Canadian
Cancer
Society

Canadian Cancer Society Submission to Standing Committee on General Government

Bill 3, An Act providing for the development of a provincial framework on hospice palliative care

November 2020

Overview

The Canadian Cancer Society (CCS) is the only national charity that supports people with all cancers in communities across Ontario and Canada. With nearly 1 in 2 Ontarians expected to develop cancer in their lifetime, it is vital that we work together to strengthen our efforts to reduce the cancer burden in the province. CCS is well-positioned to play a key role in delivering a person-centered approach to cancer care, focused on seeing all Canadians living with cancer realize a positive patient experience. We offer a range of services available to Ontarians that address the emotional, physical and practical needs of all those touched by cancer, from the date of diagnosis through to survivorship or end-of-life.

While there are many different operational definitions of palliative care in Canada, it can be understood as care that focuses on the quality of life of patients with progressive, life-altering illness. Palliative care was largely developed for and is still largely delivered to, patients with advanced cancer. Cancer Care Ontario previously reported that 80–85% of patients receiving palliative care are patients with cancer, while in Nova Scotia this proportion was more recently reported to be 80–90.[1][2] At CCS, our Cancer Information Helpline data from 2018 shows that over the past 5 years, "palliative care" was a logged topic in 2,834 inquires nationally. "Bereavement" was a logged topic in 1,020 inquiries. Ontario data from fiscal year February 1, 2017-January 31, 2018 shows that palliative care represented nearly 29% of all inquiries.

In 2016, CCS published *Right to Care: Palliative care for all Canadians*. This policy report highlights the major gaps in care and existing barriers to ensuring all Canadians have access to quality palliative care, when they need it and in the setting of their choice. It outlined the importance of palliative care in healthcare delivery for Canadians dealing with cancer. We strive to inform our advocacy, research programs and information delivery activities as well as those of our partners, such as governments, and other organizations, so that we can improve accessibility, affordability and quality of palliative care for all Canadians affected by a life-altering illness.

CCS supports Bill 3, Compassionate Care Act, 2018 and looks to be a partner of the Ontario government as it develops and implements a palliative care framework in Ontario. This framework should address identified barriers in receiving palliative care, including misunderstandings of palliative care, insufficient funding, lack of consensus of what indicators should be used to evaluate care, insufficient training for healthcare providers, and lack of support for patients and family caregivers. While the COVID-19 pandemic brings the need to keep people out of acute care settings to the forefront, limited access to palliative care in a preferred setting of choice was an issue long before the pandemic began. Actions must be taken to improve timely access to palliative care in the setting of choice, now and long after the pandemic is behind us.

---

[1] Cancer Care Ontario, "Improving the quality of palliative care services for cancer patients in Ontario," 2006.

[2] Cancer Care Nova Scotia, "Supportive Care," 2015. [Online]. Available: http://www.cancercare.ns.ca/en/home/nscancerserivces/ palliativeandsupportivecare.aspx. [Accessed 13 April 2015].

Comments on Bill 3, Compassionate Care Act, 2018

CCS supports Bill 3 and the development and implementation of a palliative care framework for Ontario. The framework should include:

- An expansive definition of palliative care
- Inclusion of pediatric palliative care
- Increased funding for palliative care
- Clear and consistent palliative care indicators
- Training for healthcare providers
- Guaranteed support for caregivers

Expansive Definition Palliative Care

> “Palliative care focuses on quality of life of patients with progressive, life-altering illness. Palliative care includes expert pain and symptoms management; skilled psychosocial, emotional and spiritual support; and comfortable living conditions with the appropriate level of care – whether at home, in a hospital or any other settings of patients’ choice. Palliative care is applicable early in the course of illness, in conjunction with other therapies and uses a multidisciplinary team approach to address the needs of patients and their families. End-of-life care is a component of palliative care focusing on specific care needs for someone who is dying.” Canadian Cancer Society, *Right to Care: Palliative care for all Canadians*.

Palliative care refers to care for patients and their families who are facing serious, life limiting illnesses. It focuses on relieving suffering and improving quality of life for patients and their families at all stages of the illness, not just end-of-life care. This may include expert pain and symptoms management, skilled psychosocial, emotional and spiritual support, and comfortable living conditions with the appropriate level of care – whether at home, in a hospital or any other settings of patients’ choice.

Many patients, families and healthcare providers still associate palliative care with “giving up”. As a result, patients and families may not want to talk about it and physicians may be reluctant to refer patients to palliative care. Providers who lack adequate knowledge or skills believe that palliative care is only for persons in their last days of life, and they do not want to cause the patients to lose hope.[3] Many initiatives to promote knowledge of palliative care and advanced care planning in Canada exist, but more support is needed to clarify misconceptions of palliative care. Overall, too few Canadians are engaging in advance care planning, with an estimated 20% of Canadians completing an advance care plan and about

---

[3] A. De Vleminck, D. Houttekier, K. Pardon, R. Deschepper, C. Van Audenhove, R. Vander Stichele and L. Deliens, “Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review,” Scand J Prim Healthcare, vol. 31, no. 4, p. 215, 2013

47% designating a substitute decision maker.[4] A study on elderly patients at risk of dying in the next 6 months found that, although 73% had named a surrogate decision maker for healthcare, only 48% of patients questioned had completed an advance care plan.[5] A clear understanding of palliative care, embedded in a provincial framework, will help clarify misconceptions and help facilitate conversations about palliative care earlier.

Inclusion of pediatric palliative care

CCS encourages all MPPs to work together to ensure guaranteed palliative care for all those that need it. To this end, we recommend including pediatric palliative care in the Compassionate Care Act. Committee members can look to Bill 114, Nancy Rose Act (Pediatric Hospice Palliative Care Strategy) 2019, as well as pre-existing pediatric palliative care networks in Ontario for guidance on inclusion.

Increased funding for palliative care

Insufficient funding for palliative care is a common cause of the system's gaps and barriers. While some organizations are making progress in developing frameworks of care and medical curricula, many palliative care experts identify a clear need for increased support from governments to implement these projects.[6] Some researchers also noted that palliative care receives much less in research funding compared to other areas of healthcare research.

Much of the analyses on the costs of palliative care are limited to the weeks or months prior to death. Healthcare costs increase dramatically as patients approach death due to the increasingly frailty and care needs of a patient. When quality palliative care is available for people in their communities and homes, patients are less likely to be in emergency departments, intensive care units and acute care[7] – which are usually more costly than palliative care and not designed for patients whose primary needs are palliative. According to the 2014 Ontario Auditor General's report, costs of palliative care during the last month of life are $1,100 per day in an acute-care hospital versus $770 per day in a palliative care unit in hospital, $460 per day in a hospice bed and under $100 per day in the home.[8] Many of these patients could receive more appropriate care in other settings, resulting in not only more appropriate care for patients but more efficient use of healthcare dollars. CCS requests that sufficient funding accompany a provincial palliative care framework to guarantee access to palliative care for those that require it.

---

[4] A. Teixeira, L. Hanvey, C. Tayler, D. Barwich, S. Baxter and D. Heyland, "What do Canadians think of advance care planning? Findings from an online poll.," BMJ Supp & Palliat Care, vol. 5, p. 40, 2015.

[5] D. Heyland, D. Barwich, D. Pichora, P. Dodek, F. Lamontagne, J. You, C. Tayler, P. Porterfield, T. Sinuff and J. Simon, "Failure to engage hospitalized elderly patients and their families in advance care planning," JAMA Intern Med, vol. 173, no. 9, p. 778, 2013.

[6] Canadian Cancer Society, "Right to Care: Palliative Care for All Canadians," 2016. Available at: https://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en.

[7] H. Seow, K. Brazil, J. Sussman, J. Pereira, D. Marshall, P. Austin, A. Husain, J. Rangrej and L. Barbera, "Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis," BMJ, vol. 348, p. g3496, 2014.

[8] Office of the Auditor General of Ontario, "Chapt 3, Section 3.08: Palliative Care. 2014 Annual Report of the Office of the Auditor General of Ontario," Queen's Printer for Ontario, 2014.

Indicators

CCS supports the inclusion of data collection as part of the Compassionate Care Act. However, as noted above, because palliative care is currently delivered in a variety of different settings, including at home, in hospital, through outpatient clinics, or in long-term care facilities as well as hospices, data collection efforts should extend beyond the hospice care setting. This does pose significant barriers to data collection to understand the full range and scope of the palliative care services currently being provided, much less where the gaps are. Our current data systems only provide information on end-of-life care measures, which is one component of palliative care, and only in a single setting (inpatient care in acute care institutions).

A palliative care framework for Ontario needs to gather more data on how we provide palliative care throughout the healthcare system. System-wide measurement will provide data on how palliative care is used across the province and help identify opportunities where our system falls short and how to provide better care. These indicators need to reflect what is most important and relevant to stakeholders and service providers in the healthcare system so they, and the government, can make evidence-based decisions about resources. Moreover, the indicators need to be feasible to collect on a timely basis, easily interpretable by stakeholders and decision makers, and actionable, so they are useful to inform future public policy and funding decisions and improve patient outcomes. A full list of proposed palliative care indicators related to structure and process of care, access to palliative care, training and education for healthcare providers, management of pain and symptoms, psychosocial care, caregiver supports, goals of care and decision making, and setting of care and place of death can be found in Appendix A.

Similarly, the Canadian Cancer Society urges the Government of Ontario to encourage its other provincial counterparts as well as the federal government to adopt these indicators as a common set of nationwide indicators to allow for meaningful comparisons of palliative care across jurisdictions and over time.

While indicators alone will not tell the full story of access to palliative care, particularly for rural, remote, and marginalized communities for whom we know inequities are not always captured by the data, and will not guarantee adequate resourcing for palliative care, the Government of Ontario cannot address the problems it cannot see. Tracking and reporting on these indicators as part of its palliative care framework will clarify for the government and its partners the steps to take to ensure all Ontarians have access to the palliative care they deserve, no matter where in the province they live.

Minimum Care Standards

In addition to indicators, CCS feels it is critical the palliative care framework include benchmarks to ensure a minimum standard of palliative care is provided. A number of documents have been developed on guiding principles or models for palliative care, yet there is a lack of tangible universal, evidence-based, integrated care standards and guidelines to ensure delivery of quality care. There is no consensus on the number of palliative care beds, palliative care specialists and other healthcare providers to adequately support the population in the Canadian context. But this type of planning is possible and has been done in some provinces. Alberta, for example, completed capacity-planning work in 2013 and has set a benchmark of 7.7 hospice beds per 100,000 inhabitants.[9] In Quebec, this ratio was established in a 2007–2008 report at 10 palliative care beds per 100,000 inhabitants.[10]

Moreover, there is a lack of validated frameworks or policies to guide healthcare providers in the delivery of palliative care, including tools to help identify which patients can benefit from palliative care. Some provincial agencies are making progress in this area; Cancer Care Ontario launched an initiative in 2008 to screen all patients with cancer for symptoms using common assessment tools known as the revised Edmonton Symptom Assessment System (ESAS-r)[11]. The Ontario Palliative Care Network has also explored additional tools, including Risk Evaluation for Support: Prediction for Elder-life in the Community Tool (RESPECT) and the Hospital-Patient One-Year Mortality Risk (HOMR) to help guide their palliative care needs.[12] These are only a few examples that show the potential of developing standard tools of practice across large jurisdictions.

Training

CCS welcomes the inclusion of training as part of the Compassionate Care Act. Education for physicians and other healthcare workers is essential to ensure trained healthcare providers can meet the needs of the population. All healthcare professionals should have basic training in palliative care and should know when to refer a patient to a palliative care specialist. At the same time, the number of palliative care specialists must be increased. The need for more healthcare providers and specialized palliative care physicians is supported by the results of a National Palliative Medicine Survey conducted by several healthcare professional and research organizations, as well as past work by the Canadian Medical Association.[13][14] Medical and other health professional curricula and residency programs must ensure sufficient hours are devoted to palliative care. Continuing education courses on palliative care should be developed, or existing courses should be expanded across jurisdictions. CCS is also looking forward to reviewing the Canadian Inter-Disciplinary Palliative Care Competency Framework, to guide curricula for educators and reference manual for health professionals and volunteers, being created by Canadian Partnership Against Cancer in partnership with Health Canada and provincial and territorial health

---

[9] Alberta Health Services, "Palliative and end of life care, Alberta Provincial Framework", 2014, pg 16.

[10] Ministère de la santé et des services sociaux du Québec, "Rapport d'activité 2007–2008 direction de la lutte contre le cancer," Gouvernment du Québec, 2008.

[11] Cancer Care Ontario, "Symptoms Assessment Tools: Your Symptoms Mater", https://www.cancercareontario.ca/en/guidelines-advice/symptom-side-effect-management/symptom-assessment-tool

[12] Ontario Palliative Care Network, "Tools to Support Earlier Identification for Palliative Care", April 2019.

[13] Canadian Society of Palliative Care Physicians Human Resources Committee, "Highlights from the National Palliative Medicine Survey," Canadian Society of Palliative Care Physicians, 2015.

[14] Canadian Medical Association, "Palliative care: Canadian Medical Association's National Call to Action," Canadian Medical Association, Ottawa, 2014-2015

authorities.[15] Education on palliative care must be informed and developed with input from palliative care specialists.

Bolstered supports for people with cancer and their caregivers

Caregivers are a critical part of the healthcare team for people with living with cancer and other life-limiting illnesses. CCS believes caregivers ought to have a presence in developing the Government of Ontario's palliative care framework, and that the challenges they face and the supports they need should be captured in the framework.

Encouraging and promoting advance care planning should be standard practice. In addition, support for family caregivers must be improved to ensure that palliative care provided outside of a hospital setting does not result in significant financial impact. As a start, there are a number of work policies employers can develop and implement to support their employees who need to take time off to provide care and support for a critically ill family member. For instance, provincial/territorial compassionate care leave should be improved to complement the recent improvement of the Employment Insurance Compassionate Care Benefit. While the federal legislation provides up to 26 weeks of job protection, most provincial and territorial legislations provide only 8 weeks of job protection.

Furthermore, financial supports could also be implemented or improved. Quebec has a refundable caregiver tax credit, and Nova Scotia offers caregivers a small caregiver benefit. However, both programs could be improved and implemented in all provinces and territories. This request echoes asks made previously by other health charities and caregiver organizations, such as the Ontario Caregiver Coalition.

Finally, a framework for palliative care must include considerations regarding access to home care as well as access to respite care and psychosocial supports for caregivers, particularly for those primarily receiving palliative care at home. CCS has included these supports in the indicators it recommends in Appendix A and strongly urges the government to make additional investments to improve access to home, respite, and psychosocial care for patients and caregivers as part of its approach to palliative care.

Contact

We would be happy to provide more information or a briefing on the development of a palliative care framework for Ontario. If you have any questions about our submission to this consultation please contact Stephen Piazza, Manager of Public Issues (Ontario) at 647-233-6793 or Stephen.piazza@cancer.ca.

---

[15] Canadian Partnership Against Cancer. (2020). The Canadian Inter-Disciplinary Palliative Care Competency Framework: A curriculum guide for educators and reference manual for health professionals and volunteers.

Appendix A

List of indicators to measure palliative care

1. Structure and Process of Care

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment, in addition to ensuring adequate communication.

1.1. Percentage of healthcare professionals who have tools to identify people who would benefit from palliative care and assess their needs
1.2 Percentage of people identified to benefit from palliative care who have a documented assessment of their palliative care needs (physical, psychological, social, cultural, legal, ethical and spiritual)
1.3 Number of days between receiving first palliative care service and death [16]
1.4 Number of days between referral to palliative care and receiving services
1.5 Percentage of people who receive palliative care (or their caregivers) who state that they have received care from two or more healthcare providers, such as a physician, nurse, social worker, psychologist, spiritual care provider, volunteer, and others (interdisciplinary care)

2. Access to palliative care

People with identified palliative care needs have access to palliative care support as needed.

2.1 Proportion of individuals who can access palliative care support in-person (within a one-hour drive) [or virtually 24/7]
2.2 Percentage of people identified to benefit from palliative care who state that they can receive community palliative care support, including afterhours care, when needed
2.3 Proportion of patients with 2 or more emergency room visits in the last 30 days of life (negative indicator)

3. Training and education for healthcare providers

People receive palliative care from healthcare providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

3.1 Percentage of people with identified palliative care needs (or their caregivers) who state that healthcare professionals helped them understand palliative care and provided information about available resources and supports

---

[16] Palliative care services is defined to be consistent with the approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

3.2 Availability of resources and tools for healthcare professionals to provide education about palliative care to patients, families, and caregivers

3.3 Percentage of healthcare providers and volunteers who provide palliative care who state that they have the knowledge and skills to provide palliative care

4. Management of pain and symptoms

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

4.1 Percentage of people who receive palliative care who have documented assessments of their pain and other symptoms in their medical record

4.2 Percentage of people who receive palliative care (or their caregivers) who rate the level of support to relieve their pain and other symptoms as excellent

4.3 Palliative care and hospice patients are screened for pain, shortness of breath, nausea and constipation during admission visit

5. Psychosocial aspects of care

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

5.1 Percentage of people who receive palliative care who have assessments of their psychosocial needs documented in their medical record

5.2 Percentage of people who receive palliative care (or their caregivers) who state that they received timely psychosocial support to address their identified physical, psychological, social, cultural, legal, ethical and spiritual needs

6. Caregiver support

Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

6.1 Percentage of people with identified palliative care needs who have a caregiver needs assessment documented in their medical record

6.2 Percentage of caregivers of people who receive palliative care who state that they and the caregivers' family members receive as much help and support as they need

7. Goals of care and decision-making

People with identified palliative care needs and their substitute decision-makers have discussions with their interdisciplinary healthcare team about their goals of care to help inform their healthcare decisions.

7.1 Percentage of people with identified palliative care needs who state that they have shared their wishes, values, and beliefs with their substitute decision-maker regarding the kind of health and personal care they would want to receive in the future

7.2 Percentage of people with identified palliative care needs who have documented discussions with a healthcare professional about their goals of care in their medical record

8. Setting of care and place of death

People with identified palliative care needs, their substitute decision-maker, their family and their caregivers have ongoing discussions with their healthcare professionals about their preferred setting of care and place of death.

8.1 Percentage of people with identified palliative care needs who have documentation of their preferred setting of care and place of death in their medical record

8.2 Percentage of caregivers of people who died of a progressive, life-limiting illness who think that the person they cared for died in the right place