

# Being Mortal: A Health Policy Perspective on Dying Well in Canada

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Death is an inevitable reality of human existence, but the conditions responsible for the death of Canadians have changed drastically during the last century. During the 20th century, the leading cause of death transitioned from infectious diseases to chronic conditions, such as cancer and diabetes.<sup>1</sup> With Canadians experiencing greater longevity, the proportion of the population aged 65 and older has increased significantly, accompanied by an increase in the number of patients with chronic conditions and terminal illnesses. This demographic shift and change in the type of conditions that Canadians experience, carries with it demands from the healthcare system that are vastly different from when the Canada Health Act was first implemented in 1984.<sup>2</sup> One such demand is an increase in the need for palliative care services that present specific challenges for provincial health systems in Canada.

The World Health Organization (WHO) defines palliative care as an approach to healthcare that emphasizes improving the quality of life of patients with terminal illnesses. Palliative care focuses on pain-management and relief, symptom management, and providing psychosocial support to patients and their families.<sup>3</sup> While palliative care is often associated only with end-of-life care, when effectively applied in health systems, it is applicable significantly earlier in the course of treatment. Issues with palliative care delivery in Ontario are best addressed by looking at palliative care delivery across Canada. Hence, this article will focus on a Pan-Canadian approach to palliative care. To some extent, palliative care reflects a broader trend in healthcare towards providing patient-centered care. However, as this commentary will highlight, implementing an accessible, high quality, standardized, and integrated system of palliative care across Canada has real merits with respect to improving quality of care, cost-containment, efficiency and a greater degree of responsiveness to Canada's changing demographics.

### Rationale for Palliative Care in Canada

The demographics of Canada are changing, with 15% of the Canadian population comprised of individuals aged 65 and older.<sup>4</sup> This marked increase in the population of seniors in Canada is accompanied by an increase in the number of

seniors currently living with terminal illnesses. According to Statistics Canada (2008),<sup>5</sup> the old age dependency ratio was 15 in 1971, 21 in 2006, and will increase to 40 by 2056. This demographic change has resulted in a drastic shift on demands from the Canadian healthcare system to an increased need for geriatric and palliative care services. A failure to respond to these demographic changes is not only causing economic inefficiency and placing burdens on currently available resources, but it also brings into question the sustainability of our healthcare system and its ability to remain truly public and provide high quality care in the future.

Concurrent with the increase in the senior population, the rates of individuals living with chronic conditions has also increased. While in some countries there was a trend of decreasing levels of disability and chronic conditions from 1970s to late 1990s, this trend was absent in Canada. In fact, in Canada the rates of chronic conditions as respiratory diseases and diabetes increased during the same time period.<sup>6,7,8</sup> It has been reported that 70% of all deaths in Canada occur due to chronic conditions.<sup>9,10</sup> Thus, the marked increase in seniors living with terminal illnesses, and in the number of Canadians living with chronic conditions, has resulted in a significant need for accessible, high quality palliative care in Canada.

### Issues with Access and Quality of Palliative Care

A study by the Canadian Institute for Health Information (CIHI) reported that 70% of Canadians do not have access to adequate palliative care.<sup>11</sup> While a survey indicated that the majority of Canadians prefer to die in the comfort of their homes;<sup>11</sup> statistics show that 70% of deaths in Canada occur in acute-care settings.<sup>12</sup> These statistics signify a disconnect between patient preferences and the limitations of the current healthcare system in delivering palliative care. The need for effective palliative care at the provincial level is highlighted by a study which reported that 40% of Ontarians who died during 2014-2015 did not receive palliative care services.<sup>13</sup> The study also demonstrated that most patients began to receive palliative care much later in treatment. This delay in commencing palliative care highlights that not only do Ontarians lack access to palliative care, the quality of palliative care received is also an issue. Temporal delay in provision of palliative care is an issue from an economic perspective because gains in efficiency that can be made from providing palliative care rely on how early it is made accessible to patients. It is also a concern from a quality of care perspective because early access is essential to ensuring high patient satisfaction and enhanced quality of life. Lastly, the study also reported that

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among the Ontarians who received palliative care, less than half were able to access it at home. This illustrates the issue of limitations in the setting of palliative care delivery in the current healthcare system.

Setting of palliative care delivery holds importance from both an economic and quality of care perspective. In the last few weeks of life, most patients with a terminal illness express the desire to receive care at home and die comfortably at home.<sup>14,15,16</sup> This speaks to a degree of responsiveness of our healthcare system, and whether or not our healthcare system is able to provide effective high-quality palliative care. The setting of delivery can vary from patient homes, senior and long-term care homes, nursing homes, to hospital palliative care units and hospices. According to Romanow (2000),<sup>17</sup> home care for terminally ill patients and a home death is also imperative for health policies. Studies conducted in the United States and internationally show that a range of disease and demographic factors, access to community hospital beds and tertiary acute care are all predictors of home death.<sup>18,19,20,21</sup>

Research has shown that access to high quality palliative care enables a home death. According to the Canadian Hospice Palliative Care Association<sup>22</sup> and Ferris et al. (2002),<sup>23</sup> gold-standard palliative care programs include factors such as access to physicians with training in palliative medicine, personal support workers, registered nurses, psychological counselling, respite care and effective case management by the multi-professional team. Several international studies illustrate that having access to high quality and efficient palliative care services increase rate of home death.<sup>18,24,25</sup>

### Financial Rationale for an Integrated Pan-Canadian Palliative Care Program

There is a financial imperative to deliver integrated, high quality palliative care that is accessible to all Canadians. Currently, due to the lack of residential hospice facilities and unequal access to palliative care, terminal patients end up in acute-care facilities where a bed costs \$842 per day. In fact, it is estimated that 10% of all alternative level of care (ALC) days during 2013-2014 in Ontario were due to patients waiting for palliative care beds. On the other hand, the cost of a palliative care bed in residential hospice costs \$126 per day, and only \$42 at home.<sup>26</sup> This illustrates the financial benefit of increasing palliative care access to homes and building Canada's capacity to provide community-based palliative care. It would not only address the lack of access to palliative care, but also make resources in acute-care facilities available for other patients and increase the overall efficiency of the healthcare system.

It is important to acknowledge that the economic efficiency gained from accessible palliative care delivery varies with the timing of palliative care received and to adequate access to palliative care services. Early access prevents expensive and futile end-of-life medical efforts that occur due to lack of symptom management, patient and family education and psychosocial support.

### Socioeconomic Context of Palliative Care and Importance of Informal Caregivers

Another variable that influences effect of palliative care services and the likelihood of experiencing a peaceful home death is one's socioeconomic status. Howell et al. (2011) describe the results of a two-year long pilot project that provided comprehensive palliative home care to cancer patients in Toronto, Canada.<sup>27</sup> The program was implemented via community care access centres (CCACs) that provided case-management and coordinated service provision. The study evaluated factors that influenced home death, such as age, gender, clinical symptoms, type of cancer, and income.

Interestingly, they found that those with higher incomes were more likely to die at home, whereas those with lower incomes were more likely to die in acute care facilities. There are various explanations for this trend, firstly, those with higher incomes are more likely to have access to supplemental home and respite care that points to the existence of a two-tier home care system in Canada.<sup>27,28</sup> Secondly, this trend can be explained by having greater access to informal caregivers. Informal caregivers constitute friends or family who lack training or association with formal organizations but have a central role in providing personal support and care.<sup>29</sup> A study by Hollander et al. (2009) showed that care delivered by informal caregivers saves the Canadian health system \$25 billion annually.<sup>30</sup> It is possible that low-income patients do not have access to informal caregivers that can take significant amounts of time off from low-paying jobs to care for loved ones. This pilot comprehensive palliative home care program showed that while socioeconomic factors influence end-of-life care and home death in a publicly-funded palliative care program, overall it resulted in 50% of deaths occurring at home, instead of at acute-care facilities. Hence, this study highlights the importance of informal caregivers in delivering home-based palliative care and enabling a peaceful home death. It also illustrates the significance of an integrated palliative care delivery, where home care plays a central role. Lastly, it showed the socioeconomic context of palliative care delivery, which needs to be better understood by future studies.

### Access to High Quality Palliative Care in Rural and Indigenous Communities

Access to palliative care services differs between urban and rural settings. Using Ontario as a case-study for access to palliative care in rural settings in Canada, various challenges have been identified. While 15% of Ontario's population lives in rural settings (Statistics Canada, 2009), there is a significant shortage of practicing physicians with palliative care training in rural Ontario.<sup>31</sup> Access to palliative care in rural Ontario is influenced by a lack of palliative care specialists, health services, and a limited extent of palliative care education. These factors lead to limited access and affect the quality of palliative care available.<sup>32,33</sup> Specific research needs to identify palliative care needs of rural communities.<sup>34</sup> In addition to a lack of access to palliative care in rural communities, there is also a significant disparity in access to palliative care in indigenous communities. Palliative care provision to Aboriginal communities also requires research to understand their specific

needs and to provide care in a manner that is sensitive to their customs and cultural values.<sup>32,35</sup> The delivery of high quality palliative care in rural and indigenous communities seems to be largely ignored by researchers and policy makers alike.

### Health Human Resources Issues in Palliative Care

An important feature of addressing the issue of providing integrated, high quality palliative care in Ontario and nationally is the availability and planning of palliative care physicians. A recent report by the Canadian Society of Palliative Care Physicians indicates that, while Canada needs 170 palliative care specialists, it currently only has half.<sup>36</sup> Furthermore, the current education approach to palliative care is an issue due to medical and nursing students currently receiving only 20 hours of training on palliative care. A framework is required that charts national goals and progress for workforce planning, palliative care training, research, and performance measurement.<sup>36,37</sup> Such a framework would help to standardize training nationally and ensure provision of high quality palliative care across Canada. Another way to standardize and improve palliative care training nationally is to re-instate the National Secretariat on Palliative End of Life Care that was eliminated by the conservative government in 2007.<sup>37</sup>

### Importance of a Pan-Canadian Approach to Palliative Care in the Political Context

The importance for a national and provincial strategy for making integrated palliative care accessible for Canadians is highlighted by recent policy developments. Canada recently passed Bill C-14 which legalized medically assisted dying.<sup>38</sup> It is ironic that while Canadians now have access to medically assisted dying, they do not have the same access to palliative care, a care philosophy whose goal is to emphasize pain management and an enhanced quality of life. These concerns were reflected in comments made during a recent Canadian Medical Association (CMA) member dialogue on assisted dying:

“My greatest fear is that people end up having easier access to lethal injection than palliative care (currently accessible to only 30% of Canadians), one respondent stated.”<sup>39</sup>

Studies from other countries with assisted dying have shown that with access to high quality palliative care, 95% of individuals choose to live as long as they can and are able to make better-informed decisions about assisted dying (CMA, 2016).<sup>39</sup> Therefore, in the context of medically assisted dying, a recent reality in Canada, it is imperative for provincial and national governments to ensure all Canadians have timely access to high quality palliative care.

A recent bill, Bill C-277 which passed second reading on November 23, 2016, advocates for the development of a framework for palliative care delivery and aims to improve palliative care access and quality.<sup>37</sup> Establishment of a framework would standardize palliative care training nationally, ensuring that Canadians have universal access to high quality palliative care. This bill advocates for the establishment of community-based palliative care facilities and for providing palliative care at home, measures that will both improve quality of care and cost-containment.

As part of a new federal health accord, the government promised to invest \$3 billion in home care and palliative care.<sup>37,38</sup> Despite promised funding and new bills, little to no action has been taken in this regard, nor have clear guidelines been established to decide how the funds will be used to strategically improve problems in current delivery of palliative care.<sup>41</sup> Stakeholders as various organizations across Canada, such as Canadian Hospice Palliative Care Association, Quality End-of-life Care Coalition of Canada, Canadian Society of Palliative Care Physicians, and Cancer Care Canada, have released detailed reports identifying best practices in palliative care, outlining future steps to strategically address issues in the current system, and identifying factors that constitute gold-standard palliative care.<sup>42,43,44</sup> Despite this information, the problem is a lack of coordination among provinces and implementation. Hence, to truly deliver integrated, high quality palliative care across Canada, the provincial governments need to collaborate, and both the federal and provincial governments need to make palliative care reform a priority.

### Conclusions and Future Directions

In conclusion, due to Canada’s changing demographics and increasing incidence of life-threatening illnesses, the development of a high quality, integrated palliative care system is critical. We illustrate the current context of which palliative care and its complexity in Canada. Access to palliative care at home, in community settings, and in rural settings are avenues of significant improvement. Further research is needed to better understand the specific palliative care needs of rural and indigenous communities.

The article also highlights some key issues with palliative care delivery, which include the lack of a standardized system of palliative care education across Canada and the shortage of palliative care specialists. It also identifies the specific political context and recent approval of medically assisted dying that makes implementation of a Pan-Canadian palliative care approach an ethical imperative. Lastly, it is important for Canada to build its capacity to deliver community and home-based palliative care as it will improve quality of care, cost-containment and increase efficiency of the healthcare system.

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