

Palliative Care Early and Systematic (PaCES)

Overall Executive Summary

Three reports on palliative care perspectives of family physicians, oncology clinicians and rural patients and caregivers of Alberta

Submitted to Alberta Health

April 30, 2018

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Background

The incidence of cancer in Canada is expected to increase 40% over the next 15 years, in association with our aging population.^{1,2} One-in-two Albertans will develop cancer and one-in-four will die from the disease.³ Using palliative care early, e.g. concurrent with disease-modifying therapies or from the time of diagnosis of advanced cancer, enhances quality of life for patients and their families and is associated with lower healthcare resource costs at end-of-life.⁴ Despite the evidence that early use of palliative care benefits patients and the healthcare system, most patients are referred late in their disease (e.g. <2 months from death). Our health services struggle to systematically provide early and integrated palliative care, to meet the needs of the cancer population.

Supported by grant funding from Alberta Health and Canadian Institutes of Health Research, the PaCES project (2017-2021) seeks to increase by 20% the number of patients with advanced colorectal cancer referred to palliative care >2 months before death and in doing so improve both patient-reported outcomes and health system outcomes.

The three attached reports answer questions essential to understanding why palliative care services are accessed late in Alberta. The findings inform the development of PaCES project interventions and a “Palliative Care Pathway” that will enhance the integration of early palliative care, primary care and oncological colorectal care in Calgary and anticipate the scale and spread of this pathway across Alberta and across other cancers.

Questions

1. What are the barriers and facilitators perceived by oncology healthcare providers in providing palliative care concurrently with cancer treatments?
2. What are the barriers and facilitators perceived by family physicians in providing community-based palliative care in urban and rural zones?
3. What are patient and caregiver perceptions on how palliative care can be delivered in rural Alberta?

¹ Right to care: Palliative care for all Canadians [Internet]. Canadian Cancer Society. 2016 [cited 2018apr23]. Available from: <https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en>

² Fowler R, Hammer M. End-of-life care in Canada. *Clin Invest Med*. 2013;36:127.

³ CancerControl Alberta. Surveillance & reporting: The 2017 report on cancer statistics in Alberta. Edmonton: AHS. 2017.

⁴ Zimmermann C, et al. Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *Lancet*. 2014;383:1721.

Findings

1. The most frequently perceived barriers that Alberta oncology healthcare providers face in providing palliative care concurrent with cancer therapies are: (1) Time and competing priorities; (2) Patients' negative perceptions of palliative care; and (3) Capability for managing patients' social issues. The most frequently identified facilitators were: (1) Belief in the benefit of palliative care; and (2) Belief that they are responsible for addressing their patients' palliative care needs. Perceptions varied with professional role, AHS zone, and tumour group. Four overarching themes impeding earlier palliative utilization are: (1) Varied understandings of palliative care; (2) Inter-professional practice concerns; (3) Inter-sectoral practice and system structure deficiencies; and (4) Resource constraints.

2. The barriers to effective family physician and oncology relationships included: (1) An absence of relationships with oncology colleagues; (2) Communication challenges; (3) Impact on patient continuity of care with family physicians; and (4) Tension between a desire to “do no (further) harm” and support prioritizing the patient's quality of life or a comfortable death, and a fear that this represents a medical failure or failing the patient. Facilitating factors included: (1) Family physicians' long-term relationships with patients, which provide a level of understanding and trust that is beneficial during oncology treatments; (2) The broad scope of family medicine practice which provides holistic care; and (3) The central tenet of continuity of care provided by family physicians which was manifest in their desire to be involved in the ongoing care of their patients with advanced cancer with palliative needs.

3. Rural patients and caregivers (1) Misperceived palliative care as meaning end-of-life care. They wanted palliative care to be introduced early in a sensitive manner, after assessing for their readiness, by their healthcare team, especially their oncologist. (2) They saw the many benefits of palliative care, as well as the critical importance of home care teams, family physician and oncology team all working together as a single interdisciplinary team. They praised the nurse navigator role and raised the need for support groups at their local communities and cancer centres. (3) There were challenges of being their own health advocate, the physical symptoms of advanced cancer and the added financial burden of living far away from cancer centres that was compounded by multiple trips into the cancer centres.

Triangulation

There were commonalities in perspectives of oncology healthcare providers, family physicians and rural patients and family caregivers:

1. Challenges to early palliative care referral result from the misperception that it is associated with impending death, despite a shared belief in the benefits of palliative care;
2. Despite oncology healthcare providers perceiving negative perceptions of palliative care by patients as a barrier, there is a common belief by patients and caregivers that palliative care can be introduced earlier by their healthcare team, including their oncologist, with careful explanation of the benefits of palliative care;
3. Communication and coordination of care challenges between providers and across healthcare sectors;
4. Resource constraints in all sectors, most evident in community care in rural zones.

Recommendations

1. Improve palliative care materials (e.g. for patient, caregiver and provider education and awareness). This will create a shared healthcare provider-patient understanding of palliative care as: “An added layer of support for people and their families, that focuses on providing relief from the symptoms and stress of a life-limiting illness with the goal to improve or maintain quality of life. Palliative care can be used at any stage of cancer, can be provided by different healthcare providers in the community or in healthcare facilities and can be provided along with treatments for the cancer.”
2. Focus on interventions that improve communication and coordination of care across sectors particularly between oncologists and family doctors (e.g. clinic letters that include how best to contact the oncologist and clarify roles in sharing the care of the patient.)
3. Continue and expand nurse navigator program for patient support in rural areas (including Calgary and Edmonton Zones), expand cancer support groups and homecare in rural areas and expand access to earlier palliative homecare supports in all areas.