

Great Canadian Healthcare Debate

JUNE 15-16, 2015

PEI CONVENTION CENTRE
CHARLOTTETOWN, PEI



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ISSUE BRIEF

C. Integrated palliative care

Resolved, that healthcare leaders support an integrated palliative approach to care by planning for and funding of an appropriately skilled and adequately sized health care workforce with the requisite knowledge in the palliative approach to care and access to palliative care specialists.

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ISSUE

The way we die needs to change. Across Canada, we are seeing a wave of change in care for people faced with frailty and/or chronic life-threatening illnesses and choices at end of life. Palliative care services – once only offered in the last days or weeks of life to people designated as dying – need to be better integrated with treatment services to enhance people’s quality of life throughout the course of their illness or the process of aging.

Despite the fact that most Canadians would prefer to die at home and that only a small proportion need intense tertiary care in the last days or weeks of life, most (67%) still die in hospital. It is crucial that a palliative approach to care is delivered by inter-professional teams, with access to specialists as needed, and supported with the skills, knowledge and confidence to meet the wishes of individuals and their families to live well until dying whether at home, in long-term care settings, in residential hospices or hospitals.

While the recent Supreme Court decision on the issue of physician-assisted death has captured media attention, a relatively small number of Canadians are likely to meet the criteria for those services.

However, everyone has the potential to benefit from the growing willingness to acknowledge that dying is part of living, and that people deserve and should receive the integrated palliative approach to care at all stages along their illness trajectory and in all settings of care.

BACKGROUND

An integrated palliative approach to care means we need to think differently about care as people near the end of life, based on a number of relevant issues.

1. **Significant changes in illness trajectories.** Canadians are now more likely to survive heart attack or a cancer diagnosis, and to live for several years with chronic illnesses or increasing frailty. Although *when* people will die is less predictable, they will still experience the same losses throughout their illness trajectory (e.g. pain, loss of mobility and other functions, physical and mental limitations, loss of roles and relationships). They and their families would benefit from palliative care services such as psychosocial support and pain and symptom management that can enhance quality of life. Being diagnosed as “close to death” should no longer be the trigger for Canadians to receive these services.
2. **The cost of “futile” treatments at end of life.** Growing data on the cost of health care services shows that our health systems spend a significant amount on procedures in the last days or weeks of a person’s life; procedures that offer little benefit and sometimes increase the person’s discomfort. A closer look at these interventions has shown that many procedures occur simply because many people do not have advance care plans and health care providers are hesitant to have open, transparent conversations with individuals and families about the prognosis or the benefits and risks of those interventions.
3. **Increasing health care costs and pressure to manage them.** Faced with rising health care costs and pressure to manage and control budget increases, health care systems are making concerted efforts to reduce the use of costly hospital services and provide more care in the community. This disconnect between the care that people want and need and the care that they actually receive is due largely to a shortage of community providers who are skilled in the palliative approach to care and the lack of supports for family caregivers who – given changing illness trajectories – are often providing care for a loved one for years.
4. **Consumer advocacy.** As our population ages, more people are speaking out about the kind of care they want as they near end of life. They are advocating for services that focus on quality of life as well as options that allow them to die “at home” wherever that may be.
5. **A growing focus on advance care planning.** Over the past few years, a number of Canadian jurisdictions have actively promoted advance care planning – encouraging primary care providers to talk to their patients about the kind of care they want. However, the process itself raises expectations that the home-based and community-based care people want will be available as they age, which is currently not the case in many parts of Canada. Those expectations are another pressure for change.



To address these issues, the Quality End-of-Life Care Coalition (QELCCC, made up of 36 national associations and organizations) and the Canadian Hospice Palliative Care Association (CHPCA) advocated and received funding from the Government of Canada to create *The Way Forward*. This national initiative involved federal/provincial/territorial governments, the non-profit and charitable sector and communities working together to move beyond the politics of health care by leveraging existing networks of agencies and organizations to develop a national framework for action.

CONSIDERATIONS

The Way Forward includes practical and implementable tools and resources to help policy makers, health planners and service providers make changes and make them more quickly, including:

- a clear definition of the integrated palliative approach to care;
- a policy paper that explains the concept and the rationale for the integrated palliative approach;
- a summary of the literature;
- descriptions of innovative models of the integrated palliative approach to care already in place and working around the world;
- analyses demonstrating the cost-effectiveness of the palliative approach to care;
- surveys of Canadians, family physicians and nurses working in primary care to understand their attitudes and perspectives; and
- a framework or roadmap to implementing the integrated palliative approach to care with clear action steps for sectors, health care settings and providers.

The national framework or roadmap is structured in a way that has three key strengths.

1. The framework was developed as a draft and then used as the basis for consultation with people at all levels in the health care system – provincial/territorial ministries, regional health planners, health professional associations, local service providers and consumer groups. Not only did it provide a roadmap for implementing the integrated palliative approach to care, it became the way to engage people in the conversation.
2. The framework includes sector specific actions. It lays out the steps that each sector can take to shift the system to an integrated palliative care approach. As part of the consultation, people working in all sectors were asked key questions such as: Does this make sense to you? Does this reflect your reality? Will this work in your sector? Is anything missing?
3. The framework reinforces that change is organic and can start anywhere. It doesn't need to wait for provincial policy or the kind of province-wide initiative launched by Alberta, where a provincial steering committee identified 36 initiatives and developed seven in 2014 including an EMS program that provides support to patients experiencing an end-of-life emergency at home, or having enhanced 24/7 palliative physician on-call services. It can begin in a primary care practice, a home care service or a long-term care home. The goal of the framework is to empower people throughout the health care system and give them the tools to be able to start where they are and act now.



An integrated palliative approach to care will require a culture shift among providers and the public, and will mean a shift in planning and funding to address the need for upstream rather than downstream costs. It will also mean addressing silos where funding from secondary and tertiary settings would move to primary and home and community care settings. These are not small shifts in health care planning and will be difficult to address when resources are stretched and there are provincial economic pressures. Additionally, while the public is discussing end-of-life care, few people have advance care plans or advance directives, and still lack awareness about palliative care programs and services.

NEXT STEPS

CHPCA and the QELCCC members will continue to be a catalyst for change. Until all Canadians have access to the integrated palliative approach to care across settings and people are comfortable having conversations about the kind of care they want towards the end of life, these organizations will keep pushing. Federal, provincial, territorial governments and regional health organizations and professional colleges/associations need to continue to support health-care providers through the change management process and culture shift.

There also needs to be a much closer integration between two inter-related initiatives: the integrated palliative approach to care and advance care planning. Each needs the other to actually meet Canadians' expectations that they will have the kind of care they want and need when faced with a life-threatening chronic disease or frailty, and each needs to be fully and effectively engaged in by Canadian citizens and professionals.

The integrated palliative approach can start anywhere in the system. Organizations can begin this process through multiple actions:

- Developing policies that help shape organizational culture and help promote the integrated palliative approach to care and advance care planning;
- Establishing a shared vision and goal;
- Setting clear expectations for all providers and staff, including ongoing education;
- Developing tools and guidelines that help providers integrate the palliative approach to care – including those related to advance care planning;
- Forging strong relationships with other services and settings to help deliver palliative care; and,
- Communicating clearly with the health care providers, the public and patients about the palliative approach to care.

This brief was prepared by: The Quality End-of-Life Care Coalition of Canada (www.gelccc.ca).



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