Access to Palliative Care in Canada

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Abstract

Canadians are living longer and as they do so, the number of people living with life-limiting illnesses, such as cancer or kidney disease, is growing. Consequently, supporting and improving access to palliative care are goals of Canada's various health sectors. This article uses Canadian Institute for Health Information data from multiple healthcare sectors to investigate how many Canadians receive palliative care in their last year of life, how access to palliative care has changed in the past five years and what barriers to access still exist.

Introduction

Canadians are living longer and often with life-limiting illnesses, which results in an increase in the demand for palliative care services. In 2018, the Government of Canada released its *Framework on Palliative Care in Canada*, establishing the goals and priorities for palliative care services (Health Canada 2018). One of these goals was to improve equitable access to palliative care. That same year, the Canadian Institute for Health Information (CIHI) published *Access to Palliative Care in Canada*, describing palliative care services across the country (CIHI 2018). This report builds on our previous work and measures progress toward the goal of increasing Canadians' access to palliative care services. Specifically, we look at

- whether more Canadians are accessing palliative care;
- who is not getting the palliative care they need; and
- where gaps exist and what the opportunities are for improvement.

The report does not focus on the impacts of the COVID-19 pandemic but looks at the overall trends in access to care since 2016. Generally, we found that there was no major decrease in access to palliative care during the COVID-19 pandemic period.

Methods

The main analysis focuses on patients in Ontario, Alberta, British Columbia and Yukon who died between April 1, 2021, and March 31, 2022. For these patients, we looked back one year from their deaths to see if they received palliative care in acute care hospitals, emergency departments, home care or long-term care.

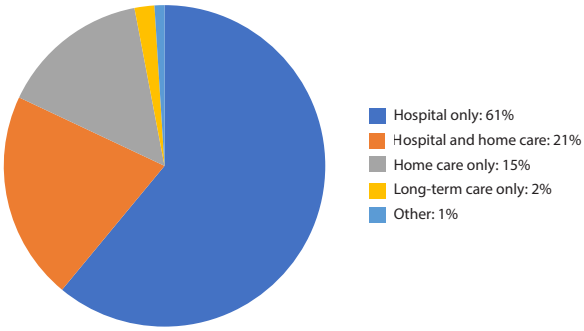
A separate analysis of acute and subacute hospitalizations only was also conducted using data from all provinces and territories to look at the resource use and flow of palliative patients. For details on the databases used and how palliative care was identified in each setting, see CIHI's 2018 report on palliative care (CIHI 2018). Interviews and informal conversations were also conducted with patients, caregivers and palliative care providers to better integrate their perspectives and to help put the data into context.

Findings

In 2021–2022, 58% of those who died in Ontario, Alberta, British Columbia and Yukon (89,000 people) were designated as palliative and received some form of palliative care. This finding is an increase from the 52% reported in 2016–2017 (for Ontario and Alberta only) (CIHI 2018). Among those who received some form of palliative care in 2021–2022, 61% received palliative care in the hospital only, while 36% received palliative home care (see Figure 1).

Access to palliative care at home has a wide-ranging impact on the experience of palliative care patients, including the likelihood of dying at home and the length of stay in hospital for those who need to be admitted. In 2021–2022, 13% of people died at home supported by palliative home care, an increase from the 7% we reported in 2016–2017 (for Ontario and Alberta only) (CIHI 2018). Compared with those who received palliative care only in a hospital, patients supported by palliative home care spent fewer days on average in hospital in the last year of their lives (18 days versus 28 days, respectively) and received fewer life-saving interventions (11% versus 26%, respectively).

FIGURE 1.
Patients designated as palliative by sector of care



There was variation in access to palliative care. Patients living in urban and rural/remote settings were identified as palliative at similar rates, overall, and were able to access home care similarly in 2021–2022. However, palliative patients living in rural areas were more likely to be hospitalized primarily for palliative care compared with those living in urban areas (36% versus 29%, respectively) and were also more likely to die in hospital than those in urban areas (29% versus 23%, respectively).

Patients with cancer have better access to palliative care than those with other conditions, possibly because cancer is well understood and has a relatively predictable progression, which makes the decision of when to start palliative or end-of-life care more clear-cut. In 2021–2022, among the common diseases we looked at, patients with cancer were the most likely to be identified as palliative (77%), while patients with dementia were the least likely to receive palliative care in the last year of life (39%).

Age also impacts access to palliative care. In 2021–2022, younger seniors – aged 65 to 84 years at the time of death – were the group most likely to receive palliative care, followed by those aged 19 to 64 years. Canadians who were 85 years and older at the time of death were less likely to receive palliative care than younger people.

People experiencing homelessness face barriers to receiving palliative care. Issues such as unstable housing and a lack of social supports can make it more difficult to get palliative care (Stajduhar et al. 2019). Caregivers whom we spoke with told us that these patients can also face challenges in accessing pain medications due to biases and stigma around drug use. People experiencing homelessness are more likely to have a longer stay in hospital and have to wait longer to be discharged to an alternate level of care setting than the typical hospital patient receiving palliative care.

Patients and caregivers whom we spoke with shared these concerns about uneven access to and gaps in the delivery of palliative care in Canada. Much of the responsibility for advocating for palliative care falls on the patients and their caregivers, though caregivers have reported a lack of information on services and resources available to them, about when a patient should start receiving palliative care and regarding what will change when they do. Across the country, caregivers reported that decisions to begin palliative or end-of-life care are made by checking the patient's condition against a checklist, such as the Palliative Performance Scale (Anderson et al. 1996). Many patients do not meet the criteria to qualify for care until they are at the end of their lives and caregivers reported that their requests for palliative support were denied because of this threshold. Our analysis shows that in 2021–2022, half of the patients died within 22 days of being identified as palliative. Half of the patients receiving care in hospital lived only 11 days or fewer once they were identified as palliative, while patients receiving palliative home care were identified earlier and lived longer – half died within 119 days of being identified as a palliative patient.

However, gaps in care still exist and some people experience barriers to accessing palliative care because of their age, where they live or their disease diagnosis. This will become more important as the population continues to age ...

Conclusion

The findings indicate that overall access to palliative care in Canada has gradually improved over the past five years as more people are receiving some form of palliative care in their final year of life, allowing more people to die at home with palliative support. However, gaps in care still exist and some people experience barriers to accessing palliative care because of their age, where they live or their disease diagnosis. This will become more important as the population continues to age and the demand for palliative care increases.

Since our first report on palliative care in Canada five years ago, CIHI has modernized and expanded its data collection, with a focus on expanding homecare data and improving data standards. This has helped to expand reporting of palliative care in this study. However, limitations in the data still exist; for example, the data can tell us whether the patient is in a palliative state but do not provide details about that care. To more thoroughly assess access to and the quality of palliative care in Canada, further improvements in data collection are needed, including the following:

- defining an appropriate set of standard palliative care services, particularly for palliative home care, to ensure that people receive consistent care across the country;
- gathering more complete data on characteristics of patients, particularly those more likely to face barriers to care; and

- assessing the quality of care and reporting on outcomes that better reflect what patients and caregivers are experiencing. These aspects include symptom management, patient and family stress and satisfaction, reduction in unnecessary tests and treatments and cost-effectiveness in palliative care by place of delivery, such as home, hospice, long-term care, day programs and acute care.

Better information on palliative care will help to identify the challenges experienced by patients, caregivers and healthcare providers. HQ

References

Anderson, F., G.M. Downing, J. Hill, L. Casorso and N. Lerch. 1996. Palliative Performance Scale (PPS): A New Tool. *Journal of Palliative Care* 12(1): 5–11. doi:10.1177/082585979601200102.

Canadian Institute for Health Information (CIHI). 2018. *Access to Palliative Care in Canada*. Retrieved April 28, 2023. <https://secure.cihi.ca/free_products/access-palliative-care-2018-en-web.pdf>.

Health Canada. 2018, December. *Framework on Palliative Care in Canada*. Retrieved April 28, 2023. <https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf>.

Stajduhar, K.I., A. Mollison, M. Giesbrecht, R. McNeil, B. Pauly, S. Reimer-Kirkham et al. 2019. "Just Too Busy Living in the Moment and Surviving": Barriers to Accessing Health Care for Structurally Vulnerable Populations at End-of-Life. *BMC Palliative Care* 18(1): 11. doi:10.1186/s12904-019-0396-7.

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