ICES Report

Activating Patients and Families to Improve Palliative Care: The Waiting Room Revolution

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Abstract

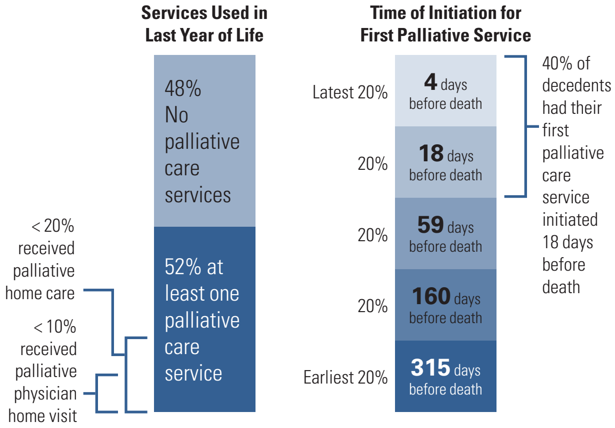
We need to support and educate palliative care specialists and generalist providers, especially family physicians, on how to integrate an early palliative care approach into care for those with a serious illness. However, there are very few care providers compared to the number of patients and caregivers in society. To increase access to palliative care at a population level, we need a waiting room revolution, one where patients and families shift from being passive to being active in shaping their experience with serious illness. A co-design approach with patients and families can help overcome barriers to accessing palliative care and improve the overall experience.

Introduction

Palliative care is an approach to care that alleviates physical, psychosocial and spiritual suffering in patients and families facing a serious, life-limiting illness (WHO 1990). Several systematic reviews have shown that palliative care improves quality of life, reduces symptom burden and lowers caregiver distress (Higginson et al. 2003; Higginson and Evans 2010; Zimmermann et al. 2008). Palliative care has also been shown to reduce healthcare costs and avoid unnecessary hospitalizations (Gomes et al. 2013a; Seow et al. 2014). Thus, palliative care is one of the few areas in healthcare where providing more of it increases value by lowering healthcare costs and improving patient outcomes.

It is estimated that more than 80% of the 280,000 Canadians who die annually could benefit from a palliative care approach (Murtagh et al. 2014; Statistics Canada 2011). Unfortunately, many Canadians do not receive palliative care, and if they do, they receive it very near death. An Ontario study showed that only 52% of decedents received any palliative care in the last year of life, of whom 40% had it initiated less than 20 days before death (Tanuseputro et al. 2017; see Figure 1). Therefore, the challenge is to not only increase access to palliative care for more Canadians but also provide it earlier in the disease trajectory to maximize benefits.

FIGURE 1.
Access to palliative care in Ontario, Canada



Source: Tanuseputro et al. 2016

To address this challenge, research has described the need to support both palliative care specialists (i.e., those with specialized training to manage complex symptoms) and generalists (i.e., all clinicians who should have "basic" palliative care skills) (Quill and Abernethy 2013). The latter should be supported to provide primary-level palliative care, especially because not every patient will have complex needs that require a specialist. In order to truly increase access to palliative care at a population level, we need to actively invite patients and families to embrace the benefits of a palliative care approach when facing serious illness.

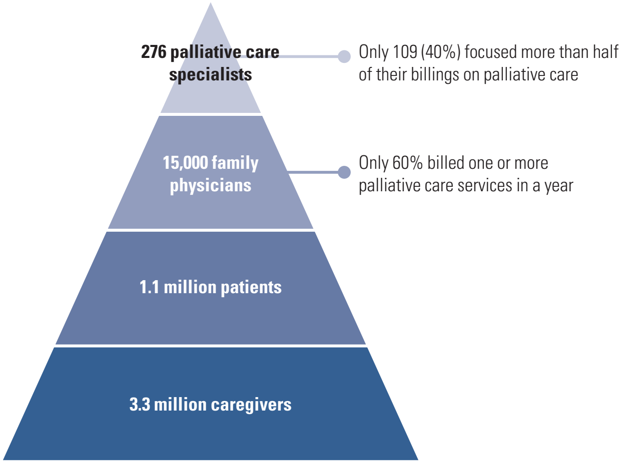
The Case for More Palliative Care Specialists

Research shows that we have grossly insufficient numbers of specialist physicians to serve the growing need. One study – which was aimed at physicians in Ontario whose practices mainly focused on palliative care – identified only 109 specialist physicians among the nearly 10,000 active family physicians included in the study (Barbera et al. 2015; see Figure 2). Juxtapose that number with the approximately 115,000 Ontarians who died in 2019 (Statistics Canada 2011). Specialist palliative care nurse practitioners are less common but an important resource, although their numbers are not captured in administrative data. While we should be expanding palliative care training programs – which also include incentives to mentor and coach other generalist providers – to increase the number of specialists available, we are very unlikely to meet the growing need with specialists alone.

The Case for Engaging Family Physicians

Generalist palliative care providers, on the other hand, are underutilized when it comes to providing palliative care. Although generalists include surgeons and other medical specialists (e.g., oncologists or cardiologists) who can also develop basic palliative care skills, the greatest opportunity lies with primary care providers, such as family physicians. Most Canadians have a primary care provider. Considering longitudinal relationships and continuity of care, primary care providers are ideally positioned to initiate palliative care earlier among their patients (Urquhart et al. 2018). Furthermore, evidence shows that palliative care home visits provided by a physician reduce in-hospital deaths by half (Seow et al. 2014; Tanuseputro et al. 2018). Receiving palliative care at home also aligns with patient preferences. Studies show that 80% of Canadians prefer to be cared for and die at home in the community (Brazil et al. 2005; Gomes et al. 2013b). However, despite these preferences, 65% of Canadians die in hospital (Statistics Canada 2007).

FIGURE 2.
Pyramid of palliative care physicians in Ontario, Canada



Source: Barbera et al. 2015; Sinha 2012

Unfortunately, many primary care physicians do not provide any palliative care services to their patients. Barbera et al.'s (2015) study showed that 40% of primary care physicians did not bill for any palliative care services. Other research has shown that in Ontario, less than 10% of patients received a palliative care home visit by a physician; even beyond physician-led care, less than 20% of decedents received any end-of-life home care services in the last year of life (Tanuseputro et al. 2017). Given that there are nearly 44,000 family physicians in Canada, this represents a major opportunity for providing enhanced education regarding palliative care so that improved outcomes can be achieved (CMA 2018). Fortunately, research shows that many primary care providers are willing to provide home-based palliative care if they have the knowledge, skills, tools and support (Pereira and Chasen 2016; Shadd et al. 2013).

The Case for Engaging Patients and Family Caregivers

Nonetheless, a strategy focused only on educating healthcare providers, including non-physicians, may still be insufficient to achieve population-wide access to palliative care. Instead, we also need to harness the power of patients who are facing serious illness and their families. This, it turns out, is a sizeable population, equating to 1.1 million patients and 3.3 million caregivers in Ontario alone (Sinha 2013; see Figure 2). To put it plainly, one in four Canadians is currently a family caregiver, and one in two Canadians will be one during their lifetime (Statistics Canada 2018). Thus, the grey tsunami of an aging population can be considered a looming threat that will overwhelm and bankrupt the healthcare system. Conversely, the aging population can be viewed as a giant army of individuals with the same goals of achieving optimal outcomes for patients and families.

The larger question is how. How do we engage this massive population of patients and families and transform them from passive recipients of care to active participants throughout their journey with serious illness?

Co-Designing with Patients and Families

The answer we propose is to use a co-design approach. Co-designing means that we work with patients and families from the start to identify problems that are meaningful to them, use language that is acceptable to them and offer solutions that they actually want and would use.

How does one apply co-design to palliative care? First, the pervasive perception is that palliative care equates to end-of-life care, dying and death. Unsurprisingly, death is something people want to avoid. However, to improve the end, you have to improve the beginning. Research shows that earlier integration of palliative care, even upon diagnosis of a serious illness, has many benefits to patients, including longer survival (Temel et al. 2010). Thus, we need to change the perception that palliative care is something offered near the end of life and instead think of it as something that is integrated into the care plan early on and used throughout the illness trajectory.

Second, we need to address the misperception and fear that discussing palliative care means giving up hope and that it leads to depression. In fact, patients with advanced illness rated "preferences for care in the event of life-threatening illness" and "prognosis" as the two most important elements to discuss with their doctors (You et al. 2014). Other qualitative research shows that palliative care enables patients and families to find more hope and peace by preparing earlier (Mistry et al. 2015). Thus, palliative care is not planning for death but rather preparing for the journey ahead.

The Waiting Room Revolution

Co-designing also means that we need a metaphorical revolution in the waiting room, where patients and families shift from being passive in affecting health outcomes to feeling empowered to shape their illness experience. Similar to clinicians, we need to devote energy to educating and providing patients and caregivers with the knowledge, skills, tools and supports about an early palliative care approach. They ought to be encouraged to initiate conversations with their provider about concurrently integrating a palliative care approach into their treatment plan rather than waiting for providers to broach the subject.

Here is an example. We heard thousands of stories from patients and families either through qualitative interviews or at the bedside during home visits. Most patients and their families felt overwhelmed and unprepared. We often heard, "I wish someone had told us that sooner." So we began compiling the bits of advice that patients and families found helpful. And we uncovered seven major themes that were common among those who were more prepared, more in control and more hopeful, even in the face of a serious illness and death. The themes are now the focus of a podcast that we aptly named *The Waiting Room Revolution* (Seow and Winemaker 2021). The podcast presents information in a way that is not focused on death and dying, can be used at any point in the illness journey and is something that patients and families actually want: synthesized advice from patients and families who have lived experience to share. As podcast hosts, we focus less on the misconceptions around the meaning and terminology of palliative care and more on illness understanding and illness education, which underlie an early palliative care approach.

In conclusion, increasing access to palliative care will improve patient outcomes, especially if provided to more individuals with a serious illness earlier in the disease trajectory. If we want to achieve this through sheer numbers alone, we need to engage with patients and families differently. We need a waiting room revolution. HQ

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