SPECIAL SERIES – END OF LIFE CARE

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End-of-Life Care in Canada

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Abstract

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End-of-life care and planning is critically important to the next decades of health care in Canada. In our country, between 2005 and 2036, the number of seniors 65 years and older is projected to increase by up to 25%, and the number of deaths by 65%. The majority of patients are currently admitted to hospital and many to intensive care units at the end of life; however, up to 70% of elderly patients say they would prefer a less aggressive treatment plan focusing on providing comfort rather than a technologically supported, institutionalized death. Herein we provide a brief overview of the end-of-life care in the Canadian context, and highlight challenges and opportunities for health care system change in the coming decades.

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Our healthcare system is under stress. The population is aging; patients are living longer with chronic illness, and the increasing demand for services at the end of life all contribute to escalating costs and utilization patterns that are unsustainable. In a recent national survey, more than 80% of respondents were concerned the quality of healthcare will decline as a result of increased strain on the health care system as our population gets older [1]. In Canada, the number of seniors 65 years and older is projected to increase from 4.2 million to 9.8 million between 2005 and 2036, leading to a doubling of the annual expected deaths [2].

Hospitals remain the provider of end-of-life care for 70% of Canadians and 10% to 15% of patients are admitted to the intensive care unit (ICU) on their final hospital admission [3-5]. The elderly tell us, however, that intensive hospital and ICU-based end-of-life care is not usually what they desire. In a study of hospitalized elderly patients, 70% reported that they wanted comfort measures as opposed to life-prolonging treatments; however, 54% of these patients were admitted to ICUs at the end of life [6,7]. With patient-focused concerns of delivery of healthcare that is neither desired nor beneficial, and universal concerns about sustainability of health care funding [8], we must critically examine current end of life practices and try to better match the healthcare desires of our patients with the capabilities of our system to deliver this care.

End-of-Life Care and Palliative Care

End-of-life care and palliative care are relatively recent concepts, and the terms are often used synonymously; however, the World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). End-of-life care as defined in a recent Canadian Institute for Health Information (CIHI) report refers to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future [9,10]. Modern end-of-life and palliative care was conceptualized in the later half of the last century in the United Kingdom, focusing upon the role of analgesia, the concept that pain is multifaceted with psychological and physical components, and endorsing the important role that family and friends play for dying patients [11]. Historically, religious and charity organizations were the predominant providers of end-of-life and palliative care; however, as the proportion of deaths due to chronic conditions, terminal illness and frailty ('old age') has grown, traditional medical providers and institutions have increasingly adopted this role.

Advance Care Planning for Death in Canada

Death and birth are the only common health events that we all experience. We have little input into our birth; however, we can anticipate death, and to some degree, help to shape the nature of care that we and our loved ones receive. The reality in Canada is that advance care planning occurs very uncommonly. A recent Canadian study of elderly hospitalized patients at high risk of dying revealed that most patients (76%) had thought about end-of-life (EOL) care, and only 12% preferred lifeprolonging care; 48% of patients had completed an advance care plan and 73% had formally named a surrogate decision maker for health care. Of patients who had discussed their wishes, only 30% had done so with the family physician and 55% with any member of a healthcare team [12]. This study highlights that there are barriers to clinicians having the conservations with patients about end-of-life care that patients need. Such barriers may be related to a perceived lack of time, interest, necessary in-person familial support for patients, skill and facility in having such difficult conversations, aids for decisional readiness, understanding prognosis or a combination of all these and others. The results of impaired communication of preferences for end-of-life care can be reduced satisfaction for patients and their families. In one recently completed study of all inpatient deaths over one period in a single tertiary care center, 72% of next-of-kin respondents believed that their relative would have preferred an out-of-hospital location of death; however, the most common location of in-patient death was the ICU [13]. Respondents who believed their relative died in their preferred location of death were 17.9 times more likely to be satisfied with the end-of-life care that was provided than those who did not (p < 0.001). There are Canadian efforts underway to highlight the importance of this advance care planning (http://www.advancecareplanning.ca) and similar international initiatives that aim to help the population plan and guide their own approach to care (http://theconversation project.org).

Decision-Making at the End of Life - Who Decides?

Decisions regarding treatment at the end of life are inherently difficult; such as the choice to decline or withhold lifesustaining therapy. Historically, physicians were looked upon to take the role of decision-maker for most forms of therapy nearing the end of life; however, a *shared decision-making* model, which involves a dialogue about options and preferences among patients, their support system and the health care team, with patient preferences ideally guiding most decisions, has evolved to be the most commonly endorsed mechanism to determine treatment [14]. Although disagreements about the optimal end-of-life treatment plan between the healthcare team and patient or their substitute decision-maker are uncommon, it is most problematic when a patient's prior wishes, values and beliefs are unknown or unclear. Jurisdictions have developed mechanisms to help provide resolution for disagreements, for example the Ontario Consent and Capacity Board (CCB). After having worked through an internal process for resolving disagreement between a patient or substitute decision-maker and the clinical team (http://www.cpso.on.ca/ policies/policies/default.aspx?ID=1582), if agreement cannot be reached and there are concerns about the patient's capacity to consent or decision-making of the substitute decisionmaker's, in some provinces, a Board can be petitioned, typically by a physician, to consider a case. In Ontario, the CCB panel is typically comprised of 2-3 members, most often a lawyer, a public representative and sometimes a psychiatrist. The CCB can convene quickly (within a day) and offers decisions within a day of conclusion of the hearing. Any of the parties can appeal the decision to the Ontario Superior Court of Justice. Without a question of consent and capacity, courts of law are still relied upon for questions about the legal standard of medical care, when this is the crux of the disagreement. Although the CCB in Ontario is designed to provide independent and efficient resolution to disagreements, an appeal to the courts can take months or longer to unfold and is sub-optimal for dying patients in need of disagreement resolution within days, not months.

End-of-Life Care: A Variable Experience

National and regional variation in end-of-life care is important to study because it may unearth generalizable issues to solve or solutions that can be applied to other jurisdictions. Using data from United States Medicare and other sources, the Dartmouth Atlas of Health Care has found that end-of-life care has strong geographic associations (i.e., where the patient happens to live), and is not necessarily based upon on patient preferences or the ability of care decisions to extend life [15]. Depending on the hospital and jurisdiction, 20-50% of the population die in hospital, while 6-30% die in the ICU. Intensity of care in the last six months of life also varies remarkably - the number of visits to physicians ranged from an average of 9 to almost 50. Not surprisingly, Medicare costs varied by a factor of three among various hospitals and jurisdictions. Preliminary examination of the Canadian experience identifies similar geographic variation across provinces.

In 2007, CIHI published a report on the use of healthcare at the end of life; finding that 58% of Western Canadians die in a hospital and 62% of decedents were hospitalized at least once during the last year of life, for an average of 30 days [16]. Hospital-based palliative care comprised a component of endof-life care for a minority (13%-16%) of those dying. Decedents from rural or northern regional health authorities were more likely to have been hospitalized and to have spent more days in hospital before death than decedents from larger, more urbanized areas, possibly reflecting differences in availability of non-hospital-based health services.

In 2011, CIHI published a second report that outlined care provided during the final year of life in the Atlantic Provinces during 2007-2008 [10]. The decedent population included 18,427 adults (age 19 and older), accounting for approximately 90% of all deaths during the study period. The leading causes of death included cancer and circulatory disease and were consistent with national rates across other provinces. Four 'trajectories' of death were identified, in order of decreasing prevalence: organ failure, terminal illness, frailty and sudden death. Overall, 63% of individuals died in hospital. Approximately 59% of those dying in hospitals did receive some type of palliative care services during their final hospital admission, but the type and extent of service varied widely. Hospitalizations during the last year of life were common – up to 71% during the final year of life – for an average of 26 days.

In addition to geographic variation in end-of-life care, there is ample evidence that cultural and religious norms influence many decisions made for care at the end of life. In a systematic review of 6259 publications of patient and healthcare professional factors influencing end-of-life care, patient and clinician race, ethnicity, and nationality appeared to influence technological intensity of end-of-life care. In general, Caucasian American (as compared to African American) patients and those of North American and Northern European origin were less likely to desire intensive end-of-life care than others. Physicians of similar geo-ethnic origin to patients appeared less likely to prescribe such therapy [17].

Communication with patients about end-of-life issues is also strongly influenced by cultural norms. Death is rarely openly discussed in many East Asian communities [18]. Although withholding information from patients is uncommon in North American, there is often differential understanding of the intent of therapies at the end of life, with the clinical team providing 'palliative' therapies, while patients and families still understand this to be an attempt at a cure [19]. Interestingly, beneficiaries of Medicare in the United States receive coverage for palliative care only if they agree to stop treatments intended to cure [20]. It is not surprising, then, that for many Americans, the idea of palliative care may be akin to relinquishing hope, and may sometimes represent a barrier to ensuring that patients receive symptom-focused care, and relief of pain, anxiety and potential suffering in the dying phase of life.

International Evaluations of End-of-Life Care

In the past decade, the performance of healthcare systems in providing palliative care has become formalized [21], with Canada performing moderately well from a global perspective. The Economist's Intelligence Unit developed a 'quality of death' index and recently applied it to 40 countries across the world, measuring numerous indicators pertaining to quality of end-oflife care, cost of end-of-life care, basic end-of-life healthcare environment and the availability of end-of-life care [18]. While the U.K. ranked first overall for quality of death, and first in both the subcategories of availability and quality of endof-life care, Canada ranked fifth. One of the chief weaknesses of Canada's provincially-administered universal health care system is the lack of a national approach and the reliance upon hospitals to provide most services, with a relative lack of hospice and home hospice care in comparison with other countries.

Costs

Healthcare is increasingly expensive and Canada now spends approximately 12% of its gross domestic product on healthcare [22]. Although this cost is rising, it is less than the United States, at 18%. A recent Canadian Health Services Research Foundation report on cost drivers highlights that increased spending is not merely due to age and demographic changes but can largely be explained by increased use of technological innovations [22]. The US experience teaches us that high resource use and high spending does not always lead to better outcomes or markers of population health [23]. There is an increase in health spending by age, with more than 40% of total health care spending accounted for by those 65 and older in Canada; however, this age group accounts for less than 20% of the total Canadian population [24]. Past work has estimated that approximately 20% of all spending occurs during the last year of life in Canada [25-27]. The provision of care at the end of life, often including aggressive diagnostic care, technologyassisted monitoring and treatment in ICUs, is among the most expensive; consuming up to 0.5-1% of the GDP (or 10-20% of the healthcare budget) [15, 28-30]. Although the proportion

of dollars spent caring for patients at the end-of-life have remained somewhat constant in recent years, overall spending continues to rise.

Rationing of Care at the End of Life: Does it Occur in Canada?

When the demand for resources exceeds available supply, some form of rationing, by definition, must occur [31]. Perspectives from critical care physicians in seven developed countries was sought in a recent international survey of perceptions of rationing. A common theme was the lack of formal guidelines or legal policies regarding rationing for acute or critical care services near the end-of-life [32]. As a result, rationing tends to occur informally, with decisions often delegated to the healthcare team as opposed to open societal debate and formal governmental policy. Although there is not wide-spread acknowledgement of the need to ration specific resources at the endof-life in Canada, there is universal acceptance that there are insufficient resources to match a patient's stated desires for end-(most commonly, out-of-hospital, symptomof-life care focused, non-technologically-laden care) and the care that we are able to deliver (predominantly hospital-based dying, frequently in the ICU on a patient's final interaction with the health care system).

Conclusions

As our population ages, and costs of health care increase, endof-life care and planning is increasingly important to patients, families and the Canadian healthcare system. The majority of deaths in Canada occur in hospitals, and often patients are admitted to the ICU during their last hospitalization; however, the vast majority of elder Canadians say they would prefer a less aggressive treatment plan, focusing on providing comfort, rather than a technologically-supported, institutionalized death. This mismatch negatively influences patient and family satisfaction with care and very likely increases costs. To improve our ability to deliver the care that patients want, we need to encourage and normalize conversations about death and advance care planning across our society, improve the skills and ability of healthcare professionals to have conversations about advance care planning with their patients and evolve Canada's healthcare delivery to include broader and more comprehensive options for hospice and palliative end-of-life care, both in and out of the hospital setting.

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