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Chidi Oguamanam* Cross-Cultural Dynamics in Palliative Care:
The Emerging Canadian Scenario

As modern technologies leverage medical sciences, life expectancy is on the rise in Canada, and indeed globally, with a remarkable increase in the elderly population in need of health care. The same is true of the diversity of cultural groups who are now patrons and stakeholders in Canada's health care landscape. An emergent feature of this landscape is the complexity of contexts for negotiating and mediating medical care delivery at the end of life. This paper examines the gaps in regulatory and legal interventions as well as the gaps and opportunities to negotiate the transition to palliative care in cross-cultural contexts that have the potential to escalate as Canada's domestic health care system increasingly engages with non-dominant segments of Canada's cultural mosaic at the end-of-life spectrum. It calls attention to the increased relevance of palliative care, identifying cross-cultural elements required for continuing and future elaboration of that care regime fully into the Canadian health care system.

Alors que les technologies modernes tirent le meilleur parti possible des sciences médicales, la hausse de l'espérance de vie au Canada et dans le reste du monde s'accompagne d'une augmentation considérable de la population âgée nécessitant des soins de santé. Il en va de même de la diversité des groupes culturels qui sont maintenant à la fois clients et intervenants en soins de santé au Canada. Une caractéristique émergente de cette situation est la complexité des contextes pour la négociation et la médiation de la prestation de soins médicaux en fin de vie. L'auteur examine les lacunes dans les interventions réglementaires et juridiques, ainsi que les lacunes et les possibilités de négocier la transition vers les soins palliatifs dans des contextes interculturels qui ont le potentiel de compliquer la situation, le système de soins de santé canadien étant de plus en plus fréquemment confronté à des segments non dominants de la mosaïque culturelle canadienne à la fin de la vie. Il attire l'attention sur la pertinence accrue des soins palliatifs et fait état d'éléments interculturels nécessaires à l'élaboration de ce régime de soins et à sa pleine intégration dans le système de soins de santé au Canada.

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Introduction

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Introduction

Life expectancy is on the rise globally, across the developed and developing world.¹ With the retirement of the baby boomer generation and significant advances in medical sciences in the past several decades, the life expectancy of many OECD countries, including Canada, is now above 80 years.² Canada's senior citizen population, those above 65, which currently stands at 20 per cent of the national population, is expected to progressively increase.³

Canada's seniors are not exclusive sources of demographic pressure on health care. Since the 1970s, Canada's immigration policy effectively opened up to other cultural and ethnically diverse parts of the world, marking a shift from its historically exclusively Eurocentric orientation.⁴ In addition, through continued recalibration of Canada's immigration policy by successive governments, considerations and accommodations for family reunion, temporary migrant workers, compassion and international obligations regarding the rights of refugees under the United Nations

1. See in particular the 2015–2016 OECD Factbook, online: <www.oecd.org/publications/oecd-factbook-18147364.htm>. Life expectancy is currently increasing by an average of three to four months per year across OECD member countries. Overall life expectancy across OECD members has increased by an average of 10 years since 1970.

2. See WHO, Global Health Observatory, online: <apps.who.int/gho/data/view.main.690g?lang=en>.

3. See Robert Fowler & Michael Hammer, "End-of-Life Care in Canada" (2013) 36:3 *Clinical Investigative Medicine* 127, who indicate that this demographic now consumes a plurality (over 40%) of Canada's provincially managed public health care dollars, a trend echoed across other OECD member countries.

4. Kelley Ninette & Michael J Trebilcock, *The Making of the Mosaic: A History of Canadian Immigration Policy* (Toronto: University of Toronto Press, 1998) at 352-380.

process are now cornerstones of Canada's immigration regime.⁵ As a consequence, that regime contributes not only to an increase in the elderly population in need of health care but also to the diversity of cultural groups who are now patrons and stakeholders in Canada's health-care landscape.

An important concern for this paper is to identify the current gaps in regulatory and legal interventions as well as the gaps and the opportunities to negotiate the transition from medical futility to palliative care, especially in cross-cultural contexts, that have the potential to escalate as Canada's domestic health care system increasingly engages with non-dominant segments of Canada's cultural mosaic at the end of life.

I. *Ethical tension at end-of-life care*

End-of-life care is a complex concept. Put simply, it encompasses the range of circumstances and contexts for the provision of care to patients at the terminal phase of life.⁶ End-of-life care is not limited to the elderly. It applies to all patient age groups and categories. Often, end-of-life care patients are recipients of technologically mediated life-prolonging treatments.⁷ In some critical end-of-life situations, often referred to as living dying situations, the survival of the patient and their existing and future quality of life calls into issue the justification for continued or continuing treatment. Such scenarios give rise to the issue of medical futility.⁸ They highlight the faint border between what may be termed conventional end-of-life care and circumstances in which terminally ill but yet conscious patients may of their own volition request physicians' assistance to end their lives—a criminalized conduct for any indulging physician before the *Carter* decision and resulting legislation.⁹

5. See Stephen Kaduuli, "Pointers to Discriminatory Canadian Immigration Policies" (2011) 1 *Transnational Social Review*, online: <papers.ssrn.com/sol3/papers.cfm?abstract_id=194998>.

6. The contexts for such care encompass every clinical setting, including hospitals and their various care or pathologically-defined units, dedicated long term care facilities, ERs, ICUs, private homes, hospices, etc. See Betty R Ferrell, "Understanding the Moral Distress of Nurses Witnessing Medically Futile Care" (2006) 33:5 *Oncology Nursing Forum* 922.

7. *Ibid.* In some cases those include application of CPR, chemotherapy, organ transplantation, invasive surgeries, sedation, ventilation, intubation and other aggressive life-sustaining practices in ICUs and various settings.

8. Deborah L. Kasman, "When is Medical Treatment Futile?" (2004) 19:10 *J General Internal Medicine* 1053.

9. See *Carter v Canada (AG)*, 2015 SCC 5, [2015] 1 SCR 331 [*Carter*] where the court mandated the government to institute a framework for decriminalization and practice of physician-assisted death. In *Carter* the court overturned its 1993 decision in *Rodriguez v British Columbia (AG)*, [1993] 3 SCR. On 16 June 2016 the Parliament passed its legislative response to the *Carter* decision in Bill C-14, *An act to amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying)*, SC 2016, c 3. For further insights on the pre-*Carter* jurisprudence and the struggle for decriminalization of aid in dying, see Jocelyn Downie, *Dying Justice: A Case of Decriminalizing Euthanasia and Assisted Suicide* (Toronto: University of Toronto Press, 2004).

Medical futility describes circumstances in which continued medical treatment diverges from its core therapeutic objective. Indeed, medical futility describes instances where this therapeutic objective is no longer feasible as it results in the counter-productive outcome of subjecting the patient to burdensome or non-beneficial treatment that raises a question regarding patient's best interest.¹⁰ In such scenarios physicians and other health-care providers are confronted with ethical dilemmas in regard to their professional responsibility and the desire of the patient, their family, or specific designated (or presumed) surrogate/substitute decision maker (SDM), for continued treatment.

As distinct from the newly legislated contexts for Medical Assistance in Dying (MAiD), which is not the subject of this article, the ethical dilemma that arises at the end of life, like all ethical dilemmas, is multifaceted. For physicians, a combination of factors constrains professional resolve to declare medical futility. These factors include the availability of technologically sophisticated procedures and life-prolonging options, the rise in "empowered patients,"¹¹ the threat and reality of litigation, the dominant place of patient autonomy in medical ethics, and direct or indirect statutory expansion of clinically determinable standard of care and the contested notion of patient's best interest. Cumulatively, these factors have a chilling effect on physicians' capacities to determine when a treatment becomes harmful and consequently activates the ethical obligation to do no harm, i.e. where the naked reality of harm is the virtual result of continuing treatment.

Given the overlap between personal and professional ethics, it is tenable for an individual physician's personal ethics to favour the use of technologically enhanced aggressive treatment for prolonging patient life in contrast to rival ethical considerations to the contrary. In any of these situations, physicians are exposed to significant ethical dilemmas at personal, professional, and even institutional levels.

II. *The Ontario and Canadian legal landscape*

In Canada, recent administrative and judicial decisions underscore emphatically the role of culture, family, values, beliefs or religion, and other socio-cultural indices in negotiating end-of-life care treatment plans, especially where these interface with medical futility.¹² They also reveal

10. Lois R Robley, "Medical Futility: Where Do We Go from Here?" (2009) 4 Critical Care 47.

11. Owing to the patient rights movement of 1980s–90s. See Robley, *ibid.*

12. See Paula Chidwick, Robert Sibbald & Laura Hawryluck, "Best Interests at End of Life: An Updated Review of Decisions of the Consent and Capacity Board of Ontario" (2013) 28:1 J Crit Care 22 at 24.

gaps in the legal approaches as between statutorily-enabled administrative mediations and direct court challenges in resolving the impasses that increasingly arise between families and care providers. To date, there are only two jurisdictions, Ontario and Yukon, that have elaborate statutory and institutional frameworks for resolving conflicts between care providers and SDMs in situations where patients' capacity to provide informed consent is compromised without a clear advanced care directive. Such circumstances often, but do not necessarily, give rise to disagreements over whether a situation of medical futility has arisen on the one hand, and what would constitute a consequential action, its nature, and when and how it could be executed, on the other.

The Ontario model issues from the 1996 *Health Care and Consent Act*.¹³ The *HCCA* offers a scheme of dispute resolution when the physician or medical team and the patient family or legally recognized SDMs do not agree on a proposed treatment plan. Dispute resolution under the *HCCA* is conducted through the Consent and Capacity Board (CCB), called the Capability and Consent Board in the Yukon.¹⁴

Even though the cases that have given the CCB some media attention are predominantly those that border on the end of life, the Board's jurisdiction is not restricted to such cases. The focus is on patients who lack mental capacity or capability to make decisions, perhaps more than it is on end-of-life patients.¹⁵ The CCB was conceived to entertain cases of disagreement between physicians and SDMs in regard to proposed treatment plans in contexts where the patient lacks capacity to provide informed consent, or where the patient's treatment preference is in doubt.¹⁶ Interestingly, the majority of cases deal with disagreement regarding the commitment of psychiatric patients to hospital treatment. Quite an insignificant number of cases dealt with by the Board relate to end of life scenarios per se. However, it is these cases that constitute the greatest source of public scrutiny, galvanizing divergent interests over the CCB and its *modus operandi*.¹⁷

13. *Health Care and Consent Act*, S.O. 1996, c. 2, Schedule A [*HCCA*].

14. Pursuant to *Care Consent Act*, SY 2003, c 21, sch B. Note that in Ontario the CCB is made up of 150 appointed members, including 50 psychiatrists, 50 lawyers and 50 laypersons. Hearings and decisions are held expeditiously and rendered by a three-person panel within one week of the initial application. The panel holds its proceeding in as proximate a venue as possible to the patient's locus of treatment.

15. Even though such lack of capacity may be one of several features of the end of life.

16. *HCCA*, *supra* note 13 at s 1.

17. Chidwick, Sibbald & Hawryluck, *supra* note 12. See also Kate Lanau, "Doctors Want the Right to Pull the Plug," *Maclean's* (29 October 2013), online: <www.macleans.ca/society/health/why-doctors-want-the-right-to-pull-the-plug-2/>.

In *Cuthbertson v. Rasouli*¹⁸ the Supreme Court of Canada appears to suggest that the *HCCA* may not apply in matters relating to giving and refusing consent when the context does not amount to patient “treatment.” The case technically boiled down to what constitutes treatment under the *HCCA*. The majority held that pursuant to section 8(2) of the *HCCA*, withdrawal of life support constitutes treatment. The Court was unequivocal that treatment is not limited “to clinical reference to what the provider considers to be of benefit to the patient.”¹⁹ Rather, it is broad enough to encompass actions that are recognized in law as having a health-related purpose, such as therapeutic, preventive, palliative, or cosmetic care.²⁰ The Court found that

Withdrawal of life support aims at the health-related purpose of preventing suffering and indignity at the end of life, often entails physical interference with the patient’s body, and is closely associated with the provision of palliative care. By removing medical services that are keeping a patient alive, withdrawal of life support impacts patient autonomy in the most fundamental way and goes to the heart of the purposes of the *HCCA*. Those purposes would be ill-served by an interpretation that holds withdrawal of life support cannot constitute “treatment” under the Act.²¹

As already noted, end-of-life scenarios constitute an insignificant fraction of cases under CCB proceedings.²² Yet these cases have elicited a significant amount of interest in a manner that puts the Canadian health care system on the spotlight. The nuances often hover around the socio-cultural, ethical, religious, and value elements and conflicts arising from Canada’s increasingly multicultural society as they unravel at end of life, when stakeholders negotiate and increasingly bicker over what constitutes the best interest of the patient and how it is determined.²³ In *Rasouli*, the respondent was a recent Iranian immigrant to Toronto. A devout Shia Muslim, he became brain-damaged following an infection he contracted after surgery to remove a benign tumor. After being on life support and in a permanent vegetative state for a while, his care providers determined that he had no chance of survival. Keeping him on life support would be harmful and futile. They decided to withdraw his life support and switch him to palliative care. As her husband’s SDM, the patient’s wife refused

18. 2013 SCC 53 [2003] 3 SCR 341, (cited to SCR) [*Rasouli*].

19. *Ibid* at 344.

20. *Ibid* at 398.

21. *Ibid* at 344.

22. See Chidwick, Sibbald & Hawryluck, *supra* note 12.

23. *Ibid*. See also Fowler & Hammer, *supra* note 3.

to give consent. She approached the Ontario Superior Court for an order restraining the physicians and requiring them to approach the CCB if they wanted to challenge her decision to withhold consent. The litigation progressed to the Supreme Court, which upheld the SDM's withholding of consent. The court rejected the care provider's argument that the Board had no jurisdiction in cases where care providers declare medical futility, because withdrawal of life support did not amount to treatment requiring the consent of the SDM. For many stakeholders, the significance of that case lies in the positive spotlight it shone on the Ontario CCB model across the county.²⁴

III. *Multi-cultural tensions and dynamics of end-of-life care*

From the decisions of the CCB and a fairly recent study that engaged the contestations over patients' best interest at the interface between end of life and medical futility in Canada, ethnicity, nationality, social cultural backgrounds, values and religious orientations feature as factors in navigating, mitigating and even escalating the tension between care providers and families or SDMs.²⁵ A 2013 Canadian study, for example, concluded that an aggregation of relevant data from other studies, including those that focused on the United States, indicates that unlike people of non-dominant ethnic backgrounds, North American Caucasians and people of European descent are likely to have advanced care plans and to appoint surrogate health-care decision makers.²⁶ The study finds they are less likely to desire intensive end-of-life care or interventions that border on medical futility than their Asian, African, and other non-Caucasian counterparts. The report is consistent with an earlier one that involved a survey of hospitalized elderly patients in Canada, which found that 70 per cent prefer comfortable end-of-life measures as opposed to life-prolonging medical interventions or medical futility.²⁷

Notwithstanding legitimate concerns over the basis for classification of the populations in the studies along increasingly fluid and contentious boundaries, these studies implicate the role of complex backgrounds, including ethnicity, nationality, race, values, beliefs, religion, cultural orientation, and world views in the making of end-of-life decisions from the perspective of families. And, secondly, the studies have ramifications

24. Lanau, *supra* note 17.

25. *Ibid.*

26. See Fowler & Hammer, *supra* note 3. See also Barbara A Noah, "The Role of Race in End-of-Life Care" (2012) 15:2 J Health Care L & Policy 349; Emese Somogyi-Zalud, Zhenshao Zhong & Mary Beth Hamel, "The Use of Life Sustaining Treatment in Hospitalized Persons Aged 80 and Older" (2002) 50 J of the American Geriatrics Society 930.

27. Fowler and Hammer, *supra* note 3.

from the perspective of care providers. In regard to the second point, the progressive shift in Canada's immigration landscape and multicultural make-up corresponds to a rise in the presence of foreign-trained (including African and Asian) care provider cadres in Canada.²⁸ Given the interface of personal and professional ethics, the presence of foreign-trained care providers would contribute to the dynamic of end-of-life care decision making in the country.

A cursory assessment of the 2009 and 2013 Chidwick, Sibbald and Hawryluck reviews of CCB decisions that explored patients' best interest at the intersection of end-of-life care and medical futility shows significant references to diverse factors or sites of tension between SDMs and care providers.²⁹ This assessment is constrained in some respects, specifically in regard to the CCB's customary practice of safeguarding the personal information and identities of parties. However, the narrative of such cases unveils critical information that provides at least a glimpse of important issues, notably ethnic identity, beliefs, religion, and the umbrella category of values canvassed to assist the arbiter to determine as between the SDM and the provider whose position reflects that illusory proposition—the best interest of the patient.

Although not the focus of this article, from those cases there is a perceptible impression that the CCB's significant patrons in real end-of-life scenarios are from the rank of immigrant, ethnic, or visible minority families. That trend could increase rather than decline given the Supreme Court's decision in *Rasouli*, the nation-wide attention that the Ontario's CCB model has garnered, and the prospects of its replication across the country. Similarly, as expected, there is a visible appeal to religion and belief and to values by SDMs or family members overall, especially those from immigrant and ethnic minority populations. In their reviews of how stakeholders (family members/SDMs, physicians and CCB) have engaged the best interest of the patient at CCB proceedings and decisions, Sibbald and Chidwick,³⁰ and Chidwick, Sibbald, and Hawryluck³¹ have noted

28. Unlike previous historic trends that favoured European-born physicians, half of Canada's foreign-trained physicians are visible minorities, with one third and one fifth born in Asia and Africa respectively. See Monica Boyd & Grant Schellenberg, "Re-accreditation and Occupations of Immigrant Doctors and Engineers," online: Canadian Social Trends, Statistic Canada <www.statcan.gc.ca/pub/11-008-x/2007004/10312-eng.htm>.

29. For the latest (2013) study, see Chidwick, Sibbald & Hawryluck, *supra* note 12. The study was preceded by a 2009 study, Robert W Sibbald & Paula Chidwick, "Best Interest at End of Life: A Review of Decisions Made by Consent and Capacity Board of Ontario" (2010) 25:1 J. Critical Care 171 [Sibbald & Chidwick, 2009].

30. *Ibid.*

31. Chidwick, Sibbald & Hawryluck, *supra* note 12.

that (1) SDMs have a tendency to conflate patient values with patient-explicit wishes, (2) a patient's religious values and positions may be of no consequence unless specifically proven to have been held by the patient, (3) SDMs are likely to focus on their own values or religion as opposed to the patient's, (4) a patient's condition should be assessed for more than life per se, and (5) physicians emphasize the patient's clinical conditions to determine whether treatment could be beneficial.

The authors' most recent review of CCB decisions identified three additional emergent sites of pressure or themes for interpreting patient's best interest, two of which are particularly relevant here.³² First, SDMs perceive patient suffering as a desirable price for living, a position that is at odds with the recent progression toward MAiD in Canada. Second, SDMs have unrealistic hopes for patient recovery as they call attention to a patient's character as "a fighter" and subjectively interpret the patient's desire to live based on their communications with patient, a situation that is often at odds with patient's clinical reality.³³ The Chidwick, Sibbald, and Hawryluck studies concluded that in interpreting a patient's best interests SDMs habitually relied on their own values and religious beliefs, while physicians or care providers essentially emphasized the patient's clinical condition.³⁴ The CCB focused on compliance with the terms of the *HCCA* and insisted that physicians' construction of a patient's "condition" must include more than "life itself."³⁵

The following religious categories have been referenced and associated with patients and SDMs of varied religious backgrounds in the CCB cases under review (2009–2015): Catholic, Greek Orthodox, Jehovah's Witness, Hindu, Jewish, Muslim (Sunni), and Muslim (Shia).³⁶ There are also neutral references to parties as being "religious" and to belief in miracles, as well as resignation to God's sphere of influence in relation to living, dying, healing, and suffering. SDMs' invocations of religion, beliefs, and values touch on the sanctity of life, sustenance of life, dying with dignity, and God as the only determinant of end of life. Like all things related to religion and values, the devil is in the detail. Even within the same religious sect there are frequent disagreements on doctrines. While religion is used to support the nebulous notion of sanctity of life, it is also

32. *Ibid.*

33. *Ibid* at 25. A third theme is the incidence of physicians' failure to properly identify antecedent consent protocols to CCB proceedings.

34. *Ibid* at 26.

35. *Ibid.*

36. See Sibbald & Chidwick, 2009, *supra* note 29, and Chidwick, Sibbald & Hawryluck, *supra* note 12.

invoked in other contexts (outside of the present task) to support horrific desecrations of that sanctity. It is not impossible that in the more robust collegial and communal context of palliative care, religion may provide a site for more elaborate spiritual closure for end-of-life decisions than its current narrow and less interrogated deployment for life prolongation in patients' purported best interest in medical futility scenarios.

Even though the CCB admits testimony from religious leaders, the composition of its membership under the *HCCA* does not account for the increasing relevance of beliefs, values, religion, and the role of the religious or faith community in determining the best interest of patients.³⁷ As Canada's multicultural composition is felt within care provider professions and institutions, values, beliefs, and associated considerations of religion will assume a new significance. Those are relevant not only at the intersection of end of life and medical futility but also in regard to palliative care. Religion is a critical social institution for the elaboration and administration of palliative care.³⁸

IV. *Palliative care: lost in translation*

The tension between SDMs, family members, and care providers at the end of life is often negotiated at the foggy juncture of transitioning to palliative care. Most treatment plans for end-of-life patients in virtually all clinical settings inherently incorporate palliative care. In a way, withdrawal of life sustaining interventions when their outcome is futile and may even aggravate a patient's suffering constitutes a palliative strategy. Analysts argue that "all intensive care unit patients are receiving palliative care from admission, concurrently with other plans of treatment and it is unnecessary to propose palliative care at this particular time because as defined it is already in place."³⁹ Aside from the relevance of this observation to ICU patients, it would seem that a dedicated transition to an exclusively palliative treatment regime when the proactive commitment

37. A review of CCB cases in the Sibbald, Chadwick and Hawryluck studies (2009, 2013) demonstrates that religion, values, and beliefs of SDMs and patients inform negotiations about the best interest of the patient in end-of-life situations. These are inherently personal and contested concepts; religion is essentially a site for streamlining beliefs and belief systems, which are shaped by values as much as values are encapsulated in religious doctrines and practices. Yet values transcend religion and are necessarily constrained by it. Both religious beliefs and values are as personal as they are social and communal. The complex relationship of these amorphous concepts account in part for why there is hardly any consensus over doctrinal interpretations of phenomena around values, beliefs and religion.

38. See, for example, Steven M Steinburg, "Cultural and religious aspects of palliative care," (2011) 1:2 *Intl J of Critical Illness & Injury Science* 154-156; S Bauer-Wu, R Barrett & K Yeager, "Spiritual perspectives and practices at the end of life: A review of the world's major religions and application to palliative care" (2007) 13:2 *Indian J of Palliative Care* 53.

39. Chidwick, Sibbald & Hawryluck, *supra* note 12 at 26.

to a curative outcome is abandoned merits elaborate engagement between care providers and SDMs as a critical site for engaging patient's best interest.⁴⁰ There comes a point when palliative care ceases to be embedded, as it becomes *the* care.

Beyond the patient, palliative care is an intervention that directly engages the interest of *all* stakeholders, including SDMs. According to the WHO, palliative care is "an approach that improves the quality of life of patients and families facing the problems associated with life-threatening illness, through the prevention of suffering by means of early identification and impeccable assessment of pain and other problems—physical, psychosocial and spiritual."⁴¹ The Canadian Hospices and Palliative Care Association (CHPCA) describes palliative care as involving "the combination of active and compassionate therapies intended to comfort and support persons and families who are living with, or dying from a progressive life-limiting illness or are bereaved."⁴² For the CHPCA, palliative care focuses on "whole-person health care that aims to relieve suffering and improve quality of living and dying."⁴³ Here, the overlaps between SDMs' values and those of the patients and the larger family become real and open to respectful and deliberate navigations with the help of a multidisciplinary team and relevant community stakeholders.

In a way, and contrary to the assumption of most SDMs, withdrawal of life sustaining treatment does not necessarily amount to cessation of active treatment or care.⁴⁴ Rather, it marks a change in the *objective* of treatment. It is indeed a proactive strategy to relieve suffering or minimize indignity and to ensure that the quality of life, as far as it goes, is preserved and treated respectfully, with opportunity to take into account the stakes of family and community, exploring and integrating, in less formal ways, the roles of religion, beliefs, and values in the transition from life to

40. In the PAD scenario, depending on the patient's state of health and care, a patient's election for aid in dying may represent a decision either to shun or to abridge exposure to palliative care. Here patients are conceivably more in charge of their decision making in the exercise of their autonomy leaving care providers and family members with incidental and secondary roles.

41. See World Health Organization, Definition of Palliative Care, online: <www.who.int/cancer/palliative/definition/en/> [WHO]; see also Robert Becker, "Palliative Care 1: Principles of Palliative Care Nursing and End-of-Life Care" (2009) 105 *Nursing Times* 13.

42. Canadian Hospices Palliative Care Association Standards Committee, *Canadian Hospice Palliative Care Nursing Standards of Practice*, at 8, online: <www.chpca.net/media/7505/Canadian_Hospice_Palliative_Care_Nursing_Standards_2009.pdf>.

43. *Ibid.*

44. See *Rasouli*, *supra* note 18 at 344, where the Supreme Court of Canada held that withdrawal of life support constitutes treatment because this process inevitably involves "physical interference with the patient's body" and is "closely associated with palliative care."

death.⁴⁵ Palliative care is “very much about helping people to live until they die and not [necessarily] about helping them to die prematurely.”⁴⁶ In the post-*Carter* era, it would seem that what constitutes premature death is contestable and the election to die “prematurely” is one exclusively within the right of certain functionally cognitive patients.⁴⁷ It is definitely conceivable that the provision of life sustaining treatment and devices in the context of medical futility can hasten death even in a most painful circumstance, which can deprive SDMs and family of the benefits of a more peaceful death under a more elaborate palliative care approach.⁴⁸

In technologically advanced countries, including Canada, new medical technologies and procedures continue to stretch the possibilities for prolonging human life, even though recent traction for MAiD reflects a symbolic counterpoise of sorts. Technology creates an illusion that questions the inevitability of death, as death assumes the nature of an option not to be exercised as advanced societies negotiate the interface between the right to life and the duty to live. Yet in Canada and elsewhere studies point to a pattern of demographic dichotomy in acceptance of death and in death denying as between Caucasians and non-dominant ethnic communities.⁴⁹ In a related sentiment, it would make an interesting study ten years from now to map the ethnic outlook of candidates who have embraced the new MAiD regime.

The tendency by ethnic minorities to insist upon life prolonging treatment in the face of clinically perceived medical futility is driven by multiple factors. The first of these is the convenience of capitalizing on the excessive, albeit false, hope of medical technologies in the circumstances where they are readily available for a population that is mostly deprived and on the margins.⁵⁰ The second, which is related to the first, is the historic mistrust by members of this plural category of the operations of ICUs and the entire medical system⁵¹. The third, is the higher tendency by this

45. WHO, *supra* note 41.

46. Becker, *supra* note 41 at 7.

47. See *supra* note 9 at ss 241.2(1)(a-e) and 241.2(2)(a-d) for a description of eligibility requirements, which are substantially more restrictive than the language in *Carter*. *Carter* will *prima facie* permit physician assisted death in instances of a “grievous and irremediable medical condition...that causes enduring suffering,” while the legislative response raises the threshold to cases where “natural death has become reasonably foreseeable.”

48. See Noah, *supra* note 26.

49. See *supra* note 38.

50. See, for example, Amber E Bernato et al, “Racial and Ethnic Differences in Preferences for End-of-Life Treatment,” (2009) 24:6 695 at 697-699.

51. Kimberly S Johnson, Maragatha Kuchibhatla & James A Tulsky, “What Explains Racial Differences in the Use of Advanced Directives and Attitudes Toward Hospice Care?” (2008) 56:10 J of the American Geriatrics Society 1953 at 1956-1957.

category to appeal to various value regimes, especially those in the domain of religion and belief systems.⁵² While most Euro-American or Caucasian societies have waxed secular,⁵³ religion and appeals to spirituality remain strong among non-European immigrants to Canada and elsewhere in the Western world.⁵⁴

So far, values, religion, and beliefs appear to have been peripherally considered only at the site of the contest between care providers and families or SDMs as they negotiate patients' best interests, especially under the CCB framework.⁵⁵ The ubiquity of references to these conflated value categories and considerations through the cases underscores their relevance for incorporation into palliative care plans. From the analysis of CCB decisions, references to values and beliefs feature within the narrow prism of either the SDMs' or the patients' value sets. But a robust palliative care setting provides an opportunity for holistic interpretation of values since its emphasis is on the "whole person."⁵⁶ This is a form of wholeness that considers individuals as embedded in their families and the larger community; the latter is constituted by shared values that have ramifications for individual experiences and applications. In such a case, all stakeholders participate in subjecting religion, value, and beliefs to deliberate rigor, often with the benefit of family or communal memories.⁵⁷ This is in sharp contrast to the present tendency to co-opt an abridged or shallow interpretive outlook on beliefs and values in a linear fashion by only the SDMs under the CCB mechanism.⁵⁸

Values, beliefs, and religions are elements in social institutional frameworks⁵⁹ that assist in palliative care as a collaborative care delivered in community, concert, and dignity between care providers and the family. In a palliative framework, care is delivered in respect and dignity, not only

52. See, for example, H Russell Searight & Jennifer Gafford, "Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians" (2005) 71:3 *American Family Physician* 515.

53. See "The Future of World Religions: Population Growth Projections, 2010–2050," Pew Research Centre, Washington, DC (2 April 2015) at 147-158, online: <http://www.pewforum.org/files/2015/03/PF_15.04.02_ProjectionsFullReport.pdf>.

54. For an overview of empirical data highlighting the religiosity of non-European immigrants, see Teresa Garcia-Munoz & Shoshana Neumann, "Is Religiosity of Immigrants a Bridge or a Buffer in the Process of Integration? A Comparative Study of Europe and the United States" (2012) Institute for the Study of Labor, Discussion Paper No 6384 at 25, online: <www.iza.org/MigrationHandbook/18_Neuman_Munoz_Immigration-Religion.pdf>.

55. See *supra* note 29.

56. *Supra* note 12.

57. Sandra A Lopez, "Honoring Cultural Diversity at the End of Life" (2007) 7:6 *Social Work Today* 36.

58. Chidwick, Sibbald & Hawryluck, *supra* note 12.

59. Patrice Richardson, "Spirituality, religion and palliative care" (2014) 3:3 *Annals of Palliative Medicine* 150 at 151-152.

for the patient but also for members of their family, including SDMs, who are saddled with the imminent loss of their loved ones. All definitions of palliative care recognize dying as a normal process in which the individual, the family, culture, psychosocial factors, belief systems, and notions of bereavement are engaged as incidents of care provision.⁶⁰ All religions and societies accept and internalize the idea of dying as a reality that is better negotiated in dignity and solemnity.⁶¹ It is possible that SDMs' invocation of values and beliefs through the CCB cases do not accurately reflect the potential applications of those considerations in a palliative care setting. The promise of palliative care and its increased potential for Canada's ageing population and increasingly complex multicultural demographic at the end-of-life spectrum has been underexplored or is at best lost in the translation of best interest negotiations through the CCB and the courts. In the wake of *Carter* and ongoing changes in Canada around MAiD, cross-cultural tensions at the intersection of medical futility and palliative care would be magnified, requiring a more uniform and predictable national approach.

Conclusion

The landscape for negotiating the ethical dynamics of end-of-life care in Canada is increasingly busy, and promises to get busier as the practice of MAiD becomes entrenched in Canadian health care service delivery. Ontario's statutory model of tasking a specialist judicial board with adjudicating frequently occurring bickering between care providers and SDMs who refuse to provide consent for withdrawal of life sustaining support in medical futility has attracted national attention. A combination of the continuing increase in Canada's seniors and its multicultural demographic produces notable sites of pressure in the emergent dynamic for end-of-life care. Although not explored in this article, as it is premature, it is conceivable that similar dynamics would manifest in the patronage, applications and experience of MAiD as it gets underway. While Ontario's experience with the CCB appears to have been positively received, it has created a potential for dichotomous outcomes across the country. Ontario's statutory model did not seem to have fully codified the common law of consent that, save for Quebec, applies in the rest of Canada's sub-national jurisdictions but one.⁶² With regard to withdrawal of life-sustaining devices,

60. See WHO, *supra* note 41.

61. See, generally, Christina M Puchalski & Edward O'Donnell, "Religious and spiritual beliefs in end of life care: how major religions view death and dying" (2005) 9:3 *Techniques in Regional Anesthesia & Pain Management* 114.

62. I.e., Yukon. See *supra* note 14.

it imposes a higher treatment or care standard and creates a situation where an SDM's preference could override the provider's professional and ethical assessment of a patient's clinical reality.

A critical examination of the contestations over patients' best interests through the CCB decisions reveals a strong reference to ethnicity, beliefs, values, and religion as crucial determinative factors. However, those considerations are not robustly elaborated within the narrow prism of the CCB process. It would seem that compared with the dominant segment of society, ethnic or visible minorities in Canada are more likely to appeal to the confluence of those factors in negotiating the patient's best interest. As more and more members of the Canadian visible minorities engage the health-care system at the end of life, their reliance on diverse value elements for negotiating the patient's best interest would take on greater intensity especially within the palliative care framework.

With the historic rise in life expectancy in Canada and indeed globally, palliative care will assume unprecedented relevance to a large number of the population. So far, it has been lost in translation in the legal battles both at the courts and Ontario's CCB. As Canada switches to a regime of MAiD, the latter's impacts on the palliative care landscape is an exciting subject for further exploration. Meanwhile, a robust palliative care framework for an ageing and increasingly multicultural Canadian society is urgently required to de-escalate the demographic pressures that threaten the quality of Canada's publicly funded care system. When applied in balance, palliative care not only reduces the cost of care, it addresses gaps in access and distributive justice while also ensuring collaboratively and communally delivered quality care in dignity, respect and in the patient's, family's and society's shared best interests. Such expectation and outcome, though possible, may not necessarily be assumed for MAiD.

