

Palliative and End-of-Life Care

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SYSTEM PERFORMANCE REPORTS

All Canadians with cancer should get the best possible palliative care when they need it and in the place of their choice. That care should address the individual physical, emotional and spiritual needs of patients and the people who care for them.

To enable cancer patients to experience that kind of care, the Canadian cancer care system needs to make two key changes:

- 1 Health care administrators should adopt, develop and implement standards or practice guidelines to identify, assess and refer patients to palliative care services earlier in their cancer journey to ensure optimal quality of life.
- 2 Provincial and territorial governments should ensure that adequate community-based multi-disciplinary palliative care services are available at home, in hospices and in long-term care facilities to ensure that palliative and end-of-life needs are met and to reduce reliance on acute care.

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹ The WHO says that patients should receive palliative care “early in the course of illness, in conjunction with other therapies that are intended to prolong life.”



Benefits of early palliative care for patients with cancer and for their family caregivers

Early integration of palliative care into a person’s cancer journey leads not only to an improved quality of life—better symptom control, reduced anxiety and pain, and more support for emotional, social and spiritual needs—but also to greater satisfaction with care. In some cases, palliative care prolongs survival.^{2,3}

Including palliative care in routine care and treatment planning earlier—and providing that care in the community—can

- reduce unplanned visits to the emergency department;
- reduce the number of avoidable admissions to hospital;
- shorten hospital stays;
- improve the way patients and their families feel, physically and emotionally; and
- increase the opportunity, when desired, of dying fully supported at home for patients with terminal cancer.^{4,5}



FIGURE 1
Palliative Care Bow Tie Model

Early integration of palliative care

The concept of beginning palliative care early in the patient’s journey is illustrated by the “Bow Tie” Model above (Figure 1).⁶ The blue triangle represents disease management, including chemotherapy, radiation, surgery and related psychosocial care. The purple triangle represents palliative care, including pain and symptom management and related psychosocial care. The patient’s illness takes them to the possible outcomes of rehabilitation and survival or end-of-life care and death, moving through a complementary continuum of disease management and palliative care, with an increasing emphasis on palliative care toward the end of life.

Palliative care can and should be extended not just to patients but to their families and other people who help care for them and may include the following:

- education about the illness and the patient’s prognosis;
- relationship building with patients and family members providing care;
- psychosocial (emotional and behavioural) and spiritual support;
- discussion of treatment goals;
- comprehensive management of symptoms such as pain, fatigue, depression and anxiety;
- coordination with a multidisciplinary care team (e.g., nurses, physicians, other health providers); and
- bereavement counselling⁷.

“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
Family Caregiver



Canadians’ views on palliative care

A recent survey of 1,540 Canadians showed that only 58% were aware that palliative care is available to people who need it. Just over half (51%) of people surveyed have had someone important to them receive palliative care in Canada in the past 10 years.⁸ But only about 16% said someone important to them had received palliative care at home or in a hospice, even though patients and family give these settings the highest satisfaction scores (up to 93%).

Most people (90%) agreed that patients should have the right to receive care in their home at the end of life.⁸ But not enough home palliative care resources or services (such as grief counselling, financial support, access to equipment at home, caregiver respite, physical therapy and emotional support) are available to make this possible.



“We talked about palliative care in the beginning but Doug did not like the word. He thought he did not need it yet. He imagined it was only for the old and dying and that he was not there yet. My sister [an oncology nurse] helped us understand that palliative care was really so much more than that. It was about supporting us to live the best possible way until the end.”

Marie

Family Caregiver

Marie reflects on her husband's experience with palliative and end-of-life care and his decision to die at home.

DIAGNOSIS

My husband, Doug, was 50 years old when he was diagnosed with Stage IV lung cancer. Given that Doug led a very healthy lifestyle and was a non-smoker, cancer was the farthest thing from our minds. He had experienced pain in his bones and chest, but had not yet been to see his family doctor. Shortly after, Doug had a massive seizure, which brought him into the hospital. It was then that a CAT scan found lesions on Doug's brain. We were told it was palliative and that there would be no recovery.

SHOCK

Needless to say, we were shocked. We did not expect this at all, but now we knew what was ahead and what the ultimate outcome was going to be—just not how long or what would happen exactly.

QUALITY OF LIFE

Doug and I had difficult conversations on how we wanted this journey to be and what was important to us. We had a business, a 13-year-old son, were in our early 50s with careers, had extended families who loved us dearly and now we had to walk this journey. We decided to face the journey ahead with courage,

commitment to one another, and do our best to live as healthy as possible and for as long as possible.

SUPPORT

We did not use all the supports palliative care had to offer at the beginning. We hired a nurse to support Doug at home during the daytime. Doug's family doctor was amazing—he made home visits, as did the minister from our spiritual community to comfort and pray with Doug. Physical, spiritual and financial support allowed us to sort out how to cope and manage.

DECISION TO DIE AT HOME

It was really important to Doug that he die at home. I left my work to be with him and support him at all times; I became his primary caregiver. Doug spent his final days at home, where he wanted to be, and stayed engaged in family life as much as possible until the end. Doug passed away surrounded by family members. It was sad and yet beautiful and respectful and it was so important that his wish to be at home was realized.

Disease Journey



Limitations to measuring and reporting on palliative and end-of-life care in Canada

The cancer control community has been limited in its ability to measure and report on palliative care services and practices across the whole care system because data are sparse. Palliative care is delivered in a number of settings, including patients' homes, hospitals, outpatient clinics, hospices and long-term care facilities, and this variety poses a huge data challenge. Data on community care, primary care services and outpatient care were not available for this analysis.

Most measures used in this report examine only end-of-life care—one component of palliative care—and only in a single sector (inpatient care in acute-care institutions), not throughout the patient journey. The data we have do not capture the full range or scope of the palliative care services provided, nor do they provide information on patients who received palliative care in other settings (e.g., outpatient palliative care).

Reporting on the information we do have should

- 1 highlight gaps in the information available on system-wide palliative care delivery in Canada;
- 2 stimulate the production of better data; and
- 3 promote higher quality palliative care delivery.

“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.”

Penelope
Family Caregiver

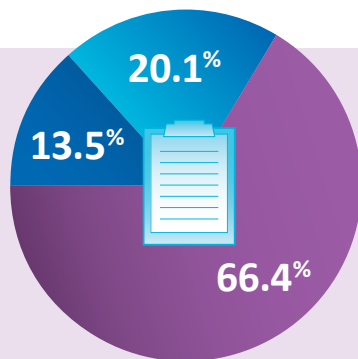
“When you are in a situation like that you sort of just accept what you have and work with it. But, if I had known then what I know now about palliative care, I might have been less accepting of the care we received. I did not understand palliative care at the time. I now know palliative care is so much more than what we had.”

Jane
Family Caregiver

Effective health care integrates palliative care into the patient’s journey as early as possible.

Data suggest that patients with cancer who die in acute-care hospitals do not always receive inpatient palliative care early in their illness. We need better national data on the delivery of palliative care across all care settings.

- Data suggest that 13.5% of patients with cancer who died in acute-care hospitals had not been identified as needing inpatient palliative care. For patients who were identified, data suggest that most (66.4%) received inpatient palliative care only during their last hospitalization, which can be too late for patients to experience the full benefits of palliative care (Figure 2).
- To allow for more meaningful reporting on palliative care, Canada’s cancer control system needs to gather more national data on how we provide such care throughout the health care system. Palliative care can be offered in a variety of settings; system-wide measurement could show how palliative care is used across the country and whether it is initiated early in the cancer journey or in the patient’s final days.
- A possible barrier to patients receiving palliative care earlier may be the misperception that palliative care means only end-of-life care. Care providers might fear that offering this type of care early could reduce hope for the patient and family (this is also often a concern of physicians not wanting to talk about palliation in the midst of treatment).



- Patients with no palliative code
- Patients who had first palliative code before final admission
- Patients who had first palliative code at final admission

FIGURE 2
Palliative care designation for people who died of cancer in an acute-care hospital, Canada – 2014–15 combined

Inpatient Palliative Care Analysis

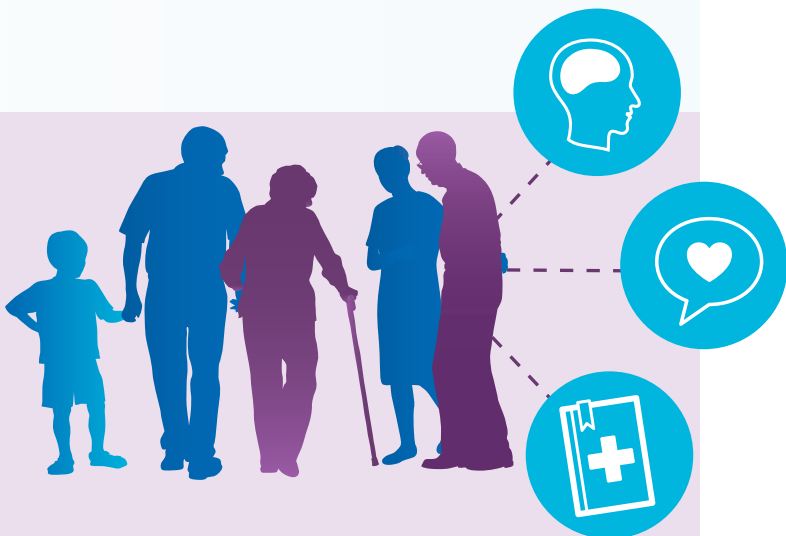
In an acute-care hospital, a palliative care designation (“coding”) should be made for a patient whenever a physician has documented that palliative care is needed. That documentation may include a palliative care consultation and initiation of a palliative care treatment plan; physician notes

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.⁹

But importantly, a palliative care code or notes in a patient’s chart does not give us information on the range or scope of palliative care services the patient actually received, nor does it mean the patient experienced optimal palliative care.

Figure 2
Data include all provinces and territories except QC.
Data source: Canadian Institute for Health Information, Discharge Abstract Database.

Providing palliative care (including palliative home care) earlier increases patients' satisfaction with their care. It also leads to better control of pain and other symptoms and it better supports patients and their families emotionally and psychologically. It can reduce hospitalizations and the overuse of potentially ineffective or aggressive treatments at the end of life. Integrating palliative care means coordinating distinct services centred on the needs and preferences of people with advanced cancer and the needs of their families.



Palliative and end-of-life care integration

In 2014, the Canadian Partnership Against Cancer 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.

An online survey was sent to all regional cancer centres in 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 at each cancer centre. By the end of February 2017, 80% of cancer centres had responded. The majority of respondents indicated that they had dedicated outpatient specialist palliative care clinics (not counting subspecialized interventional clinics such as palliative radiotherapy access clinics). Further, the respondents identified that standardized symptom screening was part of the outpatient palliative care clinics. 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 results to date provide preliminary insight into palliative care integration in cancer centres. In addition, a survey has been 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.

Patients with advanced disease should be able to access fast, effective care in the community (including primary care and home care), with acute hospitalization only when necessary.

Many patients with cancer approaching the end of life are admitted to acute-care hospitals or visit emergency departments, often several times. Community- and home-based end-of-life care may not be meeting patient needs.

Acute-care hospitals do have a role in managing the health care needs of people affected by cancer when they are at the end of life. But we should strive to provide end-of-life care in other settings, including at home or in hospice, when that is more appropriate.

Patients may be hospitalized unnecessarily at the end of life because they were not ready to go home when they were previously discharged or because community resources and supports were inadequate. This includes limited availability of palliative care that

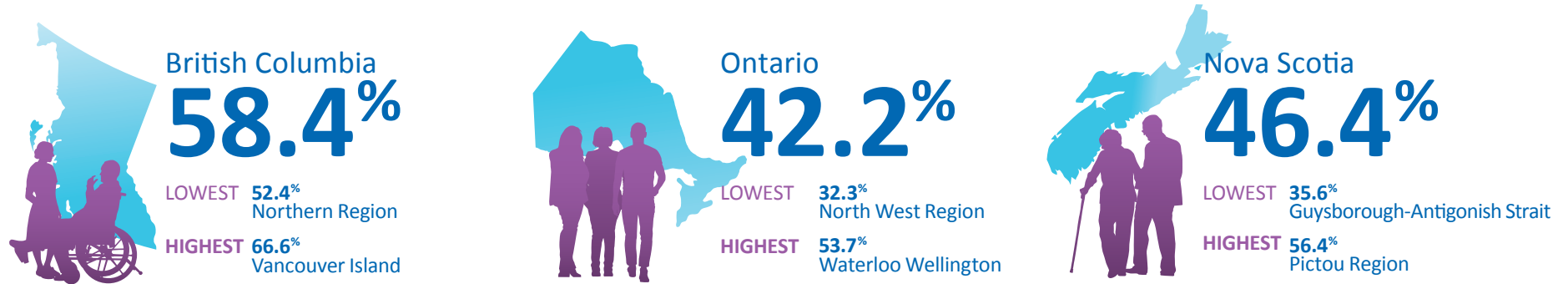
can be provided in a home environment. Sometimes a patient's family caregivers are overburdened. But multiple visits to a hospital can be distressing and exhausting for patients and the people caring for them—wait times can be long and the hospital environment can be stressful and overcrowded and can expose patients to infections. Prince Edward Island, Nova Scotia and some areas of Alberta now have paramedics supporting palliative home care programs so that patients at home have greater access to care anytime.

Access to palliative care at home provided by a physician, nurse or personal support worker is one indicator of health care quality. Such care is often associated with fewer unplanned emergency department visits and increased opportunities for patients to die at home if that is what they want.^{4,5,10} In smaller regions palliative home care is integrated with general home care.

Access to palliative home care

FIGURE 3

Palliative home care visits from a nurse or personal support worker in the last 6 months of life – 2004–09 combined



- In a three-province study, the average percentage of patients receiving palliative home care from a nurse or personal support worker in the last six months before death was 42.2% in Ontario, 46.4% in Nova Scotia and 58.4% in British Columbia (Figure 3).¹¹
- Regional variations existed within provinces. For example, in Ontario use of palliative home care varied by 21 percentage points between health regions.
- Factors that may influence access to home care include having people at home to help care for the patient (such as helping provide medications and other symptom management) and the cost of medications, which may be covered by Canada’s health care system, by private insurance or by out-of-pocket payment, depending on the situation.

Figure 3
Data source: © 2015 American Society of Clinical Oncology. Reprinted with permission. All rights reserved. Barbera, L et al: J Oncol Pract (Quality Indicators of End-of-Life Care in Patients with Cancer: What Rate Is Right?). Vol. 11(3), 2015: 279-287.

Length of stay in acute-care hospitals

- On average, half of patients dying from cancer spend two to three weeks in an acute-care hospital near the end of life: the median cumulative length of stay during the last six months of life ranged from 17 days (Ontario) to 25 days (Manitoba) (Figure 4).

FIGURE 4

Cumulative length of stay in acute-care hospitals in the last 6 months of life, by province – 2014–15 combined

Figure 4
QC and territories: Data not available.
Acute-care hospital deaths included adults 18+ discharged in fiscal years 2014/15 and 2015/16.
MB, NS and PE have palliative care units within some acute-care hospitals so the cumulative length of stay may appear higher than other provinces.
Data source: Canadian Institute for Health Information, Discharge Abstract Database.

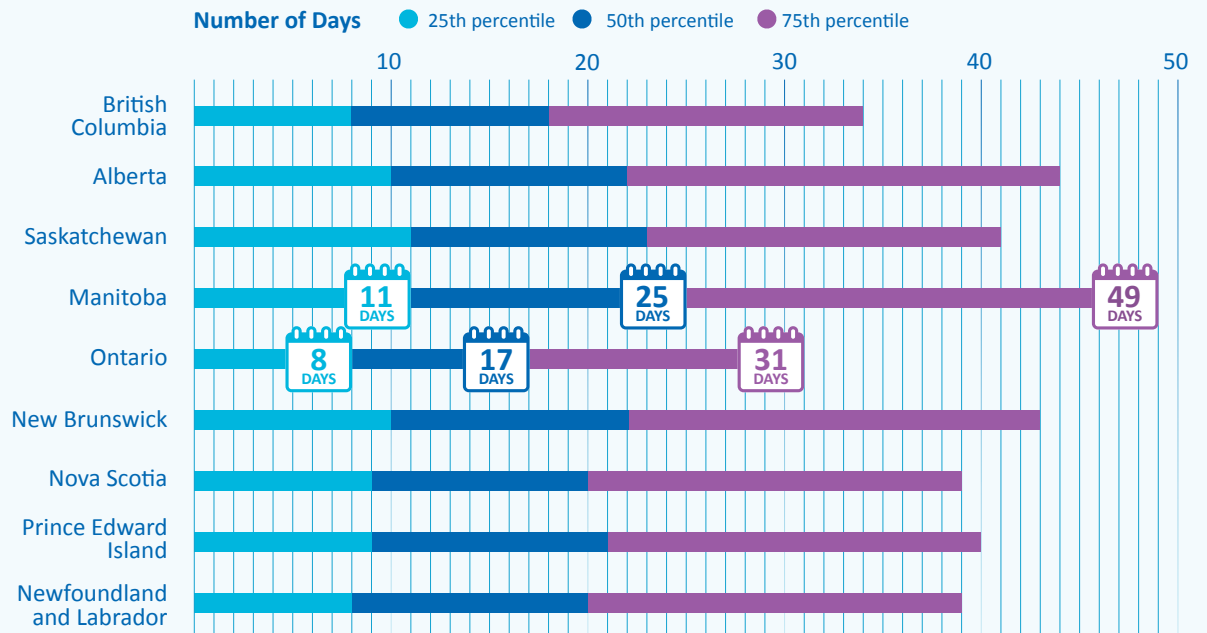
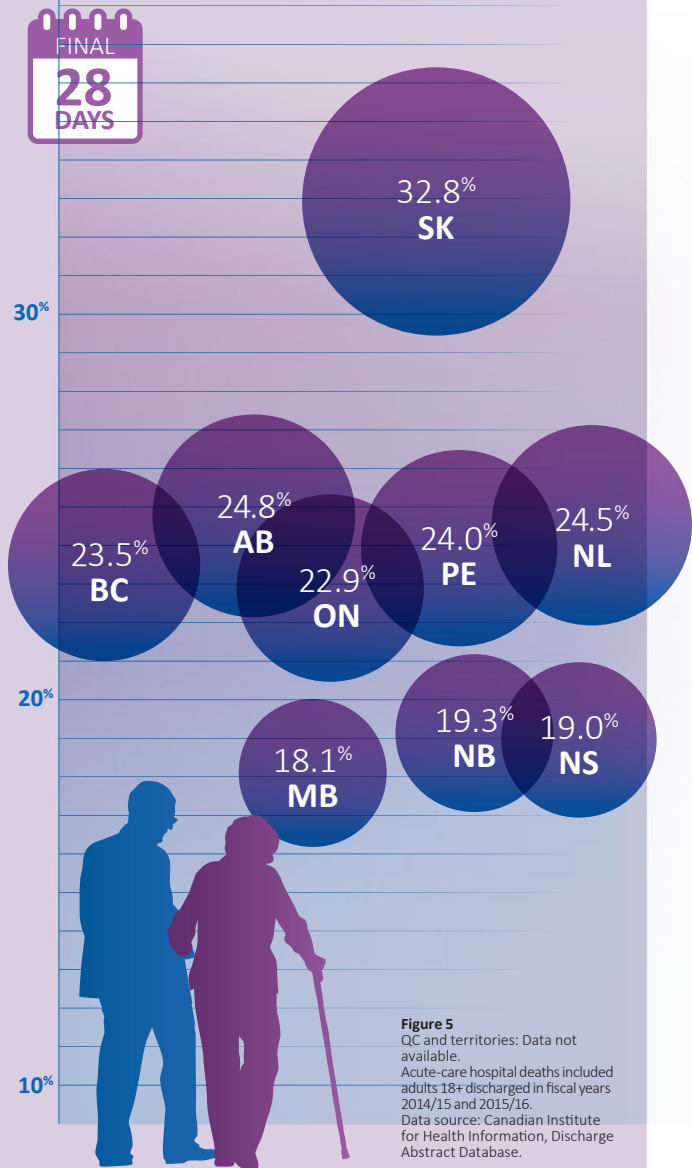


FIGURE 5

Two or more admissions to acute-care hospitals in the last 28 days of life, by province – 2014–15 combined



Patient admissions to acute-care hospitals and visits to emergency departments in the last month of life

- Nationally, almost a quarter (23%) of patients are admitted to an acute-care hospital twice or more in the last month of life (Figure 5).
 - An acute-care hospital may be the best place for patients with complex medical needs to receive care. But longer and more frequent hospital stays may signal a potential gap in outpatient or community-based palliative care services.
 - Moving between care settings numerous times near the end of life may worsen a patient's quality of life. Good communication between the patient, family and physicians, including being clear about the patient's goals of care, can enable higher-quality palliative care centred on the needs of patients and those caring for them.
- In Ontario and Alberta (the only provinces for which these data are available) 24.5% of patients with cancer visited the emergency department twice or more in the last month of their lives (Figure 6).
 - Continuing to ensure that appropriate clinic, outpatient and community services (including home care) are available will reduce emergency department visits.

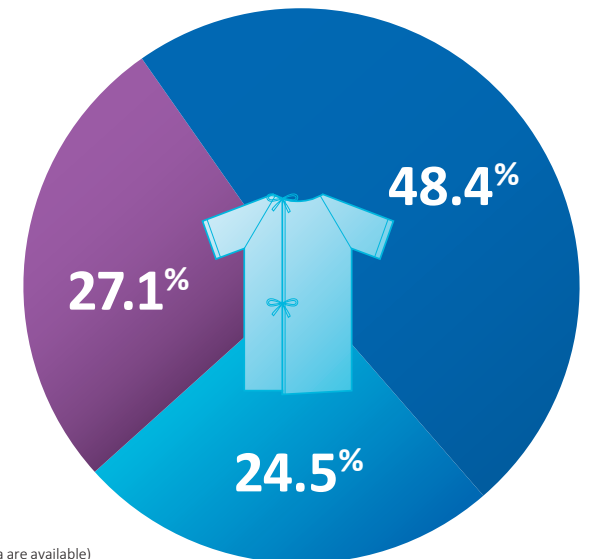
FIGURE 6

Emergency department visits in the last 28 days of life, Ontario and Alberta combined – 2014–15 combined

- No visits
- One visit
- Two or more visits

Figure 6

Data include only ON and AB patients (where comprehensive emergency department data are available) 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.



Patient admissions to an intensive care unit in the last 14 days of life

- A relatively small proportion of patients dying of cancer in an acute-care hospital were admitted to an intensive care unit (ICU) in the last 14 days of life—between 6.4% in Nova Scotia and 15.1% in Ontario (Figure 7).
 - While the use of ICUs at the end of life for patients with cancer is low, use varies among provinces, meaning it is likely that we could provide care in other settings for some patients.

“Our palliative care experience was beautiful in many ways. Many might be surprised by the fact that we knew Doug was dying and that was almost unbearable in its reality, but we were at home and together as a family. Our ability to be at home provided a sense of normalcy in some ways.”

Marie
Family Caregiver

FIGURE 7
Admissions to an intensive care unit in the last 14 days of life, by province – 2014–15 combined

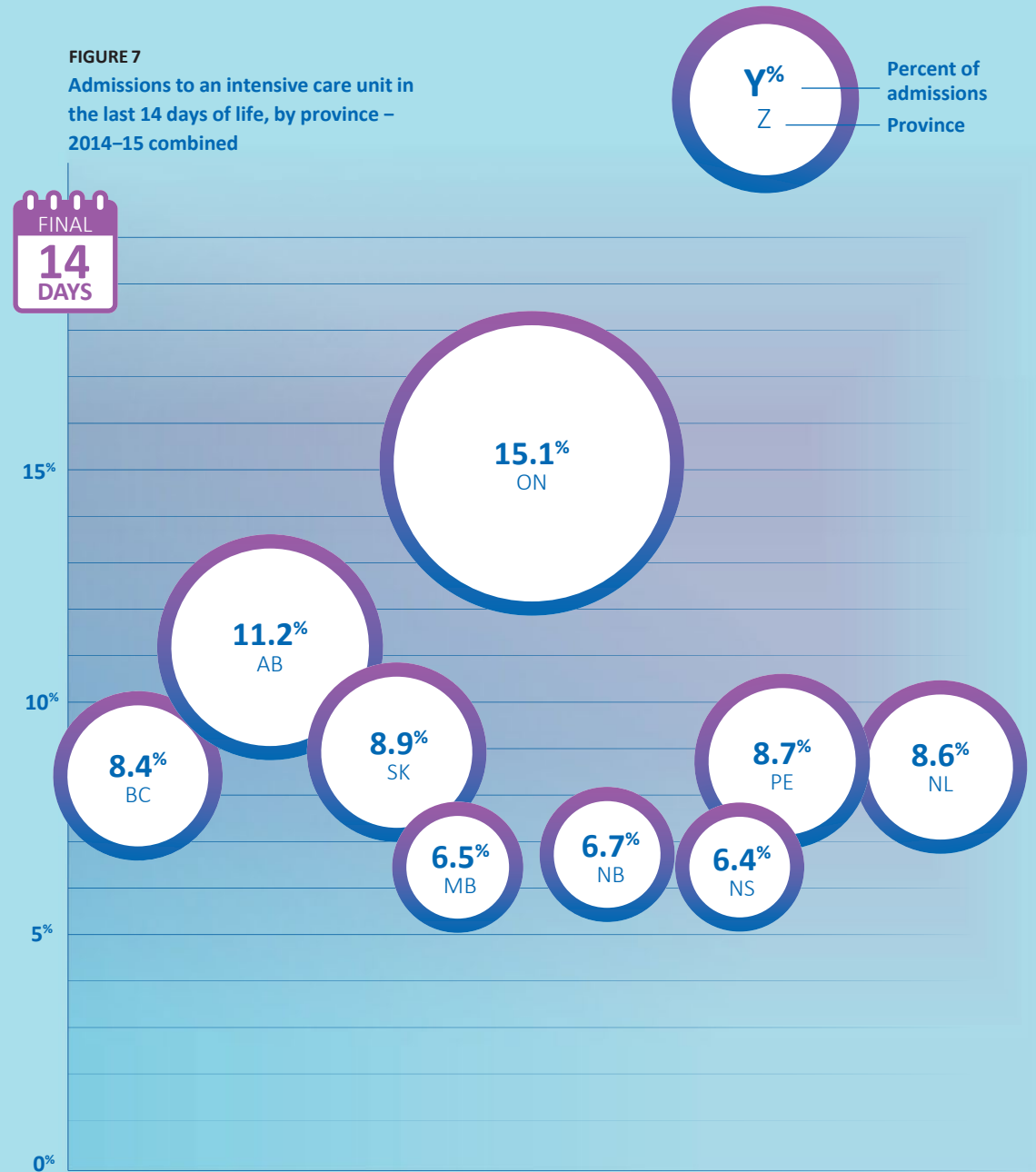


Figure 7
QC and territories: Data not available.
Data on intensive care unit admissions include only facilities that report ICU data.
Acute-care hospital deaths include adults aged 18+ discharged in fiscal years 2014/15 and 2015/16.
Data source: Canadian Institute for Health Information, Discharge Abstract Database.

From 2014 to 2015, of the patients with cancer who died in acute-care hospitals,

78%

were admitted directly from home

&

70%

were admitted through the emergency department.

Patient deaths in acute-care hospitals

Canadian surveys have shown that many patients with cancer would prefer to receive care and spend their final days at home or in a hospice rather than in a hospital.¹² But the limited availability of the right home- or community-based palliative care resources (e.g., to ensure effective symptom management) may make it more difficult for patients to be at home or in a hospice in their final days.¹³

- In Canada, 43.0% of deaths from cancer occurred in acute-care hospitals. The percentage ranged from 37.0% in Ontario to 70.0% in Manitoba and New Brunswick (Figure 8). Of patients who died in hospital, 77.9% were admitted directly from home and 70.4% through the emergency department.
 - While patient surveys have indicated that hospitals are often the least preferred setting for end-of-life care,¹⁴ many factors may influence where patients actually die. High rates of admission through emergency departments might mean inadequate availability of or access to primary care and community-based services.
 - High hospital death rates may also reflect a lack of planning for impending death, with the need for increased community support or referral to a non-acute-care setting (e.g., hospice).
 - While jurisdictions may offer effective palliative and end-of-life care services in acute-care hospitals (resulting in a higher rate for this indicator) they are still hospital-based services and cannot be considered equivalent to fully supported home-based end-of-life care.

FIGURE 8

Cancer deaths in acute-care hospitals, by province – 2014–15 combined

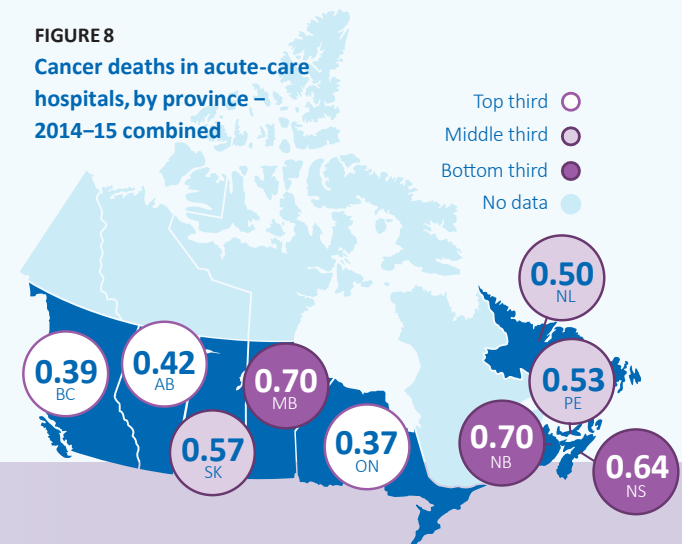


Figure 8

Data presented are ratios of the number of cancer deaths in acute-care hospitals to the projected cancer mortality cases. Projected mortality cases included all cancer deaths aged 0+ in 2014 and 2015. Acute-care hospital deaths included adults 18+ discharged in fiscal years 2014/15 and 2015/16. Number of cancer deaths in acute-care hospitals = 48,987. QC and territories: Data not available. Data source: Canadian Institute for Health Information, Discharge Abstract Database; Canadian Cancer Society, Canadian Cancer Statistics.

“Death is not optional, we will all face it one day; the teaching and learning about death should not be optional. Every provider should have core knowledge of palliative care.”

Dr. Bernard Lapointe

Palliative Care Provider

Effective health care ensures that patients nearing the end of life receive appropriate treatments aimed at reducing symptoms and providing comfort, guided by their values and preferences.

Relatively few patients with cancer started new chemotherapy regimens in the last month of life, which is positive. But access to palliative radiation may not be adequate, despite its effectiveness for managing pain and other symptoms.

For patients with advanced disease nearing the end of life, the focus of care should be more on reducing pain and discomfort in a supportive setting and less on aggressive and often futile curative treatment (e.g., chemotherapy and surgery intended to cure). Chemotherapy use in the last weeks of life can lead to lower patient satisfaction with care, more frequent hospital visits, no or very short hospice involvement and death in an acute-care setting.¹⁵

Radiation therapy plays an important role in the curative treatment of non-metastatic cancer, but it is also 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).¹⁶⁻¹⁸ Ensuring that patients with advanced cancer have access to palliative radiation is an important aspect of quality care.

- Encouragingly, fewer than 4% of patients with cancer began a new chemotherapy regimen in the last 30 days of life (ranging from 1.8% in Nova Scotia to 3.9% in Ontario) (Figure 9).

FIGURE 9

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

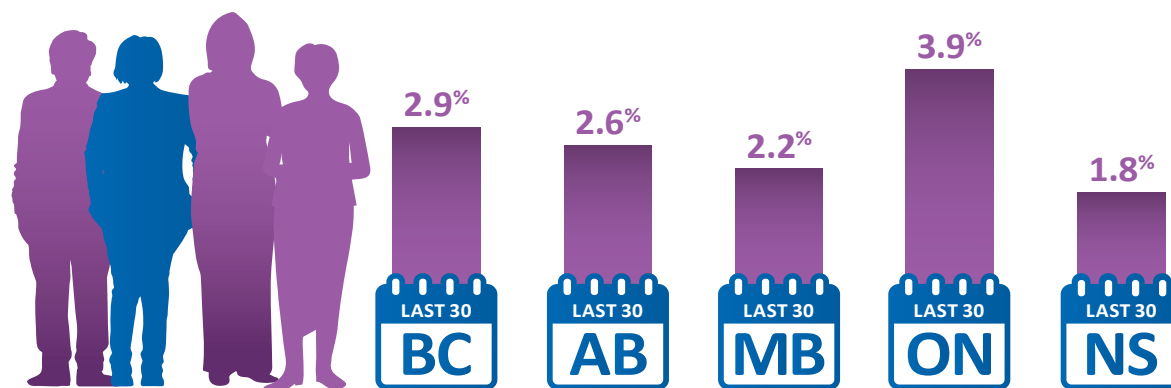


Figure 9

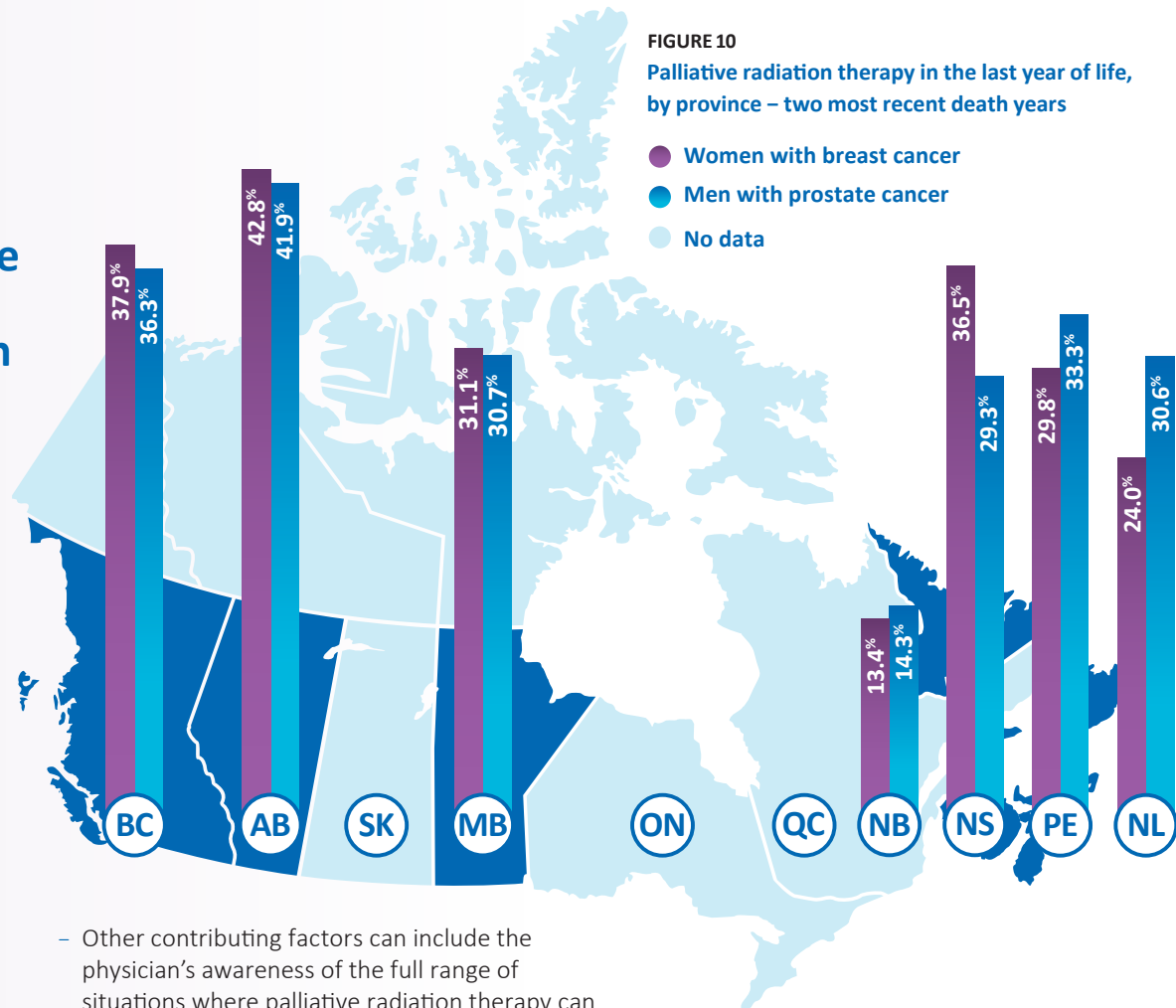
[†]AB, MB and ON included oral chemotherapy. In MB, data on oral chemotherapy were not complete in the cancer registry, but have been included if available. NS estimate is conservative since oral chemotherapy data were not available and patients with hematological cancers were excluded from the analysis. 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 not available for SK, QC, NB, PE, NL and the territories.

Chemotherapy near the end of life may be warranted in some cases. The data may also include patients without advanced disease who received adjuvant chemotherapy appropriately but died of complications (e.g., toxicity of chemotherapy) shortly after.

Data source: Provincial cancer agencies and programs.

While curative chemotherapy may not always be appropriate for patients with advanced cancer, palliative radiation is an important therapy option for patients with pain and other discomfort at the end of life.

- Fewer than 43% of patients with prostate or breast cancer receive palliative radiation therapy in the last year of life (Figure 10). Based on data reported by the provinces, the use of palliative radiation varied relatively widely across the country. For men with prostate cancer, rates ranged from 14.3% in New Brunswick to 41.9% in Alberta. Similarly, for women with breast cancer, rates ranged from 13.4% in New Brunswick to 42.8% in Alberta.
- Physician referral practices may influence palliative radiation therapy use. A physician's decision to refer a patient for this treatment can be influenced by 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.



- Other contributing factors can include the physician's awareness of the full range of situations where palliative radiation therapy can be used and of its effectiveness at managing pain, and the physician's comfort and skill in discussing this treatment with patients.¹⁹

Figure 10

Data not available for SK, ON, QC and the territories.
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.
Palliative care intent is unknown.
Data source: Provincial cancer agencies and programs.

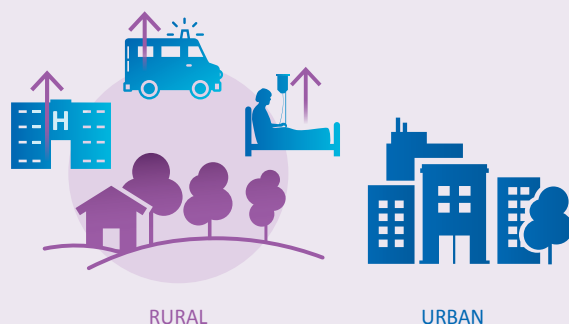
Effective health care means all patients with cancer have access to high-quality, person-centred palliative and end-of-life care regardless of their age, where they live or the disease they have.

Data suggest differences in end-of-life care that in some cases may point to inequities in access to required services based on where a person lives, their age and type of cancer.

Underserved populations, including low-income, Indigenous and rural populations, among others, often have complex needs that need to be addressed to ensure they receive equitable access to palliative and end-of-life care.

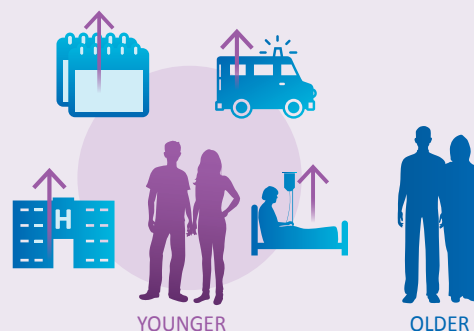
Rural disparities

- Rural residents are more likely to be admitted to an acute-care hospital numerous times, make more emergency department visits and are admitted to ICUs more often at the end of life.
 - These patients may not have adequate access to primary care (e.g., there may be no walk-in clinics or a shortage of family physicians). Lack of access to community-based services after clinic hours for rural residents may increase the likelihood of admission to hospital.



Variations by patient age

- Younger patients with cancer (aged 18 to 29 years) are more likely to die in an acute-care hospital; to stay in hospital longer; to have more hospital admissions, emergency department visits and ICU admissions; and to receive a new chemotherapy regimen near the end of life.
 - Younger patients may undergo more aggressive treatment resulting in increased hospital use. This may be appropriate in many situations but should be monitored.



Variations by type of cancer

- People with lung, colorectal or pancreatic cancer; leukemia; or non-Hodgkin lymphoma are more likely to die in an acute-care hospital. People with blood cancers (leukemia and non-Hodgkin lymphoma) are more likely to have longer stays in an acute-care hospital, more admissions to hospital and more ICU admissions at the end of life.
 - These patients are more likely to be hospitalized near the end of life than others. This fact may be related to the complexity of symptoms (which are often related to cancer type) and the types and timing of treatments. Complications of therapy may require a multidisciplinary team approach that makes a home death difficult.²⁰
 - Certain cancer types tend to be diagnosed at later stages than others, possibly resulting in less time to prepare for a death at home.

THE DATA WE HAVE SUGGEST THAT ACTION IS NEEDED IN THE FOLLOWING PRIORITY AREAS:

Priority areas for an effective health care system

Integrating palliative care as early as possible



Providing acute hospital-based care only when necessary

Focusing on palliative care and appropriate treatments at the end of life

Ensuring equitable access to palliative and end-of-life care

Report findings

- Some patients with cancer are receiving a palliative care designation only near the end of life

- Over use of or over-reliance on acute-care hospital services near the end of life

- Palliative radiation for patients with prostate and breast cancer may be underused

- Rural residents, younger patients and patients with certain cancer types have different end-of-life care experiences than the general cancer population



Examples of barriers that may contribute to care deficiencies

- Misperception that palliative care means only end-of-life care
- Concern that use of palliative care could signal clinicians are “giving up”



- Inadequate availability of or access to primary care and community-based services (e.g., nursing or paramedic care, hospice care, respite care, home visits, medications or equipment)
- Lack of people at home to care for the patient
- Cost of medications
- Lack of planning for impending death

- Physician referral practices and awareness of palliative treatment may influence uptake

- Rural areas may not have adequate primary and community-based care
- Younger patients may undergo more aggressive treatment
- Patients with certain types of cancer may experience more complex symptoms or may be diagnosed later than others, possibly resulting in less time to prepare for a death at home

“Palliative care allowed Doug to remain part of the family. We could live the best possible way until the end, knowing that the end would come, just not when exactly. The time together was a powerful time for us.”

Marie
Family Caregiver

We need better data to develop more meaningful ways to measure the quality and timeliness of palliative and end-of-life care in Canada.

There are barriers and gaps in measuring and reporting on palliative and end-of-life care in Canada.

Collecting and analyzing more pan-Canadian data will lead to better understanding of the palliative and end-of-life care experiences of Canadians with cancer and will help identify opportunities to provide better care.

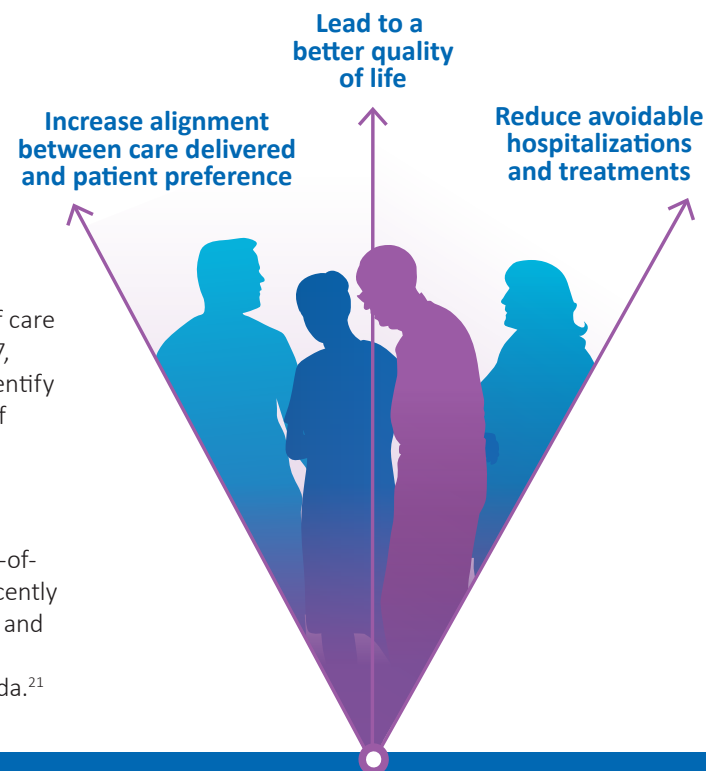
To bring about change in Canada, we need to better understand

- patterns of palliative and end-of-life care for patients with cancer across all health care settings (i.e., acute-care hospitals, outpatient care, homes, hospices, long-term care facilities);

- alignment of patient preferences and goals of care with the care they actually receive (as of 2017, no national data are routinely collected to identify a person's care needs or preferred location of death); and
- inter-jurisdictional variations in access to community-based palliative care services.

In addition, more research on palliative and end-of-life care needs and services, informed by the recently released Pan-Canadian Framework for Palliative and End-of-life Care Research, could help to identify opportunities to advance palliative care in Canada.²¹

Data suggest that earlier integration of palliative care can:



Future Considerations

This report is a first step toward understanding the current state of palliative and end-of-life care across Canada. Monitoring palliative and end-of-life care in Canada is particularly important given the growing older population and the consequent increasing costs of this type of care. Collecting, analyzing and reporting more and better data will allow us to better identify the settings in which palliative and end-of-life services are delivered, which could point to opportunities for providing more person-centred care in the appropriate settings.

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