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Expensive Endings: Reining In the High Cost of End-of-Life Care in Canada

When it comes to end-of-life care, if our goals are to reduce suffering and improve quality while limiting costs, Canadians are not getting value for their money. The authors describe some of the gaps in the Canadian healthcare system that lead to costly and low-quality end-of-life practices and suggest specific strategies that could help to address these gaps.

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THE STUDY IN BRIEF

Canadians spend more on end-of-life care than other high-income countries, including the United States, yet we achieve poor results compared to most. There are structural factors and inefficiencies within our healthcare system that facilitate unhelpful and unwanted medical interventions at the end of life. In this *Commentary*, we review these factors and suggest several structural changes to address the high costs for healthcare and low satisfaction for patients.

A major avenue to cost saving is greater use of palliative care, rather than more costly acute care, in end-of-life treatment. Palliative care primarily focuses on improving comfort and quality of life, often avoiding hospital-based, invasive, costly and potentially inappropriate care. Palliative care is preferably (but not always) delivered outside of acute-care settings, including in patients' homes. People approaching the end of life (EOL) often require an intensification of healthcare services, and at least three in four would potentially benefit from palliative care prior to death.

Yet, only one in five Ontarians, for example, receives a physician home visit or palliative home care in their last year of life, and only half receive palliative care in any setting. Instead, most Canadians facing their end of life receive acute care without a palliative focus. As a result, the cost of healthcare delivery increases significantly in the final months of life and does so in particular for hospital admissions and emergency room visits.

Several structural problems exacerbate the situation and need to be addressed. They include:

- (i) *Inadequate EOL beds and options.* There are limited options for patients who require support as they near the end of life. In-patient palliative-care units and residential hospice beds may be appropriate for people with significant symptom control and supportive needs, but there are so few such beds available that admission is usually restricted to people in the final weeks of life.
- (ii) *Siloing of budgets.* Canadian healthcare budgets are siloed by sector. Acute-care beds are substantially more expensive than hospice or in-patient palliative-care beds, long-term care (LTC) beds or home care. If budgets were global, then we would find efficiencies by increasing capacity in lower-cost settings to reduce backlogs in higher-cost settings. But since each sector or organization manages its own budget, it is more difficult to enact decisions that increase costs in one sector that will ultimately reduce costs by a larger amount in another sector.
- (iii) *Lack of timely prompts to transition to a palliative approach.* Since our healthcare system all too often uses acute-care options by default, patients must transition to a palliative approach early enough to experience the benefits of this approach and avoid EOL visits to the emergency room, hospital and the intensive care unit.
- (iv) *Barriers to home and community-care resources.* There are some notable barriers to increasing the use of home care for patients nearing the end of life. These barriers cannot be overcome by increasing the number of available caregiver hours.

If implemented, the structural changes we recommend could result in substantial improvement in end-of-life care and potentially save hundreds of millions of dollars annually for the Canadian healthcare system.

Policy Area: Public Health Policy.

Related Topics: Government Policy, Regulation, Analysis of Health Care Markets.

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The term “palliative care” was coined in Canada almost 50 years ago, but a large proportion of Canadians still die with little or no palliative-care involvement. And they often die in a place they don’t want to be, getting aggressive care that is inconsistent with their goals.

At the same time, Canada spends more on medical care delivered at the end of life than other high-income countries, including the United States – and by implication, other countries in the world. Despite this, Canada performs poorly on most measures of quality. There is little question that when it comes to end-of-life care, if our goals are to reduce suffering and improve quality while limiting costs, Canadians are not getting value for their money. In this *Commentary*, we describe some of the gaps in the Canadian healthcare system that lead to costly and low-quality end-of-life practices and suggest specific strategies that could help to address these gaps.

In terms of scope, we will focus on care or treatments provided in the final months of life that are costly and of little or no value to anyone, and that are not being requested by patients or their family members. They are provided because they are default options, given either because of poor planning or because there are no alternatives available.

However, we will not explore the cost-effectiveness of treatments that achieve some benefit but at high cost or the issue of what some people view as “futile” or “non-beneficial” therapies

that are requested by patients with advanced, incurable illnesses. These may also be important contributors to low-value, end-of-life care, but they involve value-laden discussions that are beyond the scope of this report.

Throughout the *Commentary*, there are three key themes that emerge.

- 1 Canada must stop treating end-of-life care as acute care.
- 2 Palliative and end-of-life care must be provided across multiple healthcare settings. It cannot be the sole responsibility of hospices and palliative-care facilities.
- 3 Although people may benefit from a palliative approach at almost any time in their life, the large majority of healthcare expenditure occurs in the final three to four months of life. To achieve the greatest reduction in costly and low-value, end-of-life care, we need reliable means of identifying and intervening during this period in particular.

We have attempted to use pan-Canadian data whenever possible, although we sometimes use Ontario as a case study because of the availability of more detailed data in the published literature and directly from the Institute of Clinical Evaluative Sciences. Despite the reliance on Ontario data,

Key Concept Explainer

End-of-Life Care:

This *Commentary*, uses the following definitions.

- *Palliative care* is care that aims to improve the quality of life of patients, and their families, facing life-threatening illness, by identifying and relieving the causes of suffering. Palliative care is often provided at or near the end of life, but palliative care can be provided at any point in the course of an illness, even alongside efforts to treat or cure illness. Palliative care is not specific to any location – while there are dedicated palliative care units or hospices, palliative care can be provided in many settings, including an acute-care setting, an outpatient clinic, or in a home or long-term care facility.
- *End-of-life care* is care delivered in the final days or weeks of life, which could be focused on palliative goals but may also be focused on treatment or cure without a palliative aim.
- *Acute care* is care focused on a short-term cure or treatment of a medical condition, often in a hospital setting. Acute care may address conditions that are curable (e.g., a broken arm) or exacerbations of chronic conditions that are ultimately not curable (e.g., heart failure). Acute care may include palliative care, but acute care's primary goal is typically curing illness or prolongation of life.

our analysis and recommendations are applicable nationally.

There is no precise estimate of how much Canadian governments currently spend on palliative care. In fact, palliative care funding often gets lumped in with homecare funding as pressures to reform healthcare by shifting care from institutional to community settings coincides with a growing expectation on the part of the public that they should provide care in the home. Deinstitutionalization (due to avoidance, early discharge, reduced intensity of care) and shifting care to the community underpins the economic argument advocating for investment into palliative care services and programs.

Because palliative care programs evolved independently in Canada, it should not be surprising to observe variations in funding. Strictly speaking, palliative care is not mentioned in the *Canada Health Act* and therefore differs across

regions. Funding for components of palliative care, especially residential hospices, has predominantly come from private fundraising. Pressures for increased care in the home and home-like settings have resulted in funding increases in homecare. The recent bilateral health care agreements between the federal government and the provinces state the incremental increase in funding that will be dedicated to expanded palliative care or improved training.

END-OF-LIFE CARE IN CANADA: GAPS AND RISING COSTS

Palliative care focuses on improving quality of life for people with severe or life-limiting illness. It focuses on comfort, often avoiding hospital-based, invasive, costly and potentially inappropriate care. Palliative care is preferably (but not always) delivered outside of acute-care settings, including in patients' homes. People approaching the end of life

(EOL) often require an intensification of healthcare services, and at least three in four would potentially benefit from palliative care prior to death (Morin et al. 2017, Brameld et al. 2017).

Most Canadians do not receive palliative care. Only one in five Ontarians receives a physician home visit or palliative home care in their last year of life, only half receive palliative care in any setting (Tanuseputro et al. 2017) and nearly two in three hospitalizations in the last year of life have no palliative-care component (Webber et al. 2020). Instead, most Canadians facing their end of life receive acute care and, as a result, the cost of healthcare delivery increases significantly in the final months of life and does so in particular for hospital admissions and emergency room visits. In the last 30 days of life, for example, Ontario's acute-care costs increased by 181 percent compared to the previous 30 days. In comparison, outpatient costs (e.g., physician costs, medication costs, etc.) and continuing care costs (e.g., home care, long-term care) rose only by 63 percent and 33 percent, respectively (Figure 1) (Tanuseputro et al. 2015).

The use of acute care near the end of life is not driven by patient wishes – 87 percent of Canadians indicate a preference to receive end-of-life care at home (Gomes et al. 2013, Heyland et al. 2006). End-of-life care delivery in hospital is potentially burdensome as it is often avoidable, may not improve comfort and is frequently distressing to patients and their families. It is also associated with poor quality of life. While some patients will always require EOL care in hospital settings to be comfortable, the large majority can and should be cared for in other settings. When palliative care is delivered in a community setting (e.g., patients' homes, LTC homes, retirement homes) the chance of dying in hospital decreases by half (Tanuseputro et al. 2018).

Across the healthcare system, palliative care supports a patient's desire to avoid acute care, leading to lower incidence of emergency room visits, admissions to hospital, and deaths in hospital, even after matching for patient characteristics such as age, sex and co-morbidities (Quinn et al. 2020). Palliative care usually includes interventions that are effective in reducing hospital visits such as: 24-7 telephone/on-call access to a healthcare practitioner; medication support to address EOL symptoms, including subcutaneous formulations given when patients lose the ability to swallow oral medications; home visits for patients unable to visit physicians on an outpatient basis; and discussions regarding prognosis, goals of care and advanced care planning. Each of these interventions can reduce the chance of a hospital visit that may be necessary to address otherwise unmet needs.

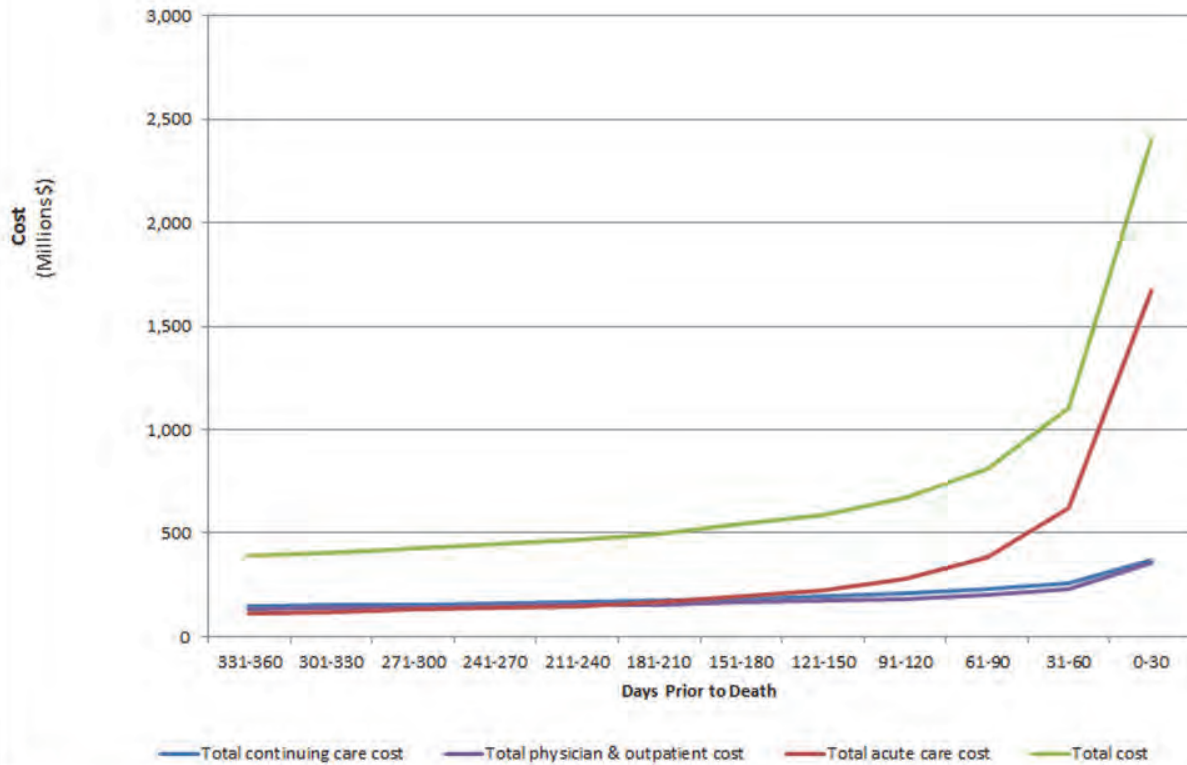
CANADIAN EOL CARE VERSUS OTHER HIGH-INCOME COUNTRIES

In this section, we compare the EOL care provided in four countries that use different funding models: Canada (single public payer by province), United Kingdom (single national public payer), the Netherlands (multi-payer private insurance) and the United States (public and private multi-payer).

Among the four, Canada has among the highest rates of hospitalization in the last three months of life (61 percent) compared with other high-income nations such as England (68 percent), the Netherlands (49 percent) and the US (57-to-65 percent, depending on the type of health insurance). Most Canadians die in hospital (61 percent), far more than in England (47-to-51 percent), the Netherlands (28-to-31 percent) and the US (20 percent).¹

1 For a discussion of the Canadian data see Bainbridge and Seow (2018) and CIHI (2018); for more on the England data, see UK National Health Service website; for the Netherlands, see Pivodic et al. (2016); and for the US, see Teno et al. 2018.

Figure 1: Healthcare Costs among Ontarians in the Final Year of Life



Source: Tanuseputro et al. 2015.

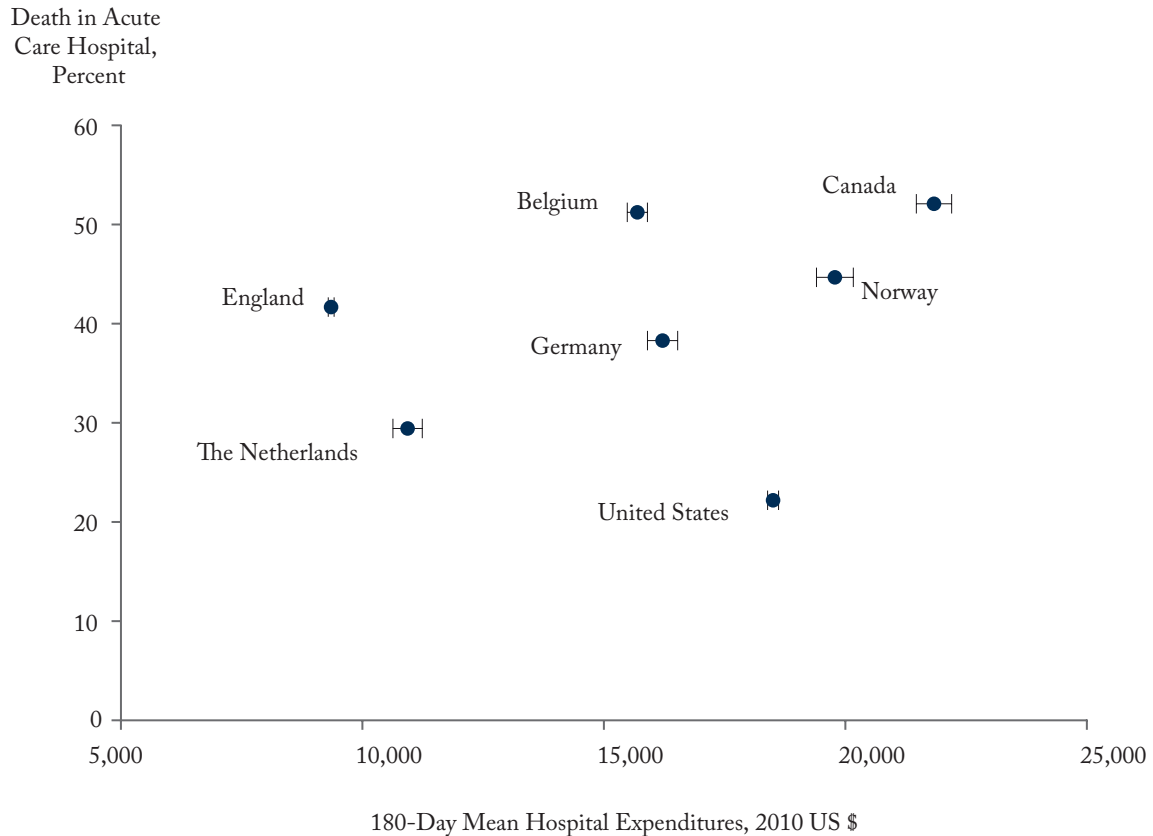
Similar patterns exist for subgroups of patients with terminal diseases such as cancer, where death is often more predictable. Among these patients, Canada (52 percent) had the highest rate of hospital deaths compared to England (42 percent), the Netherlands (29 percent) and the US (22 percent). Canadians with cancer also experience the highest rates of hospitalization in their last six months of life (87 percent), compared to England (83 percent), the Netherlands (77 percent) and the US (75 percent) (Bekelman et al. 2016).

The use of chemotherapy at end of life is considered a surrogate for low-quality, EOL care (Barbera et al. 2006, Setoguchi et al. 2008). While Canada ranks among the highest in delivery of

chemotherapy in the last 30 days of life (9 percent), rates are similar to the Netherlands (11 percent) and the US (11 percent) (Bekelman op cit.). This suggests that our high rate of EOL hospitalization cannot be accounted for by a higher desire for aggressive care compared to these other high-income nations.

Compounding the issue of EOL hospitalizations are their associated costs. Although no comparative data exist at a national level for all patients, Canada has among the highest per-capita EOL hospital expenditures for patients with cancer, which is related to generally longer lengths of stay and a higher proportion of hospital deaths. Figure 2 shows that in the last six months of life, mean per-

Figure 2: Hospital Deaths Compared with Costs in the Final 180 Days of Life



Source: Bekelman, J.E., Halpern, S.D., Blankart, C.R., et al. 2016.

capita hospital expenditures were higher in Canada (US\$21,840) compared to England (US\$9,352), the Netherlands (US\$10,936) and the US (US\$18,500) (Bekelman op cit.). Canada’s relatively poor performance in terms of costs and quality of EOL care is clearly related to the high use of hospitals as a setting in which to deliver such care.

Deep Dive into a Palliative-care Model

The UK is a good comparator to Canada given Canada’s close ties to the UK as part of the Commonwealth, and similar health insurance system and culture. The UK has a well-established

culture of palliative medicine and was the first country to recognize it as a medical specialty in 1987. In both 2010 and 2015, the UK ranked highest on the *Economist’s* Quality of Death Index. This ranking is largely attributed to comprehensive national policies, the integration of palliative care into the National Health Service and a strong hospice movement (Doyle 2007) beginning in 1967 with Dame Cicely Saunders’ founding of St. Christopher’s Hospice. Palliative care is available widely; as of 2013, the UK had 308 palliative-care hospital support teams, 189 in-patient hospices and 272 day hospice/day care centres (Centeno et al. 2013). Indeed, there are hospital palliative-care

teams in all UK major hospitals and cancer centres (Doyle 20007). There were 2,760 hospice and palliative-care beds in in-patient settings in 2017 (Hospice UK 2017) (4.2 per 100,000 population) compared to 271 hospice beds in Ontario in 2014 (Auditor General 2014) (two per 100,000 population). Training in palliative care begins early; it is a required course in all medical schools.

Current policy for the use of limited specialist palliative-care resources is a strength of the UK model. Specialist palliative care addresses complex cases by providing support to generalists in a consultative model. In England, the established National Health Service's England End of Life Care Programme aims to increase the identification of people in their last year of life to personalize care to people's needs and preferences. It also serves to secure strong clinical engagement in improved EOL care by working with regional networks (NHS website). However, even in the UK, access is not universal; it is estimated that 92,000 people annually in the UK could benefit from palliative care but are not currently receiving it (Dixon et al. 2015). But while there are areas for potential growth, the UK has a robust palliative-medicine system with many core components that could be emulated in Canada.

STRUCTURAL INEFFICIENCIES IN EOL CARE IN CANADA

An adage of the healthcare quality movement is that "every system is perfectly designed to get the results it gets." If Canada is relying on expensive acute-care beds for EOL care more than other nations, we have to understand how our system facilitates this.

Inadequate EOL Beds and Options

First and foremost, there are limited options for patients who require support as they near the end of life. In-patient palliative-care units and residential hospice beds may be appropriate for people with

significant symptom control and supportive needs, but there are so few such beds available that admission is usually restricted to people in the final weeks of life. Similarly, home palliative-care programs often provide substantial support services, but these are generally limited to people in the final month of life. This is problematic because this timeframe maps poorly onto the needs of patients as they near the end of life. While patients dying of cancer typically require assistance with activities of daily living only in the final weeks or months of life, people dying of almost every other illness (~75 percent of the population) typically require such assistance for many months or years before they die (Teno et al. 2001).

The only other options for patients requiring supportive care are long-term care homes and non-palliative homecare. There is typically a months-long waiting list for LTC beds across the country; clinical teams are reluctant to apply for long-term care when they suspect that the patient will deteriorate substantially by the time that they are offered a bed.

The availability of publicly funded homecare is also very limited. Consequently, there is no appropriate discharge destination for patients who are nearing end of life but are expected to have one-to-six months to live and who no longer require acute care but do not have the social supports to manage at home with non-palliative homecare.

Ontario's Alternate Level of Care (ALC) data illustrate this point clearly. An ALC designation is given to patients who do not require the intensity of services provided in an acute-care setting but are waiting to be discharged to a more suitable care setting. ALC patients often remain hospitalized longer than is appropriate when the services that they need are inaccessible or not immediately available; this has become a growing problem (Ontario Hospital Association 2019). An Ontario Hospital Association report estimated that in November 2019, approximately 17 percent of all patients admitted to acute-care beds at that time were classified as ALC – almost 5,400 patients.

Another way to express the ALC burden is in “ALC days” – the total number of days spent by patients in an acute-care bed while classified as ALC. In fiscal 2017/18, almost 190,000 ALC patient days (nearly 40 percent of all ALC patient days in Ontario) were accounted for by patients who were in the final 90 days of life (Table 1). Roughly 44 percent of these “end-of-life ALC” days were in patients waiting for long-term care, 24 percent were waiting for a residential hospice or palliative-care unit bed, and 12 percent were waiting to be discharged to their homes (Table 2). Sadly, 30 percent of those who spent at least one day classified as ALC in acute care in the last 90 days of their lives died before they were discharged. These patients accounted for 38 percent of all end-of-life ALC days. Although these statistics are from Ontario, other provinces and territories are experiencing similar issues.

These numbers give some idea of how much EOL care occurs in hospital among patients who are waiting to go somewhere else and how much of the ALC crisis could be alleviated if more discharge options were available for patients nearing their deaths. Other key concepts stand out.

- A large proportion of dying patients in acute care are waiting for palliative care (PC) beds, suggesting that there is a widespread shortage of hospice and in-patient PC beds. This shortage may be more acute in some regions, which is problematic because patients often have a strong preference for hospice or in-patient PC beds that are close to their family.
- A large proportion of dying patients in acute care are waiting for LTC beds rather than PC beds. This suggests that admission criteria (typically focused on a prognosis of weeks to a few months or very poor functional status) for PC beds may not be appropriate for many dying patients (e.g., those with organ failure) whose prognosis may be unclear and functional status may not reflect their prognosis. Expanding existing hospice or in-patient PC beds would not help this group unless there were also a change in admission criteria for some of those beds.

- A relatively smaller proportion are waiting for homecare to be deployed, suggesting that increased homecare resources may have only a modest effect on reducing our use of acute care.

Siloing of Budgets

Another systemic issue that impacts the availability of alternate disposition options is the fact that Canadian healthcare budgets are siloed by sector. Acute-care beds are substantially more expensive than hospice or in-patient palliative-care beds, LTC beds or homecare. If budgets were global, then we would find efficiencies by increasing capacity in lower-cost settings to reduce backlogs in higher-cost settings. But since each sector or organization manages its own budget, it is more difficult to enact decisions that increase costs in one sector but will ultimately reduce costs by a larger amount in another sector. If funding is attached to individuals, and costs are analyzed at the individual patient level, this would lead to greater resourcing of lower-cost disposition options and avoidance of acute care. For example, EOL care in the US has shifted substantially away from acute settings since the 1980s, likely due to a growing emphasis on coordination of care across settings, growth of the hospice sector and incentivization of “medical and social support services that decrease the need for emergency room and acute care services” through mechanisms such as the Medicare or Medicaid Hospice Benefit (National Academies 2015, Connor 2009).

Lack of Timely Prompts to Transition to a Palliative Approach

Many Canadians adopt a palliative approach only in the final weeks or days of life, particularly if they are dying of organ failure or frailty. We know that Canadians wish to avoid aggressive care as they near the end of life, and there are many benefits to adopting a palliative approach at this juncture,

Table 1: Total ALC Days by Institution Type – Ontario Decedents 2017/18

ALC Institution Type	All Reported ALC Days			Last 90 Days of Life		
	Number of Patients	Total ALC Days	Percent of Days	Number of Patients	Total ALC Days	Percent of Days
Acute Care	18,261	457,458	87.4	11,525	189,254	93.6
Chronic Care	172	23,795	4.5	105	5,077	2.5
Mental Health	17	2,859	0.5	5	368	0.2
Rehab Hospital	362	37,092	7.1	183	7,278	3.6
Unknown	50	1,937	0.4	10	269	0.1
Total	18,862	523,141		11,828	202,246	

Source: Ontario Palliative Care Network.

including better symptom control, EOL planning and support for grieving family members (Heyland et al. 2006, Detering, et al. 2010). But since our healthcare system all too often uses acute-care options by default, patients must transition to a palliative approach early enough to experience the benefits of this approach and avoid EOL visits to the emergency room, hospital and the intensive care unit. However, there are few mechanisms in place to prompt this transition. Even when patients have a longstanding preference to avoid acute care at the end of life, they often have not discussed this with their medical team (Heyland et al. 2013). As a result, many people only adopt a palliative approach in reaction to a critical event (e.g., pain crisis, medical complication or unscheduled admission) that occurs late in the disease course, often during an admission to acute care.

Acute-care default practices can continue to affect dying patients until very late in their lives. One study found that hospitalized Canadians

followed by a palliative-care consultant were prescribed an average of seven non-comfort medications during the final week of life (Ma et al. 2013). Another study of frail elderly adults who were scheduled to undergo non-emergent surgical procedures found that 75 percent of them were inconsistent with the patient's goals and wishes (Moorhouse et al. 2012). In summary, our high use of acute care and non-palliative interventions among those nearing their end of life reflects a system that relies heavily on acute care as the default option and fails to offer viable alternatives in a reliable and timely manner.

PREVIOUS INTERVENTIONS WITH LITTLE OR NO IMPACT

Many of the gaps and structural inefficiencies mentioned above have been highlighted in previous reports (CIHI 2018, Ontario Ministry of Health and Long-Term Care, website, Carstairs

Table 2: Number of Patients and Total ALC days (last 90 days of life) by Most Appropriate Discharge Destination (MADD) – Ontario Decedents 2017/18

MADD	Number of Patients	Percent of Patients	Percent MADD = Discharge Destination	Total ALC Days -Last 90 Days	Percent of Days	ALC Days		
						Q25	Median	Q75
Complex Continuing	866	7.3	60.7	13,596	6.7	4	9	20
Care Convalescent Care	171	1.4	55.6	2,310	1.1	6	10	17
Home	1,780	15.9	61.2	23,521	11.6	4	7	15
Long Term Care	2,341	19.8	33.8	88,083	43.6	12	29	60
Mental Health	29	0.2	44.8	991	0.5	6	20	63
Palliative Care: Residential Palliative	1,239	10.5	42.9	13,939	6.9	2	5	12
Palliative Care: Palliative Hospital Placement	3,545	30.0	52.4	33,888	16.8	2	5	11
Rehabilitation	963	8.1	68.5	8,900	4.4	3	6	12
Supervised or Assisted Living	690	5.8	58.3	13,614	6.7	6	12.5	24
Unknown	204	1.7	-	3404	1.7	4	7	18.5
Total	11,828			202,246				

Source: Ontario Palliative Care Network.

2000, 2010) and are well known to the palliative-care community. But bridging these gaps and correcting these inefficiencies is not always straightforward. We will briefly review some of the common interventions and why they have failed to substantially improve EOL care in Canada.

Standalone Educational Interventions.

Educational interventions are clearly necessary to improve palliative care throughout our healthcare

system. Palliative-care competencies have been identified for all healthcare professions, depending on their role and degree of involvement in care at the end of life, and these have been adapted and adopted in many provinces (Health Canada 2018). Integrating these competencies in the training and continuing education of all healthcare professionals is a vital part of expanding the capacity of our existing workforce to deliver high-quality palliative care. A full review of the challenges and limitations of teaching palliative-care competencies is beyond

the scope of this *Commentary*. However, we know that only a minority of Canadian medical trainees receive any clinical palliative-care exposure during their training, even in specialties that are closely involved in EOL care (Gagnon et al. 2020).

We also know that most palliative-care educational interventions are “standalone” didactic interventions that do not extend beyond the classroom, and most studies of palliative-care educational interventions have measured effectiveness only in terms of changes in attitudes and knowledge. This is problematic because attitudes and knowledge acquired in the classroom are usually replaced by the so-called “hidden curriculum” of behaviour learned in the clinical environment, usually from more senior clinicians without palliative-care training (Downar 2018). Very few studies have found changes in physician behaviour and outcomes for patients and, in the absence of such data, we cannot assume that educational interventions are effective for improving the delivery of palliative care or reducing the use of unwanted and unhelpful treatment at the end of life.

Provider-dependent Triggers for Timely Adoption of a Palliative Approach

In current practice, patients are often identified for a palliative approach by individual clinicians based on a poor prognosis, but since clinicians frequently overestimate survival, this transition is often delayed. (Dalgaard et al. 2014, Christakis et al. 2000, Amano et al. 2015). To correct for this tendency, some suggested using the “surprise” question: a clinician asking her/himself, “Would I be surprised if this patient died in the next 12 months?” This frames a prognosis in terms of what is possible rather than what is probable – an answer of “no” would trigger a more detailed assessment and appropriate palliative intervention. The surprise question has been widely advocated and integrated into frameworks for identifying patients in need

of palliative care. However, a meta-analysis of the surprise question indicated only modest accuracy at best – missing more than a third of dying patients and returning many false positives, particularly among patients with non-cancer illness (Downar et al. 2017).

The surprise question also has a poor inter-rater reliability, meaning that different physicians give different answers for the same patient and that it is dependent on a healthcare provider being willing and remembering to use it. Real-world studies of surprise-question triggered interventions have shown low uptake among providers – as low as 15 percent in one UK study (Barnes et al. 2008). Family physicians in Ontario using the surprise question identified only 0.65 percent of their patients for a palliative approach over approximately 16 months, while at least 1-to-2 percent of patients in family practices die annually (Mittmann et al. 2020).

Some clinicians are unwilling to use the SQ as a trigger for palliative care interventions, particularly in the frail elderly. Objective prognostic models are similarly modest in their accuracy (see, for example, Drame et al. 2008) and also depend on a clinician who has the time and inclination to use them at the bedside. More complicated disease-specific identification tools can be used, but they appear to identify roughly the same patients as the surprise question (Gomez-Batiste et al. 2017), and their complexity may be a considerable barrier to real-world implementation. In short, any identification tool that is provider dependent is likely to have important limitations in terms of accuracy, reliability and uptake, and the delivery of palliative care will suffer accordingly.

Increases in Home and Community-care Funding

In the 2017 federal budget, the Government of Canada committed \$6 billion in additional funding (over a 10-year period) towards homecare services, including palliative care. As part of this, provinces and territories have entered into bilateral

agreements with the government of Canada to improve access to these services, although the agreements for each province do not always specify how much of this funding will go towards additional palliative care per se. Further, the federal government places no conditional requirements on the provinces in terms of outcomes or spending amounts specifically towards palliative care in order to receive the federal transfers.

There are some notable barriers to increasing the use of homecare for patients nearing the end of life barriers that cannot be overcome by increasing the number of available caregiver hours. First, there are challenges with maintaining relational continuity of care (i.e., the ongoing relationship between patients and their healthcare providers). Due to staff turnover and scheduling patterns, it is often difficult to ensure patients consistently see the same providers in the home (namely, nurses and personal support workers). Qualitative interviews with homecare patients and their caregivers found that it was important to patients to have a consistent set of providers, especially for personal support workers providing bathing and toileting care (Morey et al. 2020).

Second, even if homecare funding were expanded, many patients cannot be cared for at home because they lack the social infrastructure (e.g., family/friends) or resources to provide the care needed when homecare staff are not present. Canadian studies have shown that unpaid caregiving costs of patients receiving homecare constituted approximately three-quarters of the total cost of palliative care (see for, example, Chai 2013). Yu et al. (2015) found the higher costs of a hospital death (compared to a home death) were offset by the combined costs of unpaid caregiving and outpatient services among those who were able to die at home. Essentially, home deaths are cheaper for the insurer but only because palliative homecare leverages patient and family resources (both financial and unpaid caregiver resources). Thus, a home death is often not feasible for people who lack the social or financial resources to absorb those costs.

Care Coordinators and Common Documentation Systems

Care coordination is a core tenet of palliative care and can be achieved through care navigators and common documentation. Various care-navigator interventions have been piloted in palliative care. While some elements of care coordination appear to hold promise, the collective research suggests inconclusive evidence to adopt this approach more widely. For example, Wong et al. (2016) examined the effect of a transitional care nurse on patients with end-stage heart failure. Each nurse conducted a pre-discharge palliative-care assessment and followed up with the patient for 12 weeks. Compared to a control group, there were improvements in depression, dyspnea, total Edmonton Symptom Assessment Score, quality of life and patient satisfaction.

Meanwhile, a qualitative study on care coordinators for patients with lung cancer at the end of life found that patients felt the coordinator responded to their needs by connecting them with services, helped them to contact their physicians, helped with financial issues and provided support (Epiphaniou et al. 2014). However, there may be disagreement about who should assume the care-coordination role (Reeves et al. 2020). As well, non-standardized use of electronic medical records, indirect communication among providers, conflicting understandings of professional roles, distrust of professional competencies, lack of time for coordination, lack of financial remuneration for coordination and lack of awareness of available services may impede care coordination (Reeves et al. 2021).

Common documentation is also considered a key component of improved care coordination. In 2009, the UK began to implement electronic registers that aim to facilitate documentation of up-to-date information about patients' preferences and plans for care, which is shared across care sites. A systematic review found that most studies on these systems were expert opinions and observational

quantitative findings focused on how many people died in their preferred place of death and how a system was related to hospital utilization. In contrast, mixed methods studies noted people had difficulty inputting data into the system and struggled with the related technology. The authors felt there was inconclusive evidence regarding the effectiveness of these systems (Leniz et al. 2020).

HOW TO INCREASE PALLIATIVE CARE AND REDUCE ACUTE CARE AT THE END OF LIFE

Although many efforts to increase the adoption of palliative care and reduce the use of acute care at end of life have been unsuccessful, there are some obvious steps that could be taken to address or overcome the structural inefficiencies identified above. In this section, we will focus on the potential role of:

- (a) reliable triggers for adopting a palliative approach;
- (b) creating appropriate and abundant discharge options for patients in acute care who are nearing the end of life;
- (c) supporting the unpaid, informal caregiving that is essential for those who are able to receive EOL care at home;
- (d) identifying and tracking relevant metrics for appropriate EOL care; and
- (e) empowering the public to initiate conversations about palliative care.

There are other factors that would help, including integrating educational interventions into more comprehensive quality-improvement initiatives aimed at driving specific changes in measurable outcomes, but this topic is beyond the scope of this *Commentary*.

Reliable Triggers for Adopting a Palliative Approach

The first step in increasing access to timely palliative care is the identification of those who are nearing

the end of life and may have unmet palliative needs. Although palliative care may offer benefit to people at any stage of life, the large majority of healthcare costs are accrued in the final three-to-four months of life. To reduce the costs associated with unwanted and unhelpful care, it is most important to adopt a palliative approach for this period. Unfortunately, clinicians, patients and caregivers often do not accurately recognize the EOL period, especially for people with non-cancer illnesses and frailty (Seow et al. 2018).

One promising approach to creating more reliable, accurate tools for identifying patients nearing the end of life is to use prognostic models based on existing clinical and administrative data in electronic health records. One such tool, based on the Hospital One-Year Mortality Risk score, has been successfully implemented in the acute-care setting to identify patients with unmet palliative needs (Wegier et al. 2017) and prompt discussions about care goals and a palliative care approach. RESPECT (Risk Evaluation for Support: Predictions for Elder-life in the Community Tool) uses a similar approach to identify patients in long-term care or receiving homecare services who are nearing the end of life, using existing data about their comorbidities, need for assistance with daily living activities, signs of cognitive decline, and symptoms or treatments they are receiving (Hsu et al. 2016). These tools can help to drive the timely adoption of a palliative approach for patients who might otherwise receive (or continue to receive) costly care that is unhelpful and unwanted.

Discharge Options for EOL Patients

As outlined above, one of the major drivers of EOL acute-care utilization is the lack of available discharge options for patients who have chosen to adopt a palliative approach. This is reflected in the large number of ALC patient-days spent in acute care for those in the final 90 days of life. Three destinations account for the large majority of ALC patient days at the end of life: (1) community

hospice or in-patient palliative-care unit beds; (2) LTC beds; and (3) homecare where homecare resources are not yet available.

Community hospice or in-patient palliative-care unit beds are in short supply across Canada. In 2014, the Auditor General of Ontario found that Ontario had only 270 hospice beds and recommended creating seven-to-10 per 100,000 population (945-1,350 beds) based on benchmarks from other countries (Auditor General of Ontario 2014). In addition, the Auditor General found wide geographic variability in the supply of hospice beds – two of Ontario’s 14 health regions (representing more than 2 million people) had no hospices at all.

The main reason for this shortage is that public funding for hospice beds is inadequate to cover their operating costs. As a result, hospices across Canada must obtain as much as 50 percent of their operating budgets from charitable sources (Canadian Hospice Palliative Care Association website). Simply put, every provincial and territorial ministry of health must ensure that hospice bed funding is sufficient to allow these facilities to operate without the need for charity and that hospices beds are ubiquitous enough that people do not have to wait for them in acute-care beds.

By far, the largest number of ALC patient-days among those in the final three months of life was accounted for by patients waiting for LTC beds. Although prognostication can be challenging for some patients, particularly if they have non-cancer illnesses or frailty, this high number suggests that the admission criteria (typically prognosis or functional status) for hospice beds may not be appropriate for many dying patients whose prognosis may be unclear. Funding for hospice or palliative-care unit beds often comes with financial penalties when a patient’s length of stay exceeds a few weeks or short months, meaning that there is a disincentive to admit patients with longer or unclear prognoses. Expanding existing hospice or in-patient palliative-care beds would not help this group unless there were also a change in admission criteria for some of those beds. They would require

“chronic palliative” beds, for which there would be no financial disincentive to admit patients where prognosis is less clear. These beds could be created in standalone hospices or in LTC facilities to promote continuity of care.

A relatively smaller proportion of ALC patients are waiting for available homecare, but this still accounts for a substantial number of ALC patient days among dying patients. Growth in the use of homecare at end of life appears to be stalling in recent years, which may be partly related to staff limitations but also to the inability of many people to supplement homecare with their own resources and unpaid care from their family and social network (Health Quality Ontario 2019). While there are existing financial supports for family caregivers in Canada, such as the Compassionate Care Benefits through Employment Insurance, the application process is complicated and lengthy. This process needs to be made more accessible to family caregivers and non-family members in the patient’s circle of care.

Moreover, while home deaths may be more desirable from a patient-centred perspective, they may not always reduce costs. An Ontario study of 50,068 deceased older adults estimated that the cost to enable people to die in the community was actually \$995 more per person in the last three months of life than for patients who died in hospital (Isenberg et al. 2018). Notably, this is not an argument against increasing funding for homecare, since achieving a higher quality home death for a similar cost to a hospital death would still be considered better value. But we should be realistic about the effects of increasing funding for homecare, and have modest expectations about the increases in the number of Canadians who will ultimately die at home and the overall cost savings that this might achieve.

De-medicalization of EOL Care

Canada’s reliance on acute-care settings for EOL care means that many dying patients

receive medications and procedures that would be appropriate only for someone with many years to live. Initiatives such as the Palliative and Therapeutic Harmonization (PATH) model developed in Halifax, Nova Scotia by Drs. Moorhouse and Mallery introduce a routine “checkpoint” prior to procedures performed on frail elderly patients to ensure that the procedure is aligned with the patient’s goals and a realistic assessment of potential benefits and harms (Moorhouse et al. 2012). In 75 percent of such cases, the procedure is cancelled as a result of this checkpoint.

Another intervention focusing on routine medication rationalization (MERA) for admitted patients in the final six months of life resulted in the discontinuation of an average of more than three medications per patient (Whitty et al. 2018)). This intervention has been automated through the MedSafer platform (medsafer.org), which is available in multiple settings and is effective when used to reduce the use of nonbeneficial or potentially harmful medications for people with advanced illness (McDonald et al. 2019).

Patient and Family Member Empowerment

Aggressive EOL care is rarely driven by an explicit request from patients or family members. A survey of 623 bereaved family members of deceased patients found that only one in six indicated the deceased received “too little” care – the primary concern was too little symptom palliation, even among those receiving hospice services (Teno et al. 2020). Often, it is the physician or the physician’s perception of the patient’s wishes that drives aggressive care. An Alberta survey of patients receiving dialysis found that some 60 percent regretted their decision to start dialysis and 52 percent indicated they chose dialysis because it was their physician’s wish (Davison et al. 2010). A more recent survey of 450 patients receiving chronic dialysis found that 19 percent

regretted their decision to start dialysis and 45 percent said they chose dialysis because of their doctor’s recommendation (Saeed et al. 2019). We need to empower and encourage patients and family members to ask questions and voice their preferences for less aggressive options when appropriate.

GAPS IN KNOWLEDGE AND AREAS FOR FUTURE STUDY

Any effort to improve EOL care should consider health equity and the fact that marginalized groups are less likely to access palliative care. Disparities in palliative-care involvement have been observed in many racial and ethnic groups (see, for example, Johnson 2013, Payne and Hampton 2003). Black Americans are more likely than white Americans to receive aggressive care at the end of life, including cardiopulmonary resuscitation, vasopressors, mechanical ventilation and renal replacement therapy (see, for example, Brown et al. 2018). Black Americans are also more likely to die in an intensive care unit (ICU) than at home, in hospice or in a palliative-care unit (Sharma et al. 2017). In Canada, those of Chinese or South Asian ethnicity are more likely to receive aggressive care at the end of life, including ICU admission, hospital admission, mechanical ventilation, percutaneous feeding tube placement, tracheostomy, dialysis and cardiopulmonary resuscitation, compared to the general population. Those of Chinese ethnicity are more likely to receive specialist palliative care, and those of South Asian ethnicity are less likely to receive specialist palliative care, relative to the general population (Yarnell et al. 2020).

There has been some research in Canada on disparities in access to palliative care among individuals who are First Nations, Inuit, Métis and urbanized Indigenous. Research suggests that these populations lack sufficient access to palliative care, especially pain and symptom management (Prince and Kelley 2010). This relates in part

to the different levels of government that have responsibility for funding services for these groups (Caxaj et al. 2018) but also to the fact that many live in remote areas. In another study, Prince and Kelly (2006) found that the need to be transferred to large urban centres for EOL care, which isolates the patient from family, runs contrary to a common preference among the Indigenous to die at home.

Studies have identified specific issues that need to be addressed when implementing palliative care in First Nations communities. For example, bereaved Ojibway and Cree family members expressed that palliative-care providers should use communication strategies that involve respectful directness and that spaces for patients should be allowed to accommodate a larger number of visitors than those spaces used by non-First Nations patients (Kelly et al. 2009). Likewise, a study by Hotson et al. (2004) among residents of remote Indigenous communities in northern Manitoba found that there was a need for culturally sensitive palliative care wherein patients had access to family supports and traditional services. A study of healthcare providers who care for Inuit patients in Nunavut similarly found the need for culturally competent palliative care that respects Inuit culture and the role of family and includes access to medical interpreters as well as provider training in Inuit EOL care (Vincent et al. 2019). This research is fuelling the creation of palliative-care services tailored to First Nations populations. Kelley et al. (2018) have described a process for doing so using participatory access research.

Disparities in access to palliative care also exist for patients in English-speaking countries whose first language is not English or who are immigrants. Patients in Australia who were born in a country whose first language is not English were less likely to receive palliative care compared to those born in an English-speaking country, despite having palliative needs (Currow et al. 2008). Furthermore, patients in Australia who were not fluent in English and accessed palliative care were more likely to be

unaware of their diagnosis, have poorer symptom control and be less likely to die at home (Chan et al. 1999). In Canada, recent immigrants are more likely than long-standing immigrants or the general population to receive aggressive care at the end of life, including ICU admission, mechanical ventilation and dialysis, and are less likely to die at home or in hospice (Yarnell et al. 2017). Despite the high prevalence of a desire for a comfort and quality focused approach to EOL care, patients who were immigrants with advanced cancer living in the US often received aggressive EOL care, including mechanical ventilation and cardiopulmonary resuscitation. In other words, immigrant patients were more likely to receive EOL care that was inconsistent with their values (Shen 2019).

There are also geographic disparities in access to palliative care. Palliative care in rural areas, for example, is often provided by generalists who may be inadequately prepared to manage EOL symptoms (Robinson et al. 2009). An Ontario-based survey of 100 informal caregivers of terminally ill patients found that rural caregivers reported greater use of family physicians, emergency room visits and pharmacy services, whereas urban caregivers reported greater use of caregiver respite services (Brazil et al. 2013).

Health-equity disparities in palliative care also relate to age, sexual orientation and religious affiliation. A systematic review of 14 studies found that older patients (65 or above) with cancer were less likely than their younger counterparts to access specialist palliative care (Burt et al. 2006). In Nova Scotia, cancer patients 85 years or older were less likely than those younger than 65 years to be registered to a palliative-care program (Burge et al. 2008). There are few studies that have investigated access to palliative care by members of the lesbian and gay community, although Stein et al. (2001) suggest this population shares a majority culture preference for the relief of pain and suffering rather than the extension of life. Similarly, there are few studies that have investigated differences in access

to palliative care according to religious affiliation, though having a high level of positive religious coping was associated with mechanical ventilation or cardiopulmonary resuscitation at the end of life in a cohort of patients with advanced cancer (Phelps et al. 2009).

If the approaches to decrease the likelihood of patients receiving unwanted, unhelpful care identified earlier are to be implemented, we must do so while minimizing disparities that exist in our healthcare system. In this case, it means specifically addressing the fact that racialized groups receive more care that is typically viewed as unwanted or unhelpful. It is important as well to acknowledge the heterogeneity within marginalized groups; we should not apply a stereotyped approach to individuals based on demography.

POTENTIAL SAVINGS

Potential Savings from Implementation

Economic evaluations focusing on the cost-effectiveness of palliative and EOL care programs have been limited (Gomes et al. 2013, Davis et al. 2015, Bajwah et al. 2020). The generalizability of past studies on the cost-effectiveness of palliative care have been constrained by small sample sizes and short duration (Mathew et al. 2020). Furthermore, the variability in the interventions being evaluated, the study populations (primarily, of patients with advanced cancer) and outcomes being compared have also made it difficult to establish consensus about the cost-effectiveness of palliative-care interventions; that is, the added benefit for each dollar invested in these services. The heterogeneity in outcomes and methodology used in published studies may reflect how researchers who seek to study the cost-effectiveness of palliative-care interventions have to adapt recommended health technology assessment methodology. Economic evaluations typically evaluate an intervention based on lives saved (cost-effectiveness analysis) or increased wellbeing using

quality-adjusted life years (cost-utility analysis) (Canadian Agency for Drugs and Technologies in Health, website). These health outcomes, arguably, are not directly applicable to patients nearing the end of life.

Studies do not consistently indicate whether providing more palliative care in the home would result in a net cost savings. Among those published so far, many are based on comparisons to individuals who did not receive any palliative care, which can lead to the conclusion that there is a greater cost associated with palliative care delivery. Despite this, since patients who receive palliative and EOL care tend to rely on fewer acute-care resources in the final months of life, the incremental cost to provide palliative care tends to be modest (Hsu and Garner 2020). For example, using recent data from Ontario, Isenberg et al. (2020) estimated that the added cost to enable older adults to die at home by providing EOL care was just \$995 per person over the last three months of life, compared to those without any palliative services.

The high cost of EOL care is partially attributed to a misalignment between patients' preferences for more services to be provided in their homes or communities and the settings or sectors where such services are available. Using the same case example from Isenberg et al., when the total cost of care among decedents who received homecare *without* palliative-care intent was compared to individuals who received homecare *with* palliative-care intent, Ontarians who received palliative homecare were far more likely to have died in non-institutional settings, such as their home or a hospice. The difference in location of death was striking: only 21 percent among those who received EOL homecare died in hospital while 71 percent of those who received homecare without palliative intent died in hospital (ibid.). Despite having received more hours of homecare services, the average cost of care for those in the palliative homecare group was lower – a net cost difference or cost saving of approximately \$6,737 per decedent in the last 90 days of life. This

was mainly attributed to their lower acute-care use. As illustrated by this case example, potential cost savings can be derived from the delivery of palliative care that is aligned with patients' preferences at the end of life.

How Many Canadians Could Die Outside of Hospital?

In 2015, only 15 percent of Canadians decedents died in their home. That number rises to approximately 30 percent when other types of residential care facilities, such as nursing homes and residential hospices, are included (CIHI 2018). Secular trends in the location of death suggest only small improvements over time. In Ontario, the proportion of home deaths (including nursing homes) currently sits at 45-47 percent (Hill et al. 2019). Delivery of home-based palliative-care services and physician home visits in the last 30 days of life has plateaued at approximately 25 percent, despite the fact that palliative home visits are associated with a 50-percent reduction in the likelihood of dying in hospital (Health Quality Ontario website).

Using trends from other high-income nations such as the United States and the Netherlands, a reasonable goal for the proportion of Canadians who die in hospital should be 20-30 percent.² Considering that 61 percent of Canadians currently die in hospital, we have a tremendous opportunity to change where EOL care is delivered, from our current over reliance on acute care to the home.

Cost Savings by Reappropriating Care

To be sure, the goal of palliative care is not to reduce healthcare costs. But reducing the time people spend waiting for the most appropriate bed, reducing the use of non-beneficial or harmful

medications and avoiding unwanted medical interventions are all patient-centred goals. The focus of this *Commentary* has been potential cost savings because this is a key consideration for policymakers, and it is important to understand that patient-centred goals can be achieved alongside cost savings.

Despite the current lack of consensus around the magnitude of savings that could be achieved by providing more palliative care, evidence from Canada and internationally has consistently demonstrated that the receipt of such support (irrespective of the care setting) is associated with less reliance on more expensive acute-care services in the final months of life (Hsu et al. 2020). Fewer days spent in hospital will lead to lower spending on EOL care and better alignment with patients' preferences. Using the case example from Ontario above (Isenberg et al. 2020), if all 3,806 decedents who received homecare *without* palliative care had received services as part of a palliative-care approach, nearly \$25 million in health system spending might have been saved.

Beyond homecare services, approximately 10 percent of Ontarians spend at least one day in hospital with an ALC designation in their last 90 days of life, accruing a total of some 190,000 hospital days per year (Ontario Palliative Care Network, Data and Information Advisory Council meeting). With an average cost of \$1,100 per day in an acute-care setting, this translates to more than \$208 million per year spent on hospital services for EOL patients while they wait for care in a more appropriate setting. Estimates provided by the Ontario Palliative Care Network suggest that nearly half of the 190,000 ALC days accrued by Ontarians in their last 90 days of life can be attributed to wait times for LTC placement or for services that can be provided in assisted living facilities (ibid.).

2 For European and US analyses see Pivodic et al. 2016, and Teno et al. 2018), respectively.

Obviously, wait times cannot be reduced to zero even in a highly efficient system with ubiquitous LTC, hospice care and homecare resources. But if the costs associated with these end-of-life ALC days in acute care were spent instead on the beds in the settings where the patients were waiting for residential care (including long-term care and assisted living), palliative care (including hospices and hospital-based, palliative-care beds) and on palliative homecare – the potential savings in Ontario alone would be \$161 million annually, according to daily care costs reported by the Auditor General of Ontario (2014). And if Ontario represents 40 percent of the Canadian population, this would extrapolate to ~\$400 million per year across the country, just by moving patients in the final 90 days of life to a bed in the location they are waiting for.

Finally, a palliative approach to care focused on improving patients' quality of life may also include strategies to reduce medication burden, particularly of drugs such as statins and other lipid-lowering agents for the management of cardiovascular risk factors and disease that have little or no benefit for patients with terminal illnesses. One Canadian study examining the effectiveness of a hospital-based interprofessional intervention aimed at medication rationalization found the discontinuation of unnecessary medication was associated with a cost reduction of \$94.28 per 100 patient-days among older adults with elevated risk of six-month mortality (Whitty et al. 2018). With an annual average of more than 104,000 Canadians over the age of 60 years who are hospitalized at least once prior to death (Hsu and Garner 2020), the discontinuation of unnecessary medication in the last 90 days of life has the potential to reduce nearly \$10 million in direct drug-related costs annually,

without even considering the reduction in workload for clinical staff caring for these individuals.

Although the ability to achieve any cost saving within our healthcare system hinges on the availability of infrastructure (e.g., facilities that can provide palliative care for patients who are medically stable and can be discharged from the hospital) and healthcare providers with specialization in palliative care, current evidence favours investment in more palliative-care resources to ensure long-term sustainability of our healthcare system.

CONCLUSION

In this study, three key themes have emerged.

- 1 Canada must stop treating end-of-life care like it is acute care.
- 2 Palliative and end-of-life care must be provided across multiple healthcare settings. It cannot be the sole responsibility of hospices and palliative-care facilities.
- 3 Although people may benefit from a palliative approach at almost any time in their life, the large majority of healthcare expenditures occur in the final three-to-four months of life. To achieve the greatest reduction in costly and low-value EOL care, we need reliable means of identifying and intervening during this period in particular.

Canadians spend more on medical care at the end of life than virtually any other country, yet we achieve poor results compared to most. There are clear structural factors within our healthcare system that facilitate unhelpful and unwanted care. We have suggested several structural changes that, if implemented, could result in both substantial improvement in EOL care and substantial savings to the healthcare system overall.

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