

April 30, 2013

End-of-Life Hospital Care for Cancer Patients

Executive Summary

Cancer is the leading cause of death in Canada, and the number of new cases is expected to increase as the population ages and grows.¹ As such, a better understanding of the experiences of cancer patients at the end of their lives is of important value to Canadians and to those responsible for improving the care delivered to patients suffering from cancer.

This study uses administrative data from the Canadian Institute for Health Information (CIHI) to examine the use of hospital services in the last month of life by cancer patients who died in acute care hospitals.

The study's main findings are the following:

1. *Close to half of Canadian cancer deaths occurred in acute care hospitals.*

In 2011–2012, about half (45%) of Canadian cancer deaths—excluding those in Quebec—occurred in acute care hospitals. Significant provincial variation existed, indicating differences across the country in how care is organized and delivered.

2. *The number of cancer patients who die in acute care hospitals can be reduced.*

Some patients who died in hospital could potentially have done so in non-acute settings, such as hospices or their homes. This is evidenced by the 22% of the study cohort who were admitted to acute care with the sole diagnosis of palliative care and the 5% who were admitted as alternate level of care patients. As well, it is likely that at least some patients with relatively long hospital stays could have been discharged to an alternative setting before they died. For example, 34% of patients with a most responsible diagnosis of palliative care had stays longer than 14 days.

3. *Many of the study's patients were admitted multiple times.*

Many of the study's patients were admitted to acute care multiple times (23%) or visited emergency departments at least once (70%) in their last 28 days of life. As well, a higher percentage of rural (30%) compared to urban (20%) patients were admitted to acute care multiple times during their last 28 days. The proportion of patients with multiple admissions varies by jurisdiction, and may indicate the need for more, or more accessible, community-based end-of-life services.



Analysis in Brief

Health System Performance

Our Vision

Better data. Better decisions.
Healthier Canadians.

Our Mandate

To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

Our Values

Respect, Integrity, Collaboration,
Excellence, Innovation

Federal Identity Program

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4. *There is little evidence of potentially over-aggressive treatment or underuse of select key services.*

This study also examined two important aspects of the quality of care received at the end of life by looking at both potentially overly aggressive treatment (measured by the use of intensive care units and inpatient chemotherapy) and underuse of key services (measured by documented palliative care diagnoses). Relatively few patients in the study used intensive care units (11% were admitted to intensive care units and 8% died there) or received chemotherapy (3%) in their last 14 days of life. Most cancer patients (82%) in the study had a documented palliative care diagnosis during their last admission. However, it is not known how many received specific inpatient palliative care services or may have had access to alternative palliative settings, such as hospice or home care.

Introduction

Cancer is the leading cause of death in Canada,¹ accounting for 30% of all deaths.² Each day, 500 Canadians are diagnosed with cancer and 200 die from it. In 2012, there were projected to be 186,400 new cancer cases (excluding non-melanoma skin cancers), and an estimated 75,700 cancer deaths were expected.³

While more Canadians are surviving cancer now than in the past, many still die from the disease, and the number of cancer deaths is expected to increase as the population grows and ages.¹ As such, a better understanding of the experiences of cancer patients at the end of their lives is of important value to Canadians and to those responsible for improving the care delivered to patients suffering from cancer.

At the end of life, consideration should be given to ensuring dignity for patients and loved ones and to providing access to palliative care as needed.⁴ The goal of palliative care is to make people as comfortable as possible by relieving symptoms (such as pain or nausea), improving their quality of life during this phase of the disease, addressing problems caused by the illness or its treatment, and providing support for patients and their families.⁵ Other issues to consider include choice of setting and quality of care provided at the time of death.

Many argue that access to appropriate end-of-life care is a challenge in Canada and that the delivery of palliative care services varies across the country.^{6–8} Governments, health care organizations and care providers have been working to improve the quality of end-of-life care for cancer patients and other Canadians. A great deal of this work has focused on delivering safe, accessible, responsive and integrated end-of-life care. Good data is a key aspect of monitoring and measuring progress in these areas. And while some improvements have been made, there continue to be challenges in collecting and reporting data across all care sectors: home, primary and community care; hospital, continuing and residential care; and hospice care.

Using CIHI's administrative data, this study examines the use of hospital services near the end of life by cancer patients who died in acute care hospitals, highlighting variation in service use across provinces. It will add to the existing body of research on end-of-life care for cancer patients and produce new, actionable knowledge on provincial differences in quality of care at the end of life for cancer patients.

Fine Print: The Study Cohort and Limitations

Study Cohort

Acute care death abstracts for 2011–2012 were extracted from CIHI's Discharge Abstract Database (DAD). Among them, adult (age 20 and older) cancer patients were identified using ICD-10-CA codes for either

- A significant diagnosis of malignant neoplasm or neoplasms of uncertain or unknown behaviour; or
- A most responsible diagnosis of palliative care, with a secondary diagnosis of malignant neoplasm.

The study focused mainly on the last 28 days of life for these patients, with some analyses restricted to the last 14 days.

Using data from CIHI's DAD and National Ambulatory Care Reporting System (NACRS) from 2010–2011 and 2011–2012, the above cohort's end-of-life inpatient admissions across Canada and ED visits in Ontario and Alberta were examined. Based on information from these patients' final inpatient admission, measures of potentially overly aggressive treatment (defined by use of intensive care units and inpatient chemotherapy) and coding of palliative care were analyzed. Additional information on cohort selection and study methodology is available upon request.

Study Limitations

Data Availability

1. Data on community-based services, primary care services and ambulatory clinic services was not available for this study.
2. Data was limited to administrative records. Important information from cancer registries, such as date of diagnosis and stage of disease, was not available for this study.
3. Data on patients treated in Quebec facilities was excluded from the study.
4. For the ED analysis, data on visits to facilities in Ontario and Alberta only was included. Data from Yukon was excluded due to the small number of visits.

Cautions on Interpreting Results

1. The study aimed to include all cancer patients (identified using significant or primary diagnosis codes for cancer or a combination of palliative care and cancer codes) who died in acute care hospitals. Patients who did not fit these criteria were excluded, such as patients with only a secondary diagnosis of cancer or history of cancer. As such, the study cohort may underestimate the true population of all cancer patients who died in acute care hospitals. However, a sensitivity analysis showed that this effect was limited. Comparisons with other studies of place of death should be made with caution.
2. The study did not differentiate between acute care facilities that had dedicated palliative care units and those that did not. This may result in relatively higher in-hospital death rates for provinces that offer more dedicated inpatient palliative care.
3. The analysis of inpatient palliative care was based on the presence or absence of ICD-10-CA code Z51.5 (palliative care) on a patient's abstract. Some palliative care experts have not fully endorsed the accuracy of the code in completely capturing what "palliative care" means.
4. The overall estimates of cancer deaths in Canada were based on projections, while the acute care deaths were based on hospital records. Percentages in this study based on the projected deaths could result in an underestimation or overestimation of the true percentages, depending on the actual overall deaths.

Where Do Cancer Patients Die?

The data shows that a significant proportion of Canadian cancer patients die in acute care hospitals. Between 2005 and 2009, the Canadian Partnership Against Cancer (CPAC) reported, using Statistics Canada's data, that approximately 70% of Canadian cancer patients who died did so in a hospital and 11% died at home.⁹ The CPAC study used a broader definition of "hospital," which included EDs or other institution types. The CPAC study also included Quebec, which had a higher proportion of in-hospital cancer deaths. As well, cancer deaths were captured using cause-of-death information in vital statistics, which may be different from using diagnosis codes.

This current study found that 25,114 cancer patients died in acute care hospitals in 2011–2012, excluding those from Quebec. This translates to nearly half (45%) of all estimatedⁱ cancer patient deaths in 2011–2012, and to 30% of all acute care deaths that year.

Based on the estimate from this study, Canadian cancer patients appear to be more likely to die in hospital than cancer patients in the Netherlands (31%) or the United Statesⁱⁱ (29%).^{10, 11} However, several countries have higher proportions of in-hospital cancer deaths, such as Belgium (61%), Wales (60%) and England (50%).¹⁰ These differences in proportion of in-hospital cancer deaths may reflect patient and family preferences or access to community-based palliative care and hospice resources. They may also be due to differences in how health care is organized and delivered in these countries.¹²

Acute care hospitals are not generally designed to provide the specialized care required for terminally ill cancer patients; they are primarily focused on short-term, curative care.¹³ A better understanding of cancer patients who die in acute care hospitals can facilitate improved planning for them at the end of life. Table 1 below provides a detailed description of the cancer patients who died in acute care hospitals in Canada, excluding Quebec, in 2011–2012.

Table 1: Profile of Cancer Patients Who Died in Acute Care Hospitals, 2011–2012 (N = 25,114)

Description	Percentage of Patients	Description	Percentage of Patients
Gender		Arrival via Ambulance	56%
Male	55%	Admitted From	
Female	45%	Home or Home With Support	82%
Age		Another Acute Care	9%
20–44	3%	Residential Care	4%
45–64	26%	Admission Type	
65+	71%	Emergency Department	69%
Most Common Cancer Types		Direct Admission	28%
Lung	24%	Admitted to Hospital Type	
Colorectal	9%	Teaching Hospital	24%
Pancreatic	5%	Large Hospital	42%
Leukemia	4%	Medium or Small Hospital	35%
Non-Hodgkin's Lymphoma	4%	Length of Stay	
Place of Residence		Less Than 1 Week	36%
Urban	73%	1–4 Weeks	46%
Rural	27%	More Than 4 Weeks	18%

Notes

Includes all provinces and territories except Quebec. Not all categories are shown in all cases. As such, some percentages do not add to 100.

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

- i. Overall cancer deaths based on projected deaths for 2012 from the Canadian Cancer Society's Steering Committee on Cancer Statistics. This projection may overestimate or underestimate actual cancer deaths.
- ii. Included only cancer patients age 65 and older.

Decisions related to place of death are complex and take a variety of health system factors into account, including variations in both culture and practice patterns of the medical and oncology systems. From the patients' perspective, a range of cultural, social and legal factors also need be taken into account.^{14–16} Some experts have suggested that a growing and aging population may contribute to an increase in in-hospital deaths in the future, due to the expected increase in new cancer cases. Where people live is another important factor. Some studies have found that rural cancer patients were more likely to die in hospital than their urban counterparts.^{17, 18} This study also found that 34% of rural cancer patients died in urban hospitals, suggesting they were relatively far from family and other community-based supports at the end of life.

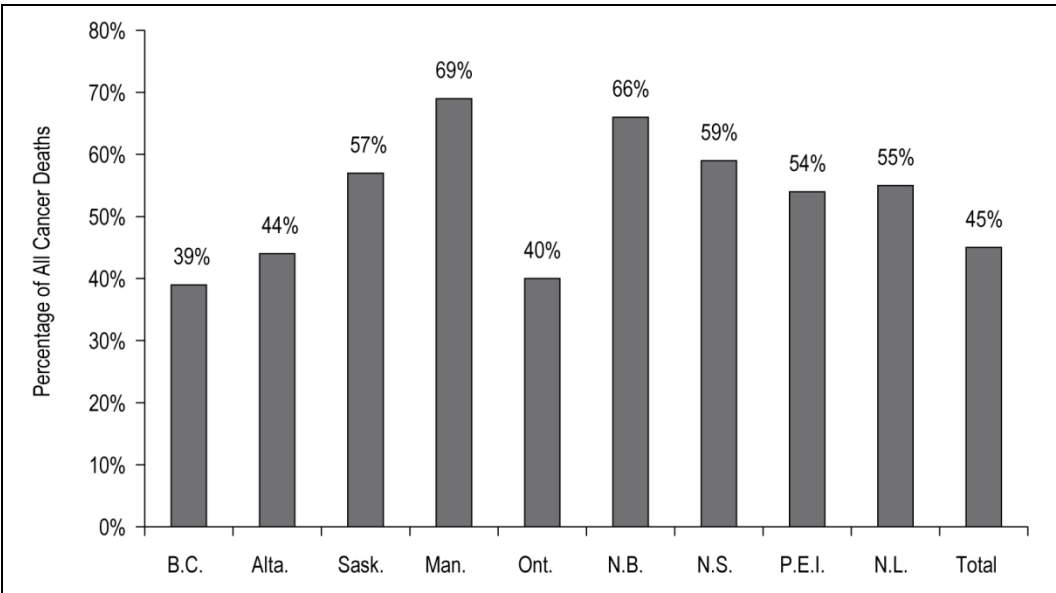
Cancer Patient Deaths in Emergency Departments

Data from NACRS, which tracks ED use, was used to examine the number and characteristics of cancer patients who died in EDs in Alberta and Ontario in 2011–2012. During the study period, 486 cancer patients age 20 and older died in EDs. This represents a small percentage of all cancer patients' deaths (less than 2%) and all ED deaths (9%) in both provinces combined. About one-third (34%) of the cancer patients who died in the ED had a cancer-related diagnosis as the main reason for the visit. The most common non-cancer-related diagnoses among the other two-thirds (66%) included cardiac arrest, pulmonary embolism, respiratory arrest and acute myocardial infarction.

Variations in In-Hospital Deaths by Cancer Patients Across the Provinces

While this study found that 45% of cancer patients died in acute care hospitals in 2011–2012, there was wide variation by province (see Figure 1). For example, 69% of Manitoba and 66% of New Brunswick cancer patients died in acute care hospitals, compared with 40% and 39% of patients in Ontario and British Columbia, respectively. Overall, cancer patients who died in hospital had a median length of stay (LOS) of 10 days. There was also some variability across the provinces in how long patients stayed in hospital before they died. Ontario and B.C. patients had the shortest median LOS at 9 days, while Prince Edward Island patients had the longest at 14 days.

Figure 1: Provincial Variations in the Proportion of Cancer Patients Who Died in Acute Care Hospitals as a Percentage of Total Projected Cancer Deaths, 2011–2012



Notes
Total includes all provinces and territories except Quebec. Includes only acute care facilities. Overall cancer deaths based on projected deaths for 2012.

Sources
Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.
Canadian Cancer Society's Steering Committee on Cancer Statistics. *Canadian Cancer Statistics 2012*. Toronto, ON: Canadian Cancer Society; 2012.

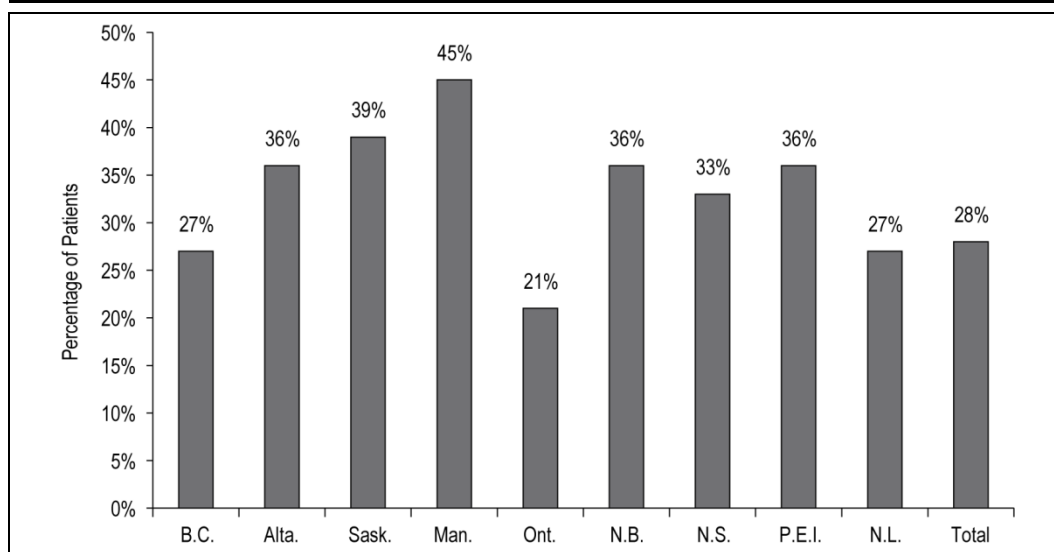
The most populous—and most urbanized—provinces (Ontario, B.C. and Alberta) had the lowest percentages of in-hospital deaths. This could reflect wider availability of community-based services—particularly home palliative care and hospices—in urban centres. However, access to community palliative care services can also vary within different urban centres.¹⁹ None of the other factors investigated in this study (hospital type, location of hospital, distance travelled by patient, type of cancer, age/sex of patient and transfers in from residential care) appeared to explain a significant amount of the interprovincial variation.

Experts have suggested that differences in the availability of palliative care beds in some provinces, and the location of such beds in others, may be contributing to variations in in-hospital deaths. For example, many of the palliative care units in Manitoba are located in acute care hospitals and are classified as acute care. 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). Detailed comparable information on designated palliative care units in hospital was not available for this study. It is also not known how the differences in availability of palliative care beds outside hospitals may account for variations in interprovincial comparisons; this may be a valuable area to explore in future studies.

Overall, patients with certain types of cancer were at higher risk of dying in hospital than others. Similar to previous studies,²⁰ this study found that of all estimated cancer deaths, patients with hematological cancers (leukemia and non-Hodgkin's lymphoma) were more likely to die in hospital relative to those with other cancers. These cancers were generally among the top cancers resulting in in-hospital deaths across all provinces included in the analysis. Because these types of cancers are typically treated quite aggressively, and usually in a hospital, these patients are at a higher risk of dying during treatment in hospital.²¹ As well, complications such as bleeding or severe infections may limit the capability to manage these patients at home or in hospice palliative care beds.²²

Figure 2 illustrates differences across provinces in the percentage of cancer patients whose final admission to acute care hospitals (that is, the admission in which they died) was direct. The figure shows the percentage of patients admitted to hospital directly, out of all patients who died in acute care hospitals in each province. The pattern of results is similar to that in Figure 1. It shows generally that provinces with a larger percentage of direct admissions also had a higher percentage of in-hospital deaths overall. Taken together, this suggests that provision of end-of-life care may be organized differently in different provinces, with a greater emphasis on use of acute care services in some provinces.

Figure 2: Provincial Variations in Direct Admissions Among Cancer Patients' Final Admissions, 2011–2012



Note

Total includes all provinces and territories except Quebec.

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

Highlighting Examples of Community-Based End-of-Life Programs

Several reports have highlighted different factors that are associated with lower rates of in-hospital death, including the availability of alternative supports such as home care or hospice care and strong advance care planning.^{23, 24} These factors may contribute to the provincial variations in cancer patients' in-hospital deaths. Across the country, several programs have been developed to provide alternatives to hospital for patients at the end of life. Following are a few examples:

- In Alberta, the Edmonton Zone Palliative Care Program, in operation since 1995, is a community-based model of palliative care services. The program was designed to provide access to palliative care support by shifting end-of-life care from hospital to home and hospice care. A 2012 report found an increase in the number of physicians referring their patients to this program, as well as 19,113 fewer hospital bed days in 2010–2011. The report also noted that wait times for hospice care in Edmonton had decreased to a median of two days from three days the year before.²⁵
- The Extra-Mural Program in New Brunswick is responsible for administering complete care to patients who are palliative. The program provides planning and coordination for all service agencies involved with the patients' care. As part of this program, the Hospice of Greater Saint John opened in 2010. It is the first residential hospice in Atlantic Canada, providing 24-hour care to an anticipated 150 end-of-life patients each year.²⁶
- In 2003, the Princess Margaret Hospital in Toronto, Ontario, opened an acute palliative care unit (APCU) in its cancer centre. The goals of the APCU are to manage symptoms and provide terminal, transitional or respite care, based on individual patient needs. Over a five-year study period, 1,748 patients were admitted to the centre. Patients were assessed by the palliative care team and had to discuss a "do not resuscitate" order. Patients who were expected to live longer than two weeks and could not be discharged home were provided with options, including three hospices or long-term care programs. Over the study period, the mean length of stay decreased from 12 to 11 days. There was also a decrease in the percentage of patients who died in hospital, from 65% to 40%.²⁷

Frequent Admissions at End of Life Suggest Need to Improve Community-Based Services

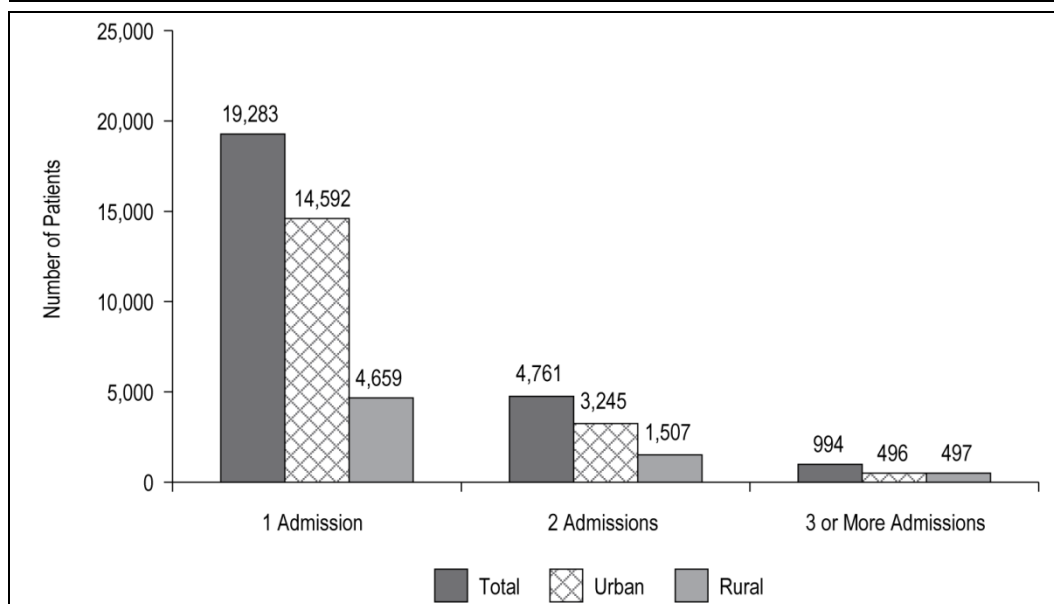
Well-organized and -coordinated end-of-life care should help prevent unnecessary emergency and acute inpatient care services. At times, transitions between care settings are necessary (for example, planned admissions to acute inpatient care or visits to the ED as a result of immediate medical problems). However, they can also lead to anxiety for both patients and caregivers. In addition, multiple transitions near the end of life create challenges for the continuity of care experienced by cancer patients. Such transitions may increase the risk of either miscommunication or lack of documentation of preferences and care goals among changing care providers.²⁸ High rates of hospital use may indicate challenges with access to primary health care or other community-based services for cancer patients.

The following section examines the frequency of admissions to acute inpatient care and visits to the ED in the last 28 days of life.

Multiple Acute Inpatient Care Admissions at End of Life

This study included only cancer patients who died in acute care hospitals. As such, they were all admitted to hospital at least once. Still, one in four (23%) were admitted to the hospital more than once in their last 28 days of life, and nearly 1,000 (4%) were admitted three or more times (see figures 3 and 4). Three-quarters (77%) had only one admission. However, about one in four of this group were in hospital for more than 28 days before they died. Therefore, the relatively high proportion with only one admission may be influenced by those with a long LOS.

Figure 3: Frequency of Acute Care Admissions by Cancer Patients in Last 28 Days of Life



Notes

Includes all provinces and territories except Quebec. Includes last admission, in which patients died. Total includes patients who could not be classified as rural or urban. Admission time frame was measured between discharge date of final admission and discharge date(s) from previous admission(s). Includes only records with sufficient information for data linkage.

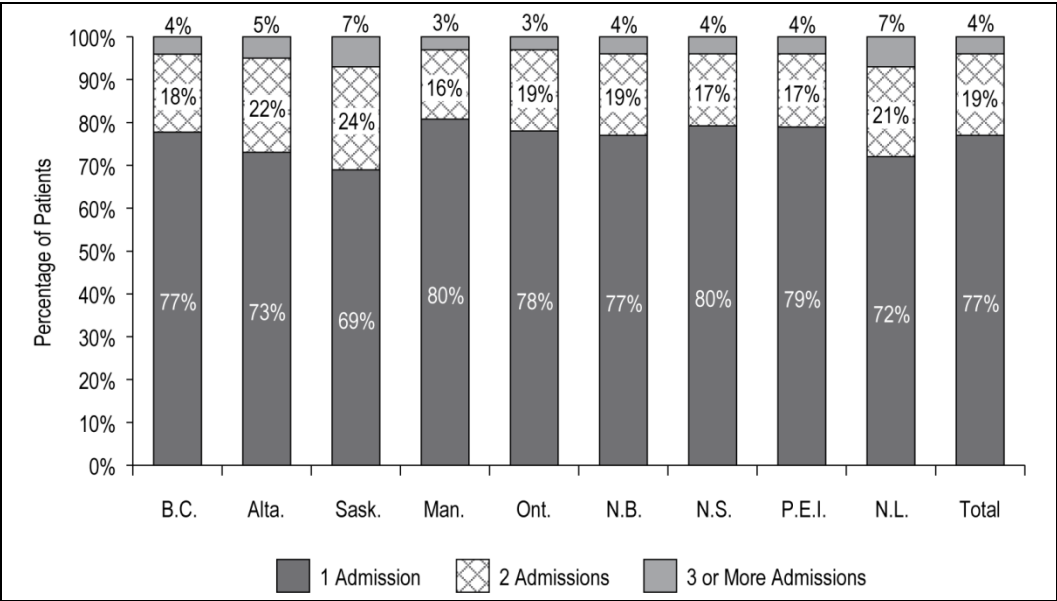
Source

Discharge Abstract Database, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

Multiple hospital admissions at the end of life may indicate that primary care or community-based services (such as home, hospice and palliative care programs) may not be meeting care needs. This challenge may be further complicated for patients in rural areas, where availability of and access to local, 24-hour, community-based services or specialized care is more limited.^{29, 30} A higher percentage of rural (30%) than urban (20%) patients were admitted to acute care multiple times during their last 28 days of life.

This study also identified variations across provinces in the proportion of patients admitted to acute care multiple times in their last 28 days of life (see Figure 4). The proportion ranged from 31% to 19% of patients. This variation may be driven in part by differences in underlying LOS. For example, 26% of patients in Manitoba and P.E.I. stayed longer than 28 days during their final admission. This is higher than the 15% of patients in Ontario. This may be—at least in part—a reflection of differences in models of care. For example, Manitoba has designated palliative care units within acute care hospitals.

Figure 4: Provincial Variations in the Frequency of Acute Care Admissions by Cancer Patients in Last 28 Days of Life



Notes
Total includes all provinces and territories except Quebec. Includes last admission, in which patients died. Admission time frame was measured between discharge date of final admission and discharge date(s) from previous admission(s). Percentages may not add to 100 due to rounding.

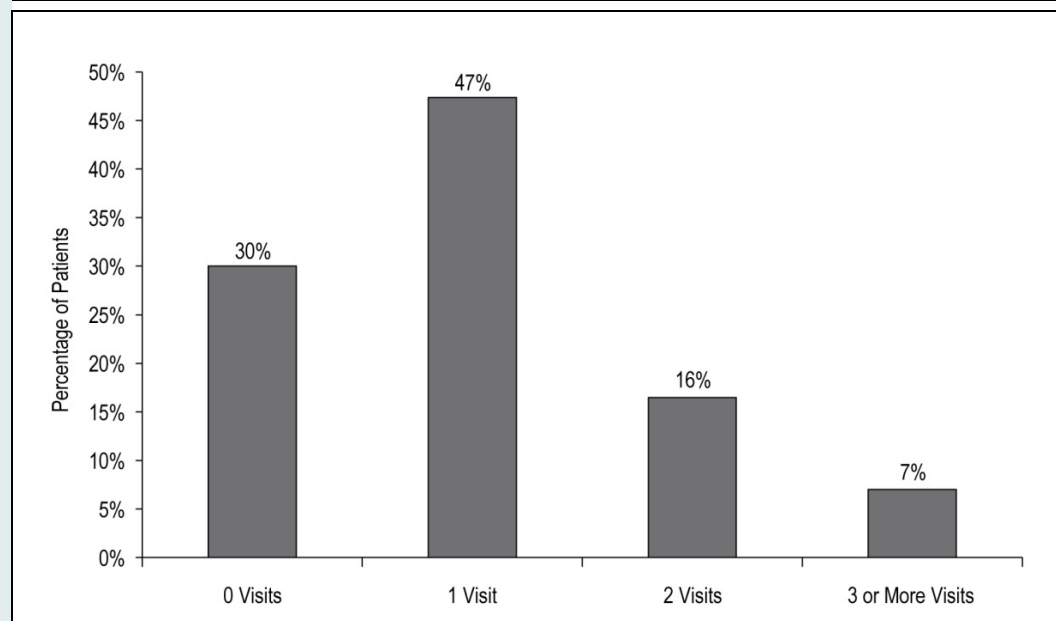
Source
Discharge Abstract Database, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

Frequency of Visits to and Time Spent in Emergency Departments by Cancer Patients at End of Life

Data from CIHI's NACRS, which tracks ED use, was used to examine the frequency and duration of cancer patients' ED visits in 2010–2011 and 2011–2012. Of the 13,996 patients in the study's cohort from Alberta and Ontario (where ED data is available), 9,855 (70%) visited the ED in their last 28 days of life. While most had only one ED visit in the last 28 days, 16% had two visits and 7% had three or more visits. As well, 16% of patients did not visit the ED because they were already in hospital 28 days before they died.

Time spent in the ED was also measured for those patients admitted through the ED on their final admission. Half of the patients spent more than 10.4 hours in the ED, and 10% spent more than 31.3 hours there. See appendices A and B for more information on Ontario and Alberta cancer patients' ED visits at the end of life.

Figure 5: ED Visits by Cancer Patients in Last 28 Days of Life



Notes

Includes only Ontario and Alberta cancer patients from the study. "0 Visits" includes patients already admitted to hospital 28 days before death.

Source

National Ambulatory Care Reporting System, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

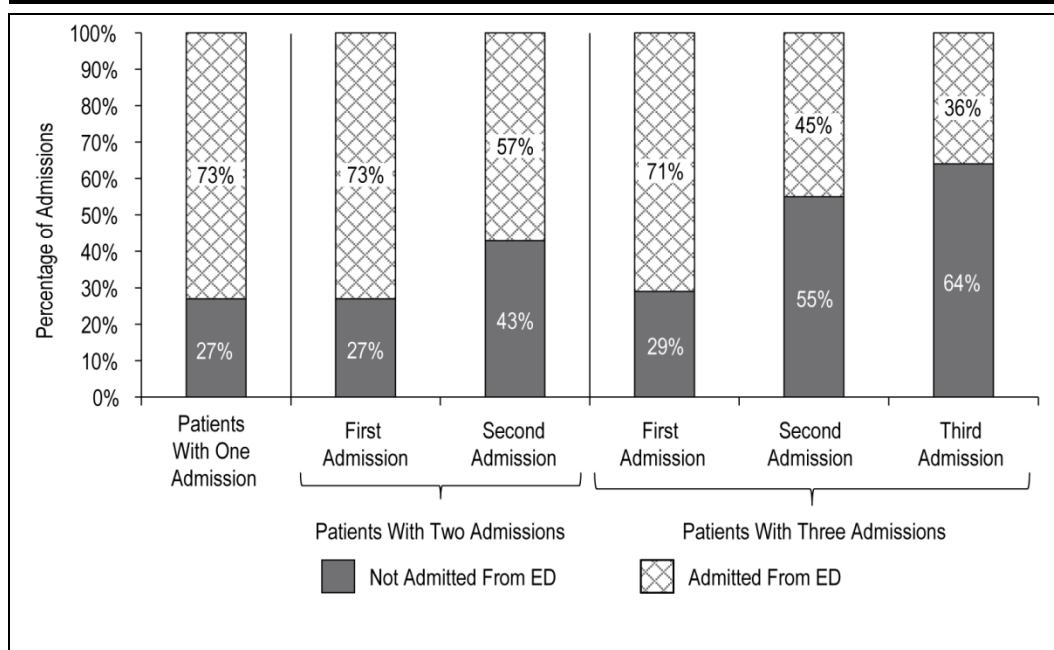
Acute Inpatient Care Admissions Through Emergency Departments

According to the Cancer Quality Council of Ontario, patients visit the ED at the end of life because their symptoms are uncontrolled, community-based services are unavailable after hours, or they or their families have exhausted their physical or emotional resources.²⁴ As such, frequent ED visits at the end of life may be an indicator of suboptimal care.^{31, 32}

More than two in three (69%) cancer patients in this study were admitted through the ED in their final acute care admission. However, a closer examination of all of their admissions through the ED in the last 28 days of life revealed some encouraging results. Specifically, the likelihood of admission through the ED decreased with successive admissions in the last 28 days of life. This may suggest that care became better managed, palliative care was arranged or coordination of care became better established as patients got closer to death (see Figure 6).

In contrast, this shift from admission through the ED to more direct admission may not be related to patients' health status or better care management. Patients may be more likely to be scheduled for admission near the end of life as providing needed care at home becomes less feasible. At this point, an acute care bed may be the only alternative, particularly if hospice care is not available. The fact that the likelihood of arriving via ambulance increased with successive admissions supports this. A variety of factors may be connected to higher rates of ambulance use, including decreased patient mobility from disease progression, acute oncological emergencies, more complicated care requirements or increased levels of physical and emotional distress for the patients.

Figure 6: Shift From Admission Through ED to Direct Admission in Last 28 Days of Life



Notes

Includes all provinces and territories except Quebec. Includes only patients with one, two and three admissions. Admission time frame was measured between discharge date of final admission and discharge date(s) from previous admission(s).

Source

Discharge Abstract Database, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

The availability of informal caregivers and the provision of integrated care for patients at the end of life can help minimize repeat hospital admissions and ED visits. Studies also show that access to high-quality community palliative and end-of-life care provided at home can reduce frequent hospital visits. Access to these services varies across Canada. There are some provincial programs to support home care, but most cancer-specific programs are managed regionally.^{19, 25, 33}

In combination with better home care services, a more integrated and easily accessible palliative prescription drug plan could also help ensure that patients receive their care in the most appropriate setting. Across the country, palliative drug programs have been developed either separately or as part of larger provincial drug coverage initiatives. These programs can differ—in comprehensiveness, eligibility and coverage—but generally support patients' preferred location of care by covering the cost of palliative drugs in settings outside of hospitals.³⁴ The impact, uptake and effectiveness of these programs have not yet been systematically evaluated.

Highlighting Examples of Community-Based End-of-Life Programs

The following are highlights of programs across Canada that help reduce acute care hospital admissions and ED visits at the end of life, through high-quality community and hospital partnerships:

- In Victoria, B.C., a 24-hour on-duty Palliative Response Team (PRT) has operated since 1989 with the goals of reducing hospital admissions and supporting deaths at home.³³ A PRT nurse, counsellor and on-call palliative physician are involved, and a PRT Drug Kit is placed in the home during the average 3.4 days of intervention. Of the 479 episodes of care for 364 patients seen in 2011–2012, 73% remained at home, 21% were admitted directly to the inpatient palliative care unit and 6% were transferred to an ED (most often when there was no bed available in the palliative care unit).
- In P.E.I., the Palliative Home Care Drug Program started in 2008 to provide drug coverage for pain and symptom management for palliative patients. As of 2010, the 158 registered patients were able to remain at home for a total of 7,764 days (80% of their palliative care). This corresponded to a 25% increase in time spent at home, compared with patients receiving care prior to the pilot.²⁶
- In New Brunswick, liaison nurses are responsible for coordinating care among the hospital, home and community, which reduces inappropriate hospital admissions. This role forms part of the province's Extra-Mural Program, which aims to provide care outside the hospital setting.²³
- The Temmy Latner Centre for Palliative Care in Toronto, Ontario, is one of the largest home palliative care programs in Canada.³⁵ In order to meet patient preferences to die at home, the home care program provides a team of doctors who are dedicated solely to providing palliative home care. In addition, palliative patients receive a coordinator from the Community Care Access Centre who organizes the other members of the patients' home palliative care team (for example, personal support workers or home care nurses).³⁶

Federal programs have also been developed to help ease the burden of care faced by family caregivers. Two examples are the Compassionate Care Benefit provided through Employment Insurance³⁷ and the Family Caregiver Tax Credit.³⁸

Are There Indications of Potentially Overly Aggressive Treatment or Underuse of Key Services at End of Life?

One component of measuring the quality of end-of-life care often reported in the literature is avoiding both potentially overly aggressive treatment and underuse of services.^{21, 24}

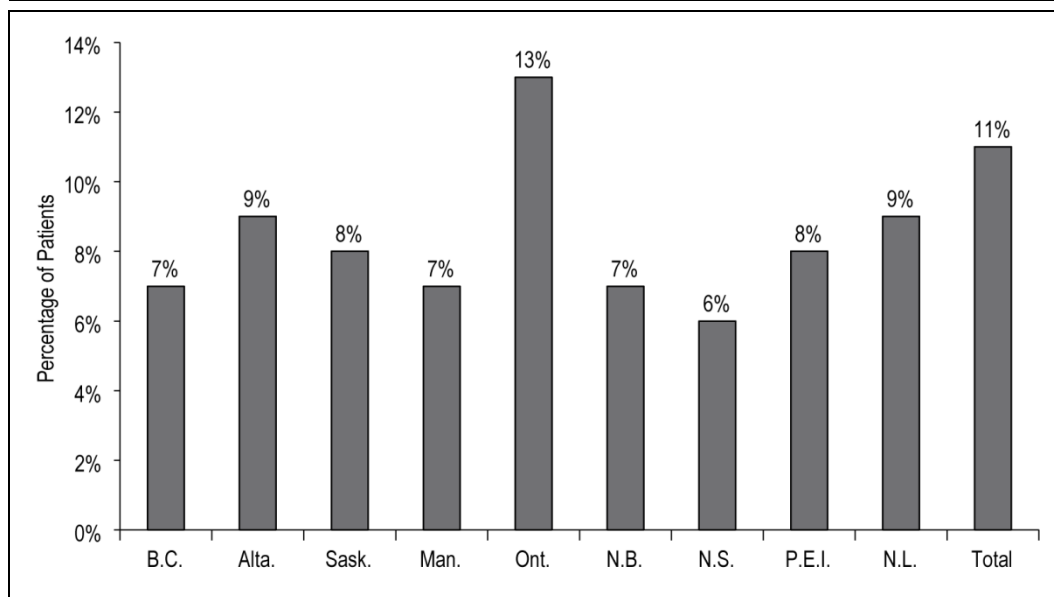
Few patients at the end of life are expected to receive typically life-prolonging services. Researchers have suggested that many patients receiving such services may indicate overuse—or aggressiveness—of care. Potentially overly aggressive treatment may indicate that an unexpected death occurred during the course of therapy that was hoped to be either curative or likely to induce a remission. However, it may also reflect an effort to continue invasive and aggressive therapy even when the probability of extending quality life time is remote.²¹ Some experts have suggested that the issue of aggressive therapy could also be related to the lack of clarity on the value of such therapy or treatment.³⁹ This can also be complicated by challenges with who decides—the care provider, patient or another decision-maker—when to start or stop such treatment.

This study looks at two specific measures: care in intensive care units (ICUs) and provision of inpatient chemotherapy in the last 14 days of life. It also looks at one measure of potential underuse: documentation of palliative care.

Little Evidence of Potentially Overly Aggressive Treatment at End of Life

The current study found that relatively few patients from the study cohort were admitted to ICUs. Most of the study cohort (84%) died in a hospital that provided ICU care. Only 11% (2,211 out of 21,039) of cancer patients who died in these hospitalsⁱⁱⁱ were admitted to the ICU in their last 14 days of life and only 8% died there. The variation across provinces in the proportion of patients admitted to the ICU in the last 14 days of life is provided in Figure 7.

Figure 7: Provincial Variations in the Percentage of Patients Admitted to ICU in Last 14 Days of Life



Notes

Total includes all provinces and territories except Quebec. Includes only facilities in the study that reported ICU data.

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

The characteristics of cancer patients admitted to the ICU indicate that they may have seemed at the time more likely to survive the hospital visit than those not admitted to the ICU. The study found that cancer patients in the ICU were less likely to have a diagnosis of palliative care (52% compared with 85%) than their counterparts who were not admitted to the ICU. The cancer patients admitted to the ICU were also younger than those who were not admitted (median age of 70 versus 73). Thus it is likely that a proportion of these patients were admitted to the ICU with the expectation of a positive outcome for this particular hospital admission.

In addition, relatively few patients in the study cohort received chemotherapy, another measure of potentially overly aggressive treatment, during their last admission. Only 3% (421 out of 15,380)^{iv} of cancer patients who died within 14 days of admission received inpatient chemotherapy. Similar to the ICU findings, some of the chemotherapy may have been administered with the hope it would be curative or induce remission. These patients who received inpatient chemotherapy were less likely to be diagnosed as palliative (63% versus 81%) and were younger (median age of 68 versus 72) than those who did not. There was minimal variation across the country in use of inpatient chemotherapy.

iii. Based on patients admitted to facilities that reported ICU data only, to better reflect use and potentially remove access or reporting bias. A total of 21,039 out of 25,114 of the study's patients died in facilities that reported ICU data.

iv. To capture chemotherapy use in the last 14 days, the analysis included only patients who died within 14 days of admission.

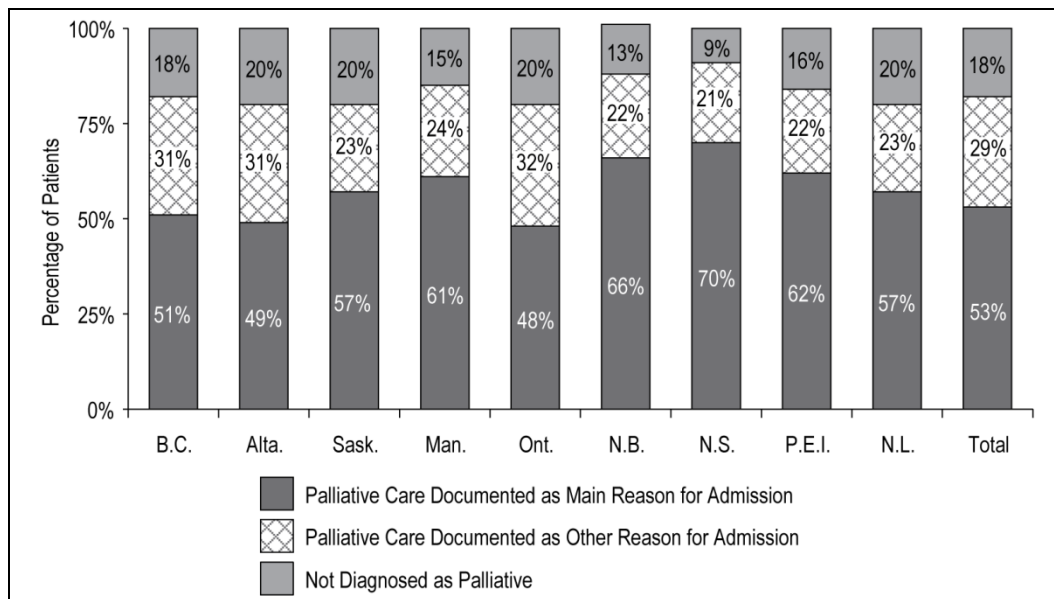
Most In-Hospital Cancer Patients Coded as Palliative on Final Admission

Palliative care is recommended for cancer patients at the end of life. It can include a wide range of services, including pain management; radiation therapy; and support for emotional, spiritual and cultural needs.^{14, 16} Palliative care can help improve the quality of remaining life for patients and their families. It can be provided in many settings, including at home, in residential care or in a hospital. The kind of palliative care provided, how well integrated it is into overall health care delivery and who delivers specialized palliative care differs across Canada. When palliative care is not provided, it may be an indication of underuse of recommended care.

While comprehensive palliative care information is not available, this study was able to identify which patients had a documented palliative care diagnosis on their hospital records at the time of death. Specifically, the analysis was based on the presence of a palliative care code (ICD-10-CA code Z51.5) in the records of cancer patients' final inpatient admissions.

Overall, 82% of cancer patients who died in acute care hospitals were documented as being palliative during their last admission (see Figure 8). Palliative care was also the main reason for hospitalization for more than half (53%) of all patients.

Figure 8: Provincial Variations in the Percentage of Patients Diagnosed as Palliative in Final Admission



Notes
Total includes all provinces and territories except Quebec. Percentages may not add to 100 due to rounding. "Palliative Care Documented as Main Reason for Admission" was determined by a palliative care code as the most responsible diagnosis on the record. "Palliative Care Documented as Other Reason for Admission" was determined by a palliative care code as an other diagnosis on the record. "Not Diagnosed as Palliative" was determined by the absence of any palliative care diagnosis code on the record.

Source
Discharge Abstract Database, 2010–2011, Canadian Institute for Health Information.

There are some challenges to understanding the specific reason a patient may be documented as palliative in administrative data. It could mean the patient is imminently dying or that the cancer is advanced. It could also mean that the patient is refusing treatment or that treatment is not successful. The complexities involved in designating a patient as palliative can also be further compounded by where care is provided (community or institution), the type (teaching versus small) and location (rural versus urban) of the hospital, and the region or province of the hospital. These differences in definitions, provision of programs and organization of care may help explain the variations across the provinces in the proportion of patients coded as palliative in the study.

Some clinicians have suggested that ward patients, including those coded as palliative, may not receive the full range of palliative care services, such as registration with a palliative care program or ward consultation by a palliative team or specialist. Documentation of a palliative diagnosis on a hospital record does not speak to the degree or nature of the specific services provided.

Consequently, caution must be used in determining whether there is good access to palliative care for in-hospital cancer patients at the end of life. It may be that some patients were offered only palliation, where treatment is intended to reduce or cure a specific symptom. As such, this study could not determine the level or appropriateness of palliative care services provided to the study cohort. This could represent an area for future studies to examine further.

However, being admitted to the hospital for the sole purpose of palliative care or being admitted directly to an alternate level of care (ALC)^v bed may help identify patients whose place of death could have been in a different care setting (such as hospice). This study found that 22% (5,570) of patients were admitted to acute care with the sole diagnosis of palliative care. In addition, 5% (1,281)^{vi} were admitted directly to ALC beds.

More than one-third of patients (34%, or 4,565) with palliative care as their main reason for admission had an LOS longer than 14 days. This relatively long LOS suggests that there could have been enough time to adequately prepare alternative arrangements, such as hospice care, for at least some of these patients. It could also be a reflection of the way palliative care is documented on patients' hospital records.

Overall, there was little evidence that too many cancer patients were admitted to ICUs or received chemotherapy in their final acute care admissions. While there was less-clear evidence of the level of use of specific palliative care services, the majority of these patients did have a documented palliative care diagnosis. Challenges remain in understanding the type and quality of palliative services they received, as well as the barriers to receiving palliative care services in other settings.

Conclusion

Research on end-of-life experiences will become increasingly important as Canada's population grows and ages.³ End-of-life care comprises a significant part of overall health care utilization.⁴⁰ As reported in other studies, patients and their families may also face financial challenges at the end of life, particularly when needs are at their peak yet services are neither comprehensive nor easily accessible.⁶ Experts have suggested that a more integrated approach to end-of-life care can provide a more efficient use of resources, both for patients and the system.⁴¹ But before the system can adapt to meet changing health care needs, a better understanding of those needs and experiences at the end of life is required.

v. ALC describes patients in acute care beds who no longer require acute care services who are waiting to be moved to another setting, such as hospice or palliative care.

vi. Almost all (99%) of the patients admitted directly to ALC beds had palliative care as the reason for the ALC.

This study aims to add to the body of knowledge on end-of-life care for cancer patients by studying those who died in acute care facilities. The study found that almost half (45%) of Canadian cancer patients outside Quebec died in acute care hospitals in 2011–2012. While this is higher than in some countries, like the U.S. and the Netherlands, it is lower than in others, including Wales and England.^{10, 11} Although previous research and surveys would suggest that a lower proportion of cancer patients would prefer to die in a hospital,⁴² a patient's preferred place of death and medical condition can change within the last days and hours of life.

The significant variation across the provinces in the proportion of in-hospital cancer deaths suggests that at least some of these patients could have received end-of-life care in non-acute settings, such as hospices or their homes with support services. This is also supported by the 22% of the study cohort who were admitted with the sole diagnosis of palliative care and the 5% admitted as ALC.

Many patients were admitted to acute care multiple times (23%) or visited EDs at least once (70%) in their last 28 days of life. The high number of patients affected indicates that there may be need for more, or more accessible, community-based end-of-life services. In addition, cancer patients not only visited the ED but were also often admitted to acute care through the ED. This could indicate the seriousness of their condition or a challenge with controlling symptoms at home. The results showed that the likelihood of admission through the ED does decrease with successive admissions in the last 28 days of life, suggesting that care became better managed, palliative care was arranged or coordination of care became better established as patients got closer to death.

This study also examined two important aspects of the quality of care received at the end of life by looking at both potentially overly aggressive treatment (measured by the use of ICUs and inpatient chemotherapy) and underuse of key services (measured by documented palliative care diagnoses). There was little indication of potentially overly aggressive treatment among cancer patients who died in acute care hospitals. Only 11% were admitted to an ICU and 3% received inpatient chemotherapy in their last two weeks of life. There was less-clear evidence on the level of use of palliative care. The majority (82%) of cancer patients in the study were coded as palliative during their last admission (based on diagnosis information in the patients' hospital records). However, information on the type and level of palliative care patients might have received was not available. Further research in this area would be valuable.

Improving End-of-Life Care in Canada

In the last 20 years, a significant effort has been made to bring public attention to the issue of end-of-life care. A major part of this effort was a report released in 2000 by the Canadian Senate on the quality of end-of-life care for Canadians. One of the key recommendations was that the federal government, in collaboration with the provinces and territories, develop a national strategy for end-of-life care.⁷ In 2000, collaboration among 24 national stakeholders set the groundwork for the development of a Canadian strategy for end-of-life care. This resulted in the creation of the Quality End-of-Life Care Coalition of Canada (QELCCC).⁴³

In 2000, the QELCCC developed a blueprint for action on end-of-life care for Canada, consisting of five priority areas: availability and access; professional education; research and data; family and caregiver support; and public education and awareness. In its *Blueprint for Action 2010 to 2020*, the QELCCC noted that some progress had already been made in research, training and Employment Insurance benefits for caregivers. It also identified several priority areas to guide the future of end-of-life care in Canada for the next 10 years, with a particular focus on quality of care underlying all of the priorities.⁴⁴

Among the priorities in the blueprint is that Canadians should have access to high-quality hospice palliative end-of-life care. Other priorities include providing more support for family caregivers and improving the quality and consistency of hospice palliative end-of-life care. All organizations involved in end-of-life care are encouraged to promote standards, best practices and education for health care providers and others.⁴⁴ One example of an organization that has provided guidance on the quality of end-of-life care is the United

Kingdom's National Institute for Health and Clinical Excellence (NICE), which has developed a quality standard for end-of-life care for adults. It is expected that the standard will contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and caregivers, regardless of condition or setting.⁴⁵

Strategies aimed at improving the quality of end-of-life care include the Gold Standards Framework (GSF), also from the U.K. The GSF was developed as a systematic evidence-based approach to improve the consistency and quality of care provided at the end of life within the community.⁴⁶ In addition, several provincial cancer agencies in Canada, including Cancer Care Ontario and the Saskatchewan Cancer Agency, have identified palliative care as a strategic priority.^{47–49}

Another priority from the QELCCC blueprint is encouraging Canadians to discuss and plan for the end of life. Experts have suggested that one of the main barriers to implementing an overarching end-of-life care policy in Canada is differences in cultural, moral and ethical beliefs. To help overcome such barriers, the QELCCC has proposed that Canadians need to be better informed about the importance of advance care planning, which can include discussions with family and advanced care directives.⁴⁴ For example, the Canadian Hospice Palliative Care Association has developed Speak Up—Start the Conversation About End-of-Life Care, a public awareness program about advance care planning.⁵⁰ Another example is the U.S. Institute for Healthcare Improvement's Conversation Project. This project is a public engagement campaign advocating "kitchen table" conversations with family and friends about wishes for end-of-life care.⁵¹

The use of technology could also help facilitate end-of-life dialogue and provision of end-of-life care. For instance, increasing the utilization of telehealth services can facilitate access to care and supports, particularly for patients and families in rural or remote areas.⁵² Social media and mobile technology can help promote social interactions among patients and build a community with shared experiences. It could also foster communication between patients and their families and other loved ones, as well as their care providers.⁵³

In addition, better data would help paint a clearer picture of end-of-life care for cancer patients. Areas where improvements could be made include more comprehensive information on the level and quality of palliative care services (both in hospital and elsewhere), use of pain control medications and use of hospital EDs by cancer patients. Collecting integrated cross-sector end-of-life information would help identify service gaps, improve access and coordination, and ultimately improve patient experience and outcomes.

Finally, this study focused on cancer patients, who make up less than one-third of all Canadian deaths. However, it identifies issues related to the end of life more broadly. It is hoped that the study will enable better understanding of the relationship between hospital and community-based services, draw attention to important gaps in knowledge for future research and data collection, and highlight recommendations and programs for policy-makers to consider in improving overall end-of-life care for patients.

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Please note that the analyses and conclusions in the present document do not necessarily reflect those of the individuals or organizations mentioned above.

CIHI team members who contributed to this report include Jessica Burnett, Allie Chen, Alexey Dudevich, Josh Fagbemi, Cheryl Gula, Kristen Hart, Mark McPherson, Kathleen Morris, Michelle Parker, Karen Poon, Agustina Silva and Jeremy Veillard.

Appendix A: Summary of Ontario Cancer Patients' ED Visits

Data from CIHI's NACRS, which tracks ED use, was used to examine ED visits by cancer patients who died in acute care hospitals in 2011–2012. Of the 11,211 patients in the current study from Ontario, 8,149 (72.7%) visited the ED in their last 28 days of life. A total of 15% of patients did not visit the ED because they were already in hospital 28 days before they died. The demographics and cancer types of the patients who visited the ED are provided in Table 2 below.

Table 2: Profile of Cancer Patients Who Died in Acute Care Hospitals in 2011–2012 and Had One or More ED Visits 28 Days Prior to In-Hospital Death, Ontario (N = 8,149)

Description	Percentage of Patients	Description	Percentage of Patients
Gender		Most Common Cancer Types	
Male	56%	Lung	25%
Female	44%	Colorectal	8%
Age		Leukemia	5%
20–44	2%	Pancreatic	4%
45–64	25%	Non-Hodgkin's Lymphoma	4%
65–74	25%	Place of Residence	
75–84	30%	Urban	83%
85+	17%	Rural	17%

Notes

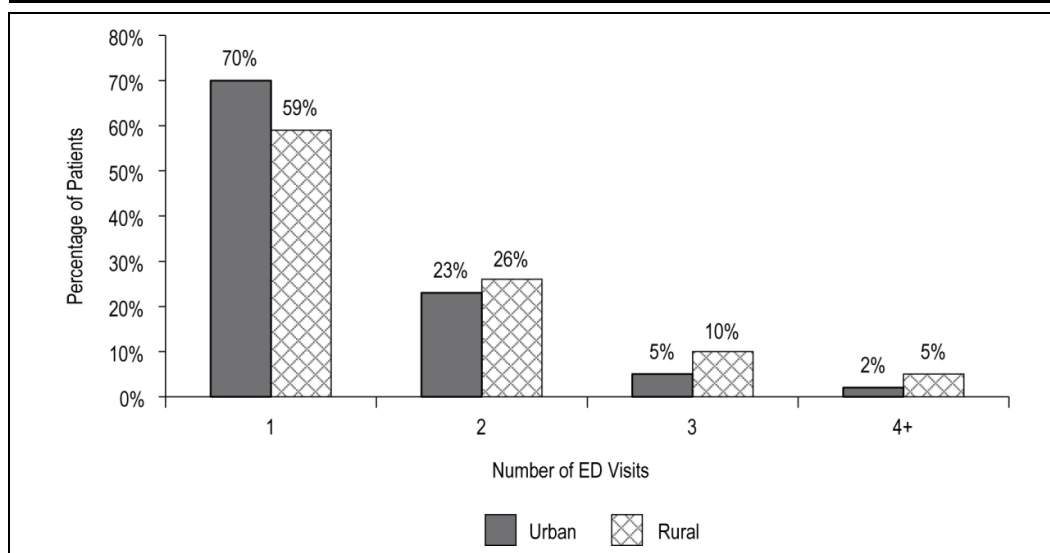
Includes only Ontario patients with at least one ED visit. Not all categories are shown in all cases. As such, some percentages do not add to 100. Percentages for some categories may not add to 100 due to rounding.

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

Overall, Ontario patients who visited the ED did so at an average of 1.4 visits per patient. The rate of visits per patient was higher for rural patients (1.7 visits) than urban patients (1.4 visits). Figure 9 shows the percentages of rural and urban patients with one or more ED visits.

Figure 9: ED Visits in Last 28 Days of Life Prior to In-Hospital Death by Rural and Urban Ontario Patients



Note

Includes visits to Ontario facilities only.

Source

National Ambulatory Care Reporting System, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

The study's cancer patients who visited the ED were admitted to hospital in 76% of their ED visits. As expected, patients were triaged at a higher acuity and had a longer LOS in the ED when they were admitted from that ED visit. Main reasons for the visits when patients were admitted were somewhat comparable with those when they were not admitted, suggesting that it was the acuity, more than the main reason for the visit, that affected whether they were admitted (see Table 3).

Table 3: Description of Visits by Cancer Patients to the ED in Last 28 Days of Life Prior to In-Hospital Death, Ontario (N = 11,780 Visits)

Admitted (76% of Visits)		Not Admitted (24% of Visits)	
Description	Percentage of Patients	Description	Percentage of Patients
Main Problem		Main Problem	
General symptoms and signs	8%	Symptoms and signs involving the digestive system and abdomen	9%
Malignant neoplasms of respiratory and intrathoracic organs	7%	General symptoms and signs	8%
Malignant neoplasms of ill-defined, secondary and unspecified sites	7%	Symptoms and signs involving the circulatory and respiratory systems	7%
Malignant neoplasms of digestive organs	6%	Persons encountering health services for specific procedures and health care	5%
Symptoms and signs involving the digestive system and abdomen	6%	Malignant neoplasms of respiratory and intrathoracic organs	4%
Persons encountering health services for specific procedures and health care	5%	Malignant neoplasms of ill-defined, secondary and unspecified sites	4%
Influenza and pneumonia	5%	Other diseases of intestines	4%
Symptoms and signs involving the circulatory and respiratory systems	5%	Malignant neoplasms of digestive organs	4%
Metabolic disorders	4%	Other dorsopathies	4%
Other diseases of intestines	3%	Influenza and pneumonia	3%
Arrival at Hospital		Arrival at Hospital	
Ambulance	65%	Ambulance	31%
No Ambulance	35%	No Ambulance	69%
Acuity Level		Acuity Level	
High Acuity (CTAS I, II and III)	94%	High Acuity (CTAS I, II and III)	80%
Low Acuity (CTAS IV and V)	6%	Low Acuity (CTAS IV and V)	20%
Length of Stay		Length of Stay	
<5 Hours	19%	<5 Hours	58%
5 to <10 Hours	29%	5 to <10 Hours	30%
10 to <15 Hours	16%	10 to <15 Hours	7%
15+ Hours	37%	15+ Hours	5%

Notes

CTAS: Canadian Triage and Acuity Scale.

Includes visits to Ontario facilities only. Not all categories are shown in all cases; as such, some percentages do not add to 100. Percentages for some categories may not add to 100 due to rounding.

Source

National Ambulatory Care Reporting System, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

Appendix B: Summary of Alberta Cancer Patients' ED Visits

Data from CIHI's NACRS, which tracks ED use, was used to examine ED visits by cancer patients who died in acute care hospitals in 2011–2012. Of the 2,785 patients in the current study from Alberta, 1,706 (61%) visited the ED in their last 28 days of life. A total of 22% of patients did not visit the ED because they were already in hospital 28 days before they died. The demographics and cancer types of the patients who visited the ED are provided in Table 4 below.

Table 4: Profile of Cancer Patients Who Died in Acute Care Hospitals in 2011–2012 and Had One or More ED Visits 28 Days Prior to Death, Alberta (N = 1,706)

Description	Percentage of Patients	Description	Percentage of Patients
Gender		Most Common Cancer Types	
Male	54%	Lung	26%
Female	46%	Colorectal	9%
Age		Pancreatic	6%
20–44	3%	Leukemia	5%
45–64	29%	Prostate	4%
65–74	26%	Place of Residence	
75–84	28%	Urban	62%
85+	13%	Rural	37%

Notes

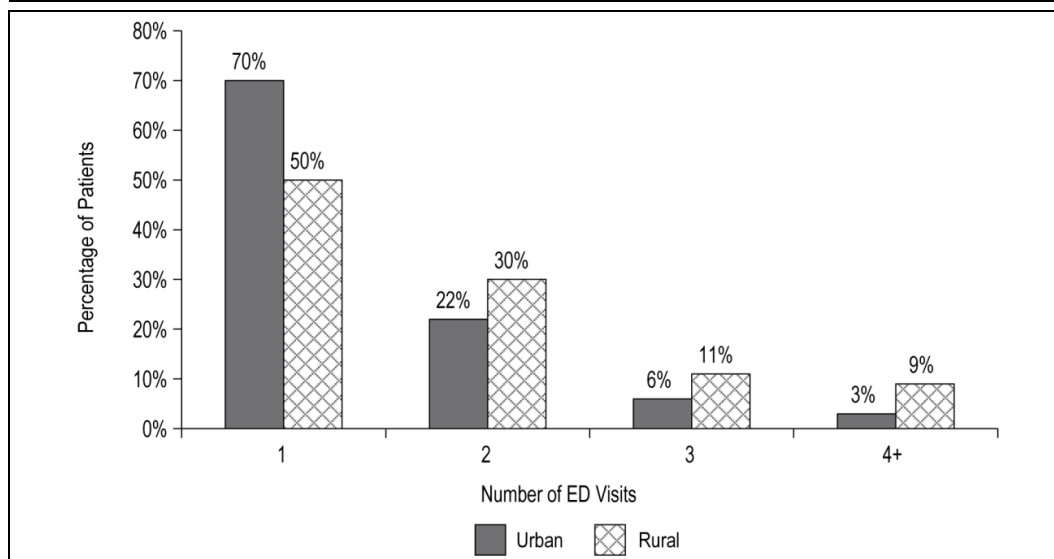
Includes only Alberta patients with at least one ED visit. Not all categories are shown in all cases. As such, some percentages do not add to 100. Percentages for some categories may not add to 100 due to rounding.

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

Overall, Alberta patients who visited the ED did so at an average of 1.6 visits per patient. The rate of visits per patient was higher for rural patients (1.9 visits) than urban patients (1.4 visits). Figure 10 shows the percentages of rural and urban patients with one or more ED visits.

Figure 10: ED Visits in Last 28 Days of Life Prior to In-Hospital Death by Rural and Urban Alberta Patients



Note

Includes visits to Alberta facilities only. Percentages may not add to 100 due to rounding.

Source

National Ambulatory Care Reporting System, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

The study's cancer patients who visited the ED were admitted to hospital in 70% of their ED visits. As expected, patients were triaged at a higher acuity and had a longer LOS in the ED when they were admitted from that ED visit. Main reasons for the visits when patients were admitted were somewhat comparable with those when they were not admitted, suggesting that it was the acuity, more than the main reason for the visit, that affected whether they were admitted (see Table 5).

Table 5: Description of Visits by Cancer Patients to the ED in Last 28 Days of Life Prior to In-Hospital Death, Alberta (N = 2,755 Visits)

Admitted (70% of Visits)		Not Admitted (30% of Visits)	
Description	Percentage of Patients	Description	Percentage of Patients
Main Problem		Main Problem	
Symptoms and signs involving the digestive system and abdomen	8%	Persons encountering health services for specific procedures and health care	19%
General symptoms and signs	7%	Symptoms and signs involving the digestive system and abdomen	7%
Malignant neoplasms of digestive organs	7%	General symptoms and signs	6%
Malignant neoplasms of respiratory and intrathoracic organs	7%	Symptoms and signs involving the circulatory and respiratory systems	5%
Persons encountering health services for specific procedures and health care	6%	Malignant neoplasms of respiratory and intrathoracic organs	5%
Symptoms and signs involving the circulatory and respiratory systems	5%	Metabolic disorders	4%
Influenza and pneumonia	5%	Malignant neoplasms of ill-defined, secondary and unspecified sites	4%
Metabolic disorders	5%	Other diseases of intestines	4%
Malignant neoplasms of ill-defined, secondary and unspecified sites	5%	Malignant neoplasms of digestive organs	4%
Other diseases of intestines	4%	Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified	2%
Arrival at Hospital		Arrival at Hospital	
Ambulance	60%	Ambulance	17%
No Ambulance	40%	No Ambulance	83%
Acuity Level		Acuity Level	
High Acuity (CTAS I, II and III)	79%	High Acuity (CTAS I, II and III)	45%
Low Acuity (CTAS IV and V)	17%	Low Acuity (CTAS IV and V)	47%
Length of Stay		Length of Stay	
<5 Hours	39%	<5 Hours	71%
5 to <10 Hours	25%	5 to <10 Hours	21%
10 to <15 Hours	13%	10 to <15 Hours	4%
15+ Hours	23%	15+ Hours	4%

Notes

CTAS: Canadian Triage and Acuity Scale.

Includes visits to Alberta facilities only. Not all categories are shown in all cases. As such, some percentages do not add to 100. Percentages for some categories may not add to 100 due to rounding.

Source

National Ambulatory Care Reporting System, 2010–2011 and 2011–2012, Canadian Institute for Health Information.

Appendix C: Differences Between Palliative and Non-Palliative Patients

Table 6: Differences Between Cancer Patients Diagnosed as Palliative and Non-Palliative

Description	Palliative Group	Non-Palliative Group
N (%)	20,571 (82%)	4,543 (18%)
Gender		
Male	54%	59%
Female	46%	41%
Age		
20–44	3%	3%
45–64	26%	24%
65+	71%	73%
Place of Residence		
Urban	74%	69%
Rural	26%	31%
Admission Type		
Emergency Department	68%	72%
Direct Admission	29%	25%
Arrival via Ambulance	58%	51%
Admitted From		
Acute Care	9%	9%
Residential Care	4%	4%
Home With or Without Support	82%	82%
Admitted to Hospital Type		
Teaching or Large Hospital	65%	66%
Medium or Small Hospital	35%	34%
Admitted to ICU	8%	30%
Died in ICU	4%	21%
Received Chemotherapy	5%	11%
Admitted as ALC Patient	6%	0%
Became ALC Patient	7%	6%
Median Length of Stay	11 Days	9 Days
Multiple Visits Within 28 Days	23%	22%
Most Common Cancer Types	Lung (24%)	Lung (22%)
	Colorectal (9%)	Colorectal (10%)
	Pancreatic (5%)	Leukemia (7%)
	Breast (4%)	Non-Hodgkin's Lymphoma (6%)
	Leukemia (4%)	Pancreatic (3%)

Notes

ICU: intensive care unit.

ALC: alternate level of care.

Includes all provinces and territories except Quebec. Not all categories are shown in all cases. As such, some percentages do not add to 100.

Percentages for some categories may not add to 100 due to rounding

Source

Discharge Abstract Database, 2011–2012, Canadian Institute for Health Information.

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