

Palliative care for cancer patients near end of life in acute-care hospitals across Canada: a look at the inpatient palliative care code

J. Tung MSc,* J. Chadder MSc,* D. Dudgeon MD,* C. Louzado MHSc,* J. Niu MSc,* R. Rahal MBA,* and A. Sinnarajah MD MPH†

ABSTRACT

Hospitals play an important role in the care of patients with advanced cancer: nearly half of all cancer deaths occur in acute-care settings. The need for increasing access to palliative care and related support services for patients with cancer in acute-care hospitals is therefore growing. Here, we examine how often and how early in their illness patients with cancer might be receiving palliative care services in the 2 years before their death in an acute-care hospital in Canada. The palliative care code from inpatient administrative databases was used as a proxy for receiving, or being referred for, palliative care. Currently, the palliative care code is the only data element routinely collected from patient charts that allows for the tracking of palliative care activity at a pan-Canadian level.

Our findings suggest that most patients with cancer who die in an acute-care hospital receive a palliative designation; however, many of those patients are identified as palliative only in their final admission before death. Of the patients who received a palliative designation before their final admission, nearly half were identified as palliative less than 2 months before death. Findings signal that delivery of services within and between jurisdictions is not consistent, that the palliative care needs of some patients are being missed by physicians, and that palliative care is still largely seen as end-of-life care and is not recognized as an integral component of cancer care.

Measuring the provision of system-wide palliative care remains a challenge because comprehensive national data about palliative care are not currently reported from all sectors. To advance measurement and reporting of palliative care in Canada, attention should be focused on collecting comparable data from regional and provincial palliative care programs that individually capture data about palliative care delivery in all health care sectors.

Key Words Palliative care, end of life, acute care, care codes

Curr Oncol. 2019 Feb;26(1):43-47

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INTRODUCTION

In most developed countries, a trend toward more patients with chronic disease dying in hospital is observed¹. In the case of cancer, nearly half of all patients who die of cancer in Canada die in an acute-care setting². With an aging population and expected growth in the number of new cancer cases by 2030, the number of deaths occurring in hospitals is likely to increase². Because hospitals play an important role in the care of patients with advanced disease, the need for increased access to palliative care and related support services for patients with cancer in acute-care hospitals is growing.

Palliative care aims to provide relief from the physical symptoms associated with a life-threatening illness and

support for associated psychosocial, spiritual, and cultural needs, all aimed at improving quality of life for patients and families alike³. The World Health Organization, along with the Canadian Hospice Palliative Care Association, recommends that palliative care be incorporated early in the course of illness and in conjunction with curative therapies⁴. Notably, most palliative care can be delivered in settings other than acute-care hospitals (for example, home, hospices, and long-term care facilities) by a range of providers, including family doctors, nurses, and other health care practitioners⁵. However, a population-based study found that, of patients with cancer receiving palliative care, 84.9% received care in acute-care hospitals⁶. Moreover, palliative care was shown to be the main reason for hospitalization for more than half of all patients with

cancer who died in acute-care settings⁷. Those observations further highlight the important role that hospitals play in the care of patients with advanced cancer and the delivery of palliative care.

In 2008, national palliative care coding standards were introduced to help consistently identify and capture palliative inpatients in administrative databases. The designation of palliative care in an acute-care hospital is based on the presence of the clinical code Z51.5 on a patient's discharge abstract. The palliative care code is applied to abstracts whenever the chart documents a palliative care consultation, with initiation of a palliative care treatment plan, or physician documentation of "palliative patient," "palliative situation," "end-of-life care," "comfort care," "supportive care," or "compassionate care"⁸. Currently, the palliative care code is the only routinely collected data element that allows for tracking of inpatient palliative care activity across Canada.

Here, we examine how often, and how early in their illness, patients with cancer might be receiving palliative care services in the last 2 years before their death in an acute-care hospital in Canada. The palliative care code was used as a proxy for receiving or being referred to palliative care services. Understanding variations in the application of the palliative care code can help with system planning, ensuring that palliative care is an integral component of cancer care for all patients and families, and informing data improvement strategies to better capture comprehensive palliative care delivery at the system level.

METHODS

The hospital records for all patients with cancer who died in an acute-care hospital from 1 April 2014 to 31 March 2016 were extracted from the Canadian Institute for Health Information's Discharge Abstract Database. Patients for the study were identified using the *International Statistical Classification of Diseases and Related Health Problems*, 10th revision, Canada⁸. Specifically, codes that listed 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 of neoplasm, were used to capture patients with cancer.

For each cancer patient who died in an acute-care hospital, the last 2 years of hospital records before death were analyzed for the presence of the palliative care code (Z51.5) to ascertain if the patient had a palliative designation. The timing of the first designation was identified as either the final admission or preceding the final admission before death. Of patients with a palliative designation preceding final admission, the interval from the first application of the Z51.5 code to death was calculated and grouped into one of two categories: first designation within 2 months of death, or first designation more than 2 months before death.

The analysis included 48,850 adult patients with cancer (18 years or older at the time of final admission) who died in an acute-care hospital in fiscal years 2014–2015 and 2015–2016. The data covered 9 provinces (excluding Quebec) and the 3 Canadian territories. Quebec was

not included because acute-care facilities in Quebec are not required to submit to the Discharge Abstract Database. Because of small numbers, data from the territories were combined.

RESULTS

Frequency of Palliative Care Code Application

Across Canada, 86.5% of patients with cancer who died in an acute-care hospital were designated as palliative within 24 months of death (Figure 1). The percentage of patients who had no record of inpatient palliative care 2 years before death varied interjurisdictionally, ranging from 4.8% in Nova Scotia to 15.9% in Alberta (Figure 1).

Timing of Palliative Care Code Application

Of patients with cancer in Canada who received a palliative care code in an inpatient setting, 76.8% were first designated as palliative during their final admission before death (Figure 2). The percentage of patients who were identified as palliative in their final acute-care admission varied interjurisdictionally, ranging from 60.3% in the territories to 80.5% in Ontario (Figure 2).

The remaining patients (23.2%) received the palliative designation before their final acute-care admission (Figure 2). Examined more closely, 47.5% of the patients who received a palliative designation before their final admission were first identified as palliative less than 2 months before death (Figure 3). Across Canada, that proportion ranged from 37.1% in New Brunswick to 56.6% in Newfoundland and Labrador.

DISCUSSION AND CONCLUSIONS

Our examination of the application of the inpatient palliative care code to patients who die in acute-care hospitals sheds light on the frequency and timing of the delivery of palliative care services to patients with cancer in those facilities. Currently, the palliative care code is the only data element routinely collected from patient charts that allows for the tracking of palliative care activity at a pan-Canadian level. The hope is that reporting on available data will improve the understanding of the delivery of palliative care in acute-care hospitals and bring awareness to the lack of available data to comprehensively capture palliative service delivery in Canada.

Our findings suggest that most patients with cancer who die in an acute-care hospital receive a palliative designation; however, there are still patients who die without being identified as palliative. It is possible that some of those patients had advanced cancer and experienced a rapid demise, but the interjurisdictional variability signals that, for some patients, palliative care needs are being missed by physicians, and that practice within and between jurisdictions is not consistent. Moreover, assignment of a palliative care code does not provide information about the range, scope, and quality of the palliative care provided to the patient. Further work is therefore needed to better understand the extent, or lack, of palliative care provided to patients with cancer, and whether the care provided is adequately meeting their palliative needs.

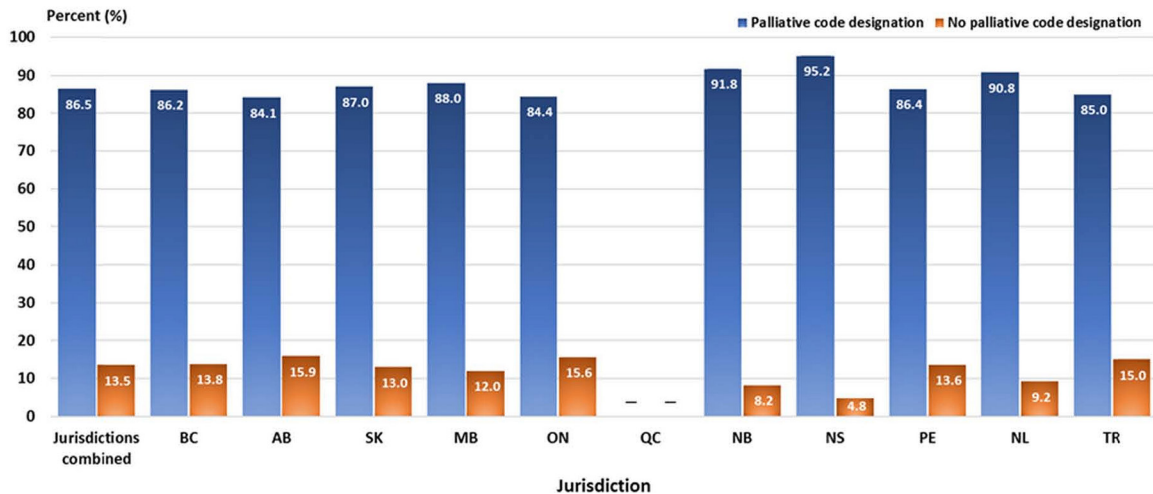


FIGURE 1 Percentage of patients with cancer designated as palliative in the last 2 years of life who died in an acute-care hospital, 2014–2015 and 2015–2016 fiscal years combined. Data source: Canadian Institute for Health Information, Discharge Abstract Database. TR = Canadian territories.

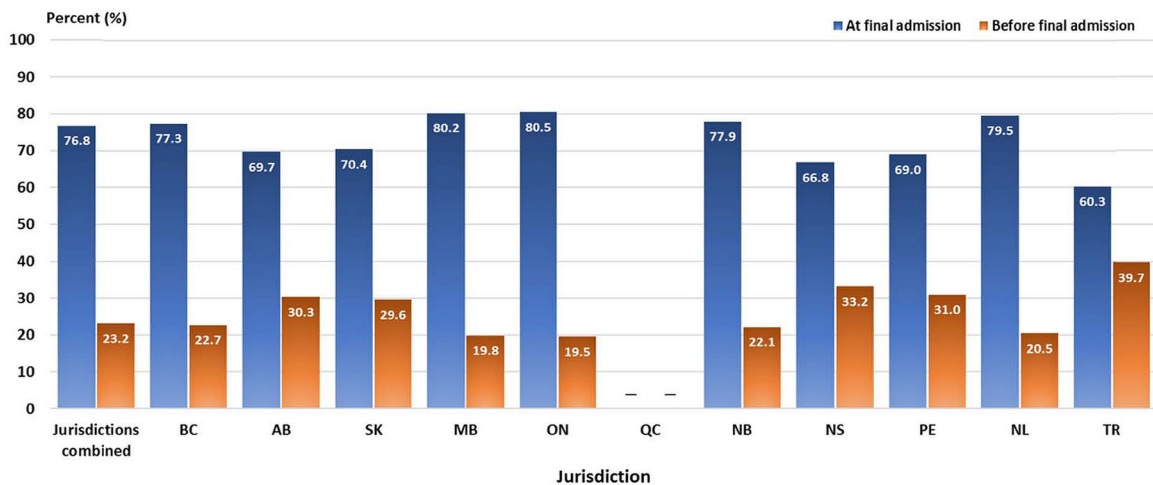


FIGURE 2 Timing of first palliative designation in patients with cancer designated as palliative in the last 2 years of life, 2014–2015 and 2015–2016 fiscal years combined. Data source: Canadian Institute for Health Information, Discharge Abstract Database. TR = Canadian territories.

With respect to the timing of palliative care code application, our findings suggest that most patients are being identified as palliative only in their final admission before death, which is in line with previous findings from the Canadian Institute for Health Information⁷. Moreover, among patients with cancer who were hospitalized multiple times and who received a palliative designation before their final admission, nearly half were identified as palliative less than 2 months before their death. A previous study looking at all health care sectors in Ontario observed that about half of all palliative care was initiated and delivered in the last 2 months of life⁶. Those findings strongly signal that palliative care is still largely seen as end-of-life care and is not recognized as an integral component of cancer care. The World Health Organization's definition of palliative care recommends that palliative care be available to all patients with cancer, concurrent with therapies aimed at prolonging life, and integrated earlier in the course of the disease³. Offering

palliative care only near end of life might therefore be an indication that recommended care is underused and that patients and families are not experiencing the full benefits of such care².

The Canadian data examined here showcase wide interjurisdictional variation in the application of the palliative care code; however, variation in coding practice is an unlikely contributor. Previous research has examined adherence to coding standards for the palliative designation and found that standardization was greatly improved and that palliative code application was confirmed by an independent second coder 96.4% of the time⁹. Our findings therefore point to two possible explanations for the variations observed: incomplete documentation of palliative care being offered to patients, or challenges in identifying patients appropriate for palliative care. Education about accurate documentation in medical records and about key phrases used in coding might assist in more consistent capture of palliative patients⁹. Additionally,

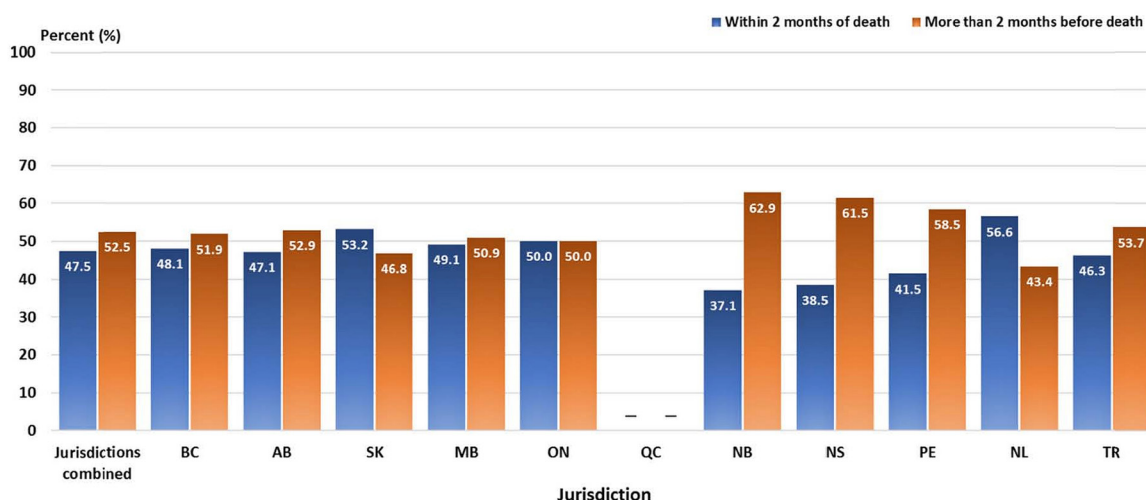


FIGURE 3 Timing of first palliative designation in patients with cancer designated as palliative before their final admission preceding death, 2014–2015 and 2015–2016 fiscal years combined. Data source: Canadian Institute for Health Information, Discharge Abstract Database. TR = Canadian territories.

the development by organizations of standardized criteria for oncologists and other hospital attending teams to identify individuals with palliative needs has been shown to increase the number of palliative care referrals, resulting in reduced readmissions and hospital mortality¹⁰.

Palliative care in Canada is described as a patchwork of uncoordinated services, delivered in multiple health care settings by multiple providers, and varying depending on location, care facility, and provider⁶—thus posing a challenge for measurement of the provision of system-wide palliative care, because comprehensive national data about palliative care from all sectors is not currently reported. To advance measurement and reporting of palliative care in Canada, attention should be focused on collecting comparable data from regional and provincial palliative care programs that individually capture data about palliative care delivery in all health care sectors. To further enhance the ability to differentiate the levels of palliative care provided to patients (and whether care is being appropriately matched to palliative needs), the introduction of a clinical code for specialist palliative care services should be considered. Such efforts will allow for a true understanding of the current landscape of palliative care delivery across Canada, within and outside of acute-care hospitals, and will identify areas in which the system is failing to meet the palliative needs of patients and families.

More information about the Canadian Partnership Against Cancer's System Performance Initiative and its reports and indicators can be found at <http://www.systemperformance.ca/>.

Limitations

Our analysis has some limitations. It was restricted to palliative care in a single sector and only to patients with cancer who died in an acute-care hospital. Information about patients with cancer who were designated as palliative in other settings or who died outside of hospital was not available. It is likely that some patients captured in this study as not being designated as palliative or being

designated only near death were receiving appropriate palliative care in another setting.

ACKNOWLEDGMENTS

The authors thank the System Performance Steering Committee and the Technical Working Group for reviewing this article.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

AUTHOR AFFILIATIONS

*Canadian Partnership Against Cancer, Toronto, ON; †Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, AB.

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