative care specialist or primary care physician. Several factors may influence a physician's decision to refer a patient for this treatment. These include the patient's age, the type and stage of cancer, the presence of comorbid conditions, the patient's personal preference and the patient's proximity to a radiation centre.^{53, 55, 56} Another contributing factor can be the physician's awareness of indications for palliative radiation therapy and of its effectiveness at managing pain.⁵⁷

Use of multidisciplinary consults (known in some provinces as tumour boards) may increase the likelihood of a patient receiving palliative radiation. Also, relatively low radiation treatment utilization rates in a province, coupled with relatively low linear accelerator (LINAC) capacity, may indicate potential access limitations. However, data on LINAC capacity from 2011 do not support this idea. For example, British Columbia reported a low LINAC capacity⁵⁸

while reporting the second highest utilization rate for palliative radiation treatment (Figures 8.1 and 8.2).

Provinces with regional rapid palliative radiation therapy programs may also have higher rates of use. These clinics provide more streamlined access to radiation therapy: patients can be seen quickly for consultation and treatment. For example, Alberta these programs at the Cross Cancer Institute in Edmonton and at the Tom Baker Cancer Centre in Calgary,⁵⁹⁻⁶² which could explain the relatively high palliative radiation therapy use in Alberta reported here.

Recent data show that approximately half of cancer patients receive multi-fraction regimens to manage bone metastases, as opposed to single-fraction regimens.⁶³ In a Choosing Wisely Canada recommendation, the Canadian Association of Radiation Oncologists recommends single-fraction regimens to decrease patient and caregiver burden (e.g., reducing the number of visits to a radiation centre, which can be a barrier for some patients)—convenience may often outweigh considerations of long-term effectiveness for patients with a limited life expectancy.⁶⁴⁻⁶⁶

Rates of palliative radiation therapy use may reflect different uptake of recommendations across provinces. For example, British Columbia reported one of the highest rates of palliative radiation therapy for breast and prostate cancer (Figures 8.1 and 8.2), while also reporting the highest percentage of patients receiving one fraction of palliative radiation.⁶³

Data and measurement considerations

- This indicator provides insight only into the proportion of prostate and breast cancer patients who received radiation therapy during the study period. It does not quantify the period of time during which they received treatment, the number of fractions received or the length of time since a patient's last palliative radiation therapy treatment.
- Palliative intent was not captured owing to limitations in the data. Whether treatment was undertaken for palliative purposes cannot be confirmed; however, it is likely that most cancer patients who received radiation therapy within the last year of life did so for palliation (i.e., pain relief).
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology, are in the full Technical Appendix.

Special Feature: Palliative home-care visits in the last six months of life

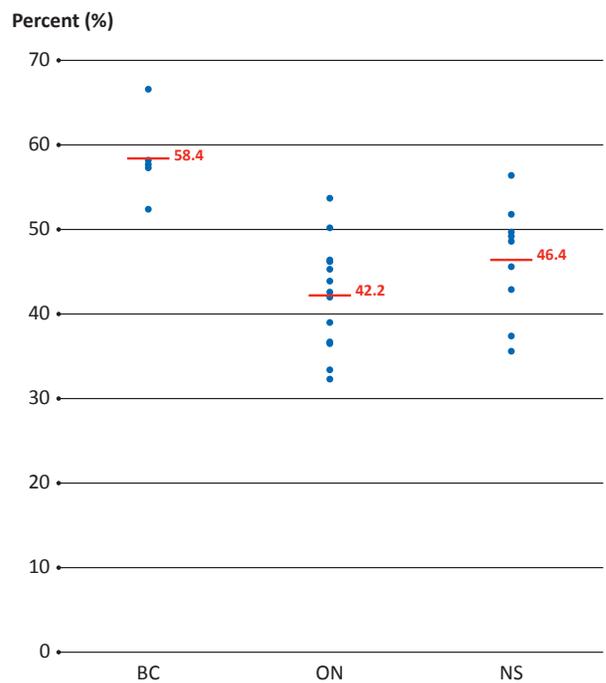
An important indicator of quality care is access to palliative care at home, provided by a nurse or personal support worker.³¹ Access to community-based services, including home care and other palliative care, is needed considering the high proportion of cancer patients who wish to spend their last days at home. The gap between patient preference for place of death (often at home) and what they experience at end of life may partly be attributable to variability in home care services across health regions. Cancer patients may visit emergency departments as a result of acute symptom management crises or for non-urgent matters that could be better managed in the community. Access to palliative care at home is often associated with fewer unplanned emergency department visits and a higher number of home deaths (a 50% reduction in the likelihood of dying in hospital).¹⁴⁻¹⁶

A Canadian study showed that there was considerable variation across three reporting provinces in the percentage of cancer patients who received home care in the last six months before death from 2004 to 2009.³¹ Six months prior to death was used as a time frame for this study because it is a clinically relevant period for commencing home care services and is often used to describe health care service use at the end of life.⁶⁷ The average proportion of patients who received home care visits ranged from a low of 42.2% in Ontario to a high of 58.4% in British Columbia in 2004–09 (Figure 9).

Variation across health regions also existed in a given province; for example, palliative home care visits ranged from 32.3% to 53.7% in different areas of Ontario (Table 1.1). People living in rural and urban centres may receive differing levels of palliative home care at the end of life. It is important to note that these data do not provide information on the quality of palliative care services provided nor do they provide information on home care visits from doctors.

FIGURE 9

Percentage of cancer patients who received palliative home care visits from a nurse or personal support worker in the last six months of life, by province and health region – 2004–09



Dots represent health regions within each province.

Data include BC, ON and NS.

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TABLE 1.1

Percentage of cancer patients who received palliative home care visits from a nurse or personal support worker in the last six months of life, by province and health region – 2004–09

Province	Health region	Study population size (n)	Palliative home care visit by nurse or personal support worker in last 6 months (%)
BC	Fraser	12,131	57.3
BC	Vancouver Island	8,672	66.6
BC	Vancouver Coastal	8,561	58.2
BC	Interior	8,404	57.7
BC	Northern	2,296	52.4
ON	Hamilton Niagara Haldimand Brant	15,951	46.2
ON	Central East	13,746	43.9
ON	Central	11,683	42.6
ON	Champlain	11,527	50.2
ON	South West	10,165	33.4
ON	Toronto Central	10,065	42.6
ON	Mississauga Halton	7,536	42.0
ON	North East	7,474	36.7
ON	Erie St Clair	7,124	46.4
ON	Waterloo Wellington	6,142	53.7
ON	South East	6,084	39.0
ON	North Simcoe Muskoka	4,895	45.3
ON	Central West	4,498	36.5
ON	North West	2,601	32.3
NS	Capital	4,400	49.7
NS	Cape Breton	2,233	42.9
NS	Annapolis Valley	1,197	45.6
NS	Colchester East-Hants	955	49.2
NS	South West	951	51.8
NS	South Shore	926	48.6
NS	Pictou	740	56.4
NS	Guysborough-Antigonish Strait	721	35.6
NS	Cumberland	629	37.4

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Data presented here examined access to palliative home care by health region. This comparison allowed each region to determine its performance relative to other regions with similar populations and to facilitate the evaluation of health care delivery in each region. British Columbia generally had the best performance for home care visits—most of its health regions performed well relative to some health regions in Ontario and Nova Scotia (Figure 9 and Table 1.1). These data also showed that there was no relationship between the health region’s population and the likelihood of patients receiving home care (Table 1.1). The theory that better access to palliative home care reduces death in hospital was not explored in these data, but previously published Canadian data showed that use of home care was associated with decreased odds of death in acute-care settings.⁶⁷

Higher neighbourhood income is associated with an increased likelihood of receiving a home care visit at the end of life.⁶⁸ This suggests that capacity constraints (e.g., financial barriers to accessing drugs, equipment and personnel) may influence whether a cancer patient receives home care. Although in Canada there is access to home care through the publically funded health care system, availability varies widely across the country.⁹ Other factors that may influence access to home care include having family or caregivers at home to support the patient (such as helping provide medications and other symptom management) as well as the cost of medications, which may be variably covered by Canada’s health care system or by private insurance and out-of-pocket payment.⁶⁸

What are some examples of efforts in this area?

The Canadian government set the expectation that palliative home care should be available in all provinces. This includes ensuring services (e.g., drugs, equipment) are adequate to support care at home. However, the type of home care and amount of time provided varies depending on the needs of people with cancer who are approaching the end of their lives. The federal government has committed to including in the new Health Accord support for the delivery of more and better home care, including palliative care.⁶⁹

Through funding from the Canadian Partnership Against Cancer, Nova Scotia and Prince Edward Island now provide emergency palliative home care support by paramedics. Paramedics are provided with education, expanded clinical skills and supports to respond to emergency calls from palliative patients and families, regardless of time of day or location. The project aims to help patients attain their goals of care, reduce emergency department visits and avoid hospital inpatient admissions.

Data and measurement considerations

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- Data on palliative home care in the last six months of life are from provincial organizations overseeing home care services for three provinces (Home and Community Care in British Columbia, Continuing Care in Nova Scotia and the Ontario Association of Community Care Access Centres in Ontario).
- For details on data specifications refer to Barbera et al.

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