

Access to Palliative Care in Canada

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Abstract

Palliative care enables a better end of life, but not all Canadians have access to it. Access to community-based palliative care has become a priority for federal, provincial and territorial governments, with an emphasis on services that can help people remain in the community even at the end of life. The Canadian Institute for Health Information (CIHI) investigated the current state of access to publicly funded palliative care across the country. The purpose of the research is to help health system planners to identify service gaps and develop strategies for improving care. Using linked administrative data, the analysis found that while many people could benefit from palliative care at the end of life, only a few (15%) received palliative home care in Alberta and Ontario in 2016–2017. The analysis also found that early palliative care in the community was associated with better end-of-life outcomes and that access to palliative care varied by age and whether a patient had cancer or not.

Introduction

Palliative care can help improve the quality of life for people of all ages with life-limiting illnesses by relieving symptoms, enabling a peaceful and dignified death and providing support to the family through the dying and bereavement process. As the population ages and rates of complex chronic conditions increase, the need for palliative care is expected to rise. Estimates suggest that up to 89% of people who die might have benefited from palliative care (Canadian Society of Palliative Care Physicians 2016). Ideally, palliative care should begin alongside curative treatments soon after the diagnosis of a condition that may be life-limiting to maximize the potential for the relief of suffering and minimize costs for the system (Hawley 2014).

CIHI's report, *Access to Palliative Care in Canada* (<https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>) (CIHI 2018a), examines how Canadians access palliative care in the community and other care settings, whether they have equitable access to care and whether the services they receive are effective and appropriate. Health workforce preparedness to provide palliative care is also explored. Patient perspectives are captured in a companion product of the report, a series of patient and family stories (<https://www.cihi.ca/en/access-data-and-reports/>

[access-to-palliative-care-in-canada/palliative-care-in-canada-inconsistent-patients-say](https://www.cihi.ca/en/access-to-palliative-care-in-canada/palliative-care-in-canada-inconsistent-patients-say)) (CIHI 2018b).

Through a jurisdictional survey, this study confirmed that variations exist in provincial and territorial palliative care policies, strategies, frameworks and funding models. An international ranking conducted by the Economist Intelligence Unit rated Canada's performance in palliative care as middle-of-the-pack among developed countries, partly because of the lack of a national palliative care strategy in Canada (The Economist Intelligence Unit 2015). However, federal legislation was passed in December 2017 to develop a national framework on access to palliative care in Canada (Parliament of Canada 2017), and as part of a Common Statement of Principles on Shared Health Priorities, federal, provincial and territorial governments have agreed to improve access to home and community care, including palliative home care and residential hospices (Government of Canada 2017).

Data Sources and Methods

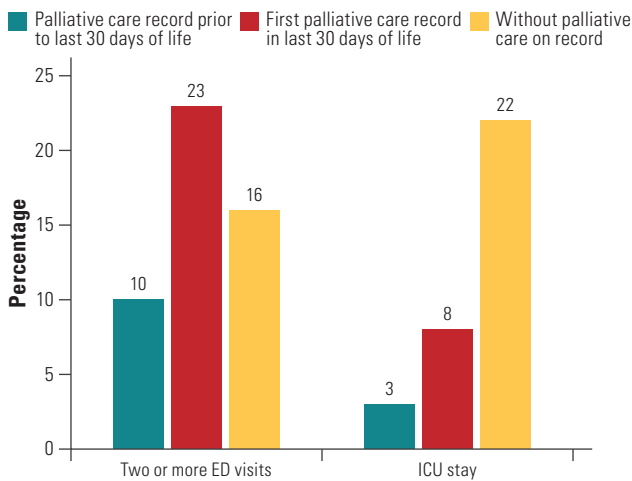
CIHI data sources were used to identify people of age ≥ 19 years at the time of death and to determine who received palliative care in the last year of life. These sources include data on acute care, emergency departments, long-term care facilities, home care, physician billings and claims to palliative care drug programs. Because of the greater availability of data in Ontario and Alberta, it was possible to take a more comprehensive look at system-wide interactions in these jurisdictions. International Commonwealth Fund Survey data were also used to examine physician preparedness to provide palliative care.

Key Findings

Surveys show that most Canadians would prefer to die at home if they could get the support they need (Canadian Hospice Palliative Care Association 2013; 2015). The findings of this study confirm that palliative home care enables home death, as palliative home care clients were 2.5 times more likely to die at home than other types of home care clients. However, although many Canadian jurisdictions consider community palliative care to be a priority, few Canadians receive formal palliative care outside of hospitals. In provinces where this could be measured (Ontario and Alberta), only 15% of those who died in 2016–2017 received publicly funded palliative home care.

Findings highlight opportunities to improve transitions of care and initiate palliative care earlier in the patient’s journey. Looking across the country at people who received palliative care and died in hospital, 84% of those hospitalizations were unplanned or admitted through the emergency department. Among deaths in Alberta and Ontario, 62% of individuals were formally identified as palliative patients only in acute care and usually in their last month of life. As seen in Figure 1, earlier integration of palliative care was found to be associated with better outcomes – a lower likelihood of intensive care unit (ICU) stays and repeat emergency department visits in the last month of life.

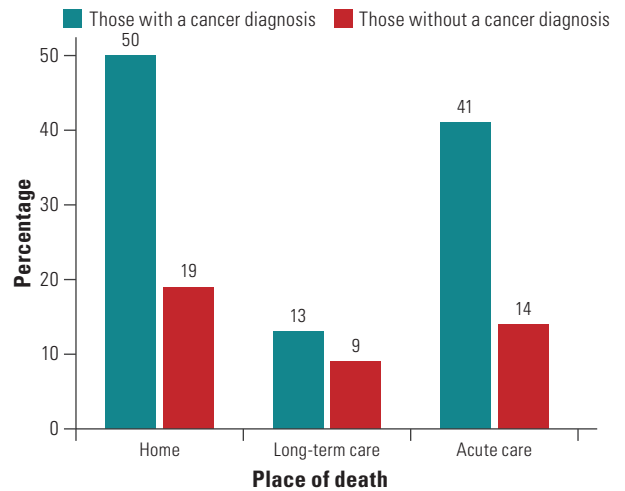
FIGURE 1. Proportion of those who died in 2016–2017 with two or more emergency department (ED) visits or an intensive care unit (ICU) stay in the last 30 days of life, by record of palliative care



Note: Data includes home care, long-term care, acute care, subacute care, emergency department and complex continuing care and takes into account deaths in Ontario and Alberta only. A greater proportion of those who have a first record of palliative care and more than two emergency department visits in the last 30 days of life may be the result of identification bias because of the likelihood of being identified as having palliative needs upon going to the emergency department. Sources: Discharge Abstract Database, National Ambulatory Care Reporting System, Continuing Care Reporting System and Home Care Reporting System, from 2015–2016 to 2016–2017, Canadian Institute for Health Information.

When looking at equity of access, variations in the likelihood of receiving palliative care were observed between age groups and were the highest between diagnosis categories. Adults between the ages of 45 and 74 were more likely to receive palliative care. As shown in Figure 2, patients with cancer were up to three times more likely to receive palliative care than patients with other diseases, particularly in hospital and home care settings. No significant differences were observed for receipt of palliative care by sex or neighborhood income level.

FIGURE 2. Proportion of those who died who received palliative care in the last year of life, by cancer diagnosis and place of death, 2016–2017



Note: Home deaths include Ontario, Alberta, British Columbia and Yukon only. Long-term care deaths include Newfoundland and Labrador, Ontario, Alberta, British Columbia and Yukon. The proportion of people who died in acute care who received palliative care includes only those who were hospitalized primarily for palliative care in their last year of life and excludes those who may have had palliative care in acute care but it did not represent the longest segment of their hospitalization. Quebec acute care deaths are excluded. Sources: Home Care Reporting System, Continuing Care Reporting System and Discharge Abstract Database, from 2015–2016 to 2016–2017, Canadian Institute for Health Information.

This study also looked into the capacity of the Canadian health workforce to provide palliative care. Although the data were limited, it was found that only a small proportion of providers were specialized or practiced primarily in palliative care. Just 1% of doctors practised primarily in palliative care in 2012–2013 in Alberta, whereas 2% of licensed practical nurses across Canada in 2016 worked most of the time in this area. In an international survey, only 41% of Canadian primary care physicians reported feeling well prepared to manage patients in need of palliative care, as opposed to 81% and 92%, respectively, in the UK and the Netherlands (The Commonwealth Fund 2015).

Discussion and Conclusion

Better data are needed to create a more complete picture of access to palliative care in Canada. In particular, more community-level data are required, as well as patient- and family-reported measures, to evaluate access, patient centredness, quality and outcomes of palliative care across the country. Other limitations in palliative care measurement include a lack of common definitions and standards for reporting palliative care services.

As a baseline report on access to palliative care in Canada, CIHI’s analysis identified opportunities for earlier integration of palliative care services in the community and smoother

care transitions. While few Canadians receive palliative home care, those who did were 2.5 times more likely to die at home. Earlier palliative care was also associated with fewer emergency department visits and ICU stays at the end of life. Findings suggest that improving identification of people with palliative needs can increase access to palliative care; cancer patients, whose disease trajectories are much better understood, were up to three times more likely to have had palliative care than those without cancer. Increasing the capacity and preparedness of healthcare providers to deliver palliative care may also help to improve the experience of Canadians in the last year of life. More broadly as a society, there is a recognized need in Canada to promote awareness of palliative care and discussions around how death can be managed better. **HQ**

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