

# Framework on Palliative Care in Canada

## Do we have a broad enough lens?

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In December 2018, Health Canada released a report entitled the “Framework on Palliative Care in Canada” (the Framework).<sup>1</sup> This document was thoughtfully prepared, incorporated broad input, and clearly identified some important changes needed in our health care system. While we applaud the directions outlined in the report, we also believe it represents a substantial missed opportunity, as its recommendations for improved palliative care focus almost exclusively on the formal health care system. A framework offers a roadmap for where we want to go and thus needs to be clear regarding the direction. If Canadians are intent on improving our experiences in the last stage of life, then considerable future attention needs to focus on communities and social structures.

Public health statistics remind us that approximately 90% of deaths in Canada are the result of progressive incurable illness and that in the last year of life, the average Canadian will spend less than 5% of his or her time in the treatment of the formal health care system.<sup>2</sup> Many jurisdictions around the world have realized that the success of their formal health care systems for palliative care is contingent on partnering with communities to provide care during these years and “the other 95%” of time.<sup>3,4</sup> In this sense, community involves all environmental elements contributing to the physical, emotional, social, and spiritual wellness and the overall quality of life of patients, families, and caregivers. In addition to the traditional health care system, community includes (but is not limited to) friends, the workplace, schools, neighbours, faith communities, and volunteer organizations advocating and providing assistance and practical support for those facing serious illness and death.

### Defining palliative care

The Framework is described as a living document, and continuous open dialogue has been encouraged by its creators. We suggest that clarification of some of the language found within the Framework (and thus its goals) might be a simple, effective, and necessary starting point in this evolution. The Framework uses the World Health Organization definition of *palliative care* created in 2002 and emphasizes the formal health care system and service-based measures for improving quality of life. However, the World Health Organization itself is currently shifting its own understanding and definition of *health* toward the concept of well-being and not merely the absence of disease. We wonder, then, if a similar shift in thinking toward a palliative approach to

care—describing a more comprehensive understanding of quality-of-life variables—would be more applicable for this evolving Framework.

We believe it would be wise for the current Framework to boldly acknowledge that the changing landscape of our societies and health care systems—affected as they are by technology, specialization, changes in disease projections, and increasing system complexities—has contributed to a collective ambiguity about what palliative care is. In many environments palliative care has been reduced to mean end-of-life care. In several Canadian jurisdictions both health systems and consumers see palliative care as merely a health system deliverable. If the intent of the Framework is for an “all-in” societal engagement on palliative care, then upstream approaches would be paramount.

Similarly, the Framework’s conceptualization of primary care seems to rely on family medicine alone. It is unclear what the responsibilities would be for other continuous, front-line providers who need good, basic palliative care skills: oncologists, respirologists, cardiologists, intensivists, paramedics, emergency department staff, allied health clinicians, and the like. Further complicating the picture is a system of silos and an overall lack of integrated care. The Framework creates a line in the sand between “a palliative approach to care” and “specialist care,” whereas the latter should merely be seen as part of the continuum of the palliative approach for the small portion of the population who require it. The evolution of the Framework might benefit from considering a palliative approach as synonymous with good, upstream care given by any front-line provider, and specialist care and hospice care as being distinct services that might or might not be needed during the illness trajectory.


### A collaborative approach

It is wonderful to see that the creators of the Framework chose to consult with patients, families, and caregivers, underscoring the complexity and effect of palliative care on society. One-third of caregivers report distress and burnout; is this reflective of failure of the health care system or a need for increased capacity and support within the community to live well until the end? Similarly, although not the choice of most, 60% of Canadians die in hospital, again highlighting deficits in community infrastructure.<sup>1</sup> Unfortunately, much of the research we use to inform our current health care system decisions focuses on access to formal health care.

## A clear goal

The Framework focuses on information such as the proportion of those with access to palliative home care services, the number of specialized palliative care providers in a region, and types of advance care planning resources available. It would be helpful to clarify whether this information is being used simply to describe a current state of affairs or as indicators of health care system success. For example, although advance care planning resources are currently important, the very need for them indicates a failure of society to acknowledge and prepare for death, rather than a long-term marker of success. Is our goal to increase access to palliative care services and providers, or is it to enable a population to have optimal well-being until death? Are we building greater care capacity in communities to accomplish the latter, or to alleviate pressure on the health care system and caregivers?

It has been said that “focusing on access to care is an excellent way to ensure that we never shift toward population health.”<sup>5</sup> The Framework does highlight the need for increased community capacity in underserved populations. We believe success of any national framework for palliative care should be dependent not solely on increased community capacity for specific populations but rather on a groundswell of national societal engagement upon which the Framework can be placed. Much of the world has come to this realization, hence the exponential rise and growth of “public health palliative care.” One framework that has emerged as a

result of this population or societal lens is the international Compassionate Communities initiative. We invite the Framework leaders to boldly embrace and co-locate with this lens. In the words of our late colleague who helped us write this piece: “To do so would allow us to truly move forward together.” 

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### Competing interests

None declared

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**The opinions expressed** in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.

### References

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Cet article se trouve aussi en français à la **page 648**.