INTEGRATING RELIGIOUS AND CULTURAL SUPPORTS INTO QUALITY CARE IN THE LAST STAGES OF LIFE IN ONTARIO

Improving the Last Stages of Life

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ABSTRACT

The last stages of life – and particularly end-of-life care, palliative care, and medical assistance in dying – have emerged as key health care issues of importance to a broad and growing diversity of multicultural Canadians. This paper presents a snapshot of how faith and cultural supports are an essential aspect of quality care in the last stages of life in Ontario. The paper begins by defining key terms and distinctions in the "last stages of life" and as between various beliefs and practices. The paper then overviews key legislative and professional regulatory frameworks, as well as various best practice models and existing community-based programs. The authors then present qualitative findings based on interviews with 17 faith leaders and health practitioners from the Greater Toronto Area and Southwestern Ontario. This is additionally supplemented by research conducted into the palliative and pastoral services available to patients at 19 of the busiest hospitals in Ontario (as identified by data obtained from Canadian Institute for Health Information). The paper concludes with recommendations to enhance the quality of care for a diverse, multicultural population contending with the last stages of life.

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I. INTRODUCTION AND SUMMARY OF FINDINGS

The last stages of life – and particularly end-of-life care, palliative care, and medical assistance in dying – have emerged as key health care issues of importance to a broad and growing diversity of multicultural Canadians.[1] This paper presents a snapshot of how faith and cultural supports are an essential aspect of quality care in the last stages of life in Ontario, before concluding with recommendations to improve the availability and provision of such care.

There is a growing need and urgency for health practitioners and faith leaders alike to adopt effective models of providing such services. A rapidly aging baby boomer generation has triggered a significant demographic shift[2] that carries with it a series of social impacts, economic pressures, and political challenges. Publicly-funded health care services are not insulated from these emerging demands.[3] New legislation and targeted investments in health care are expanding services and options in the last stages of life.[4] One practical consequence of this is that more health professionals and institutions are contending with the legal requirements and value judgments characteristic of faith and cultural beliefs.

The last stages of life are among the times when faith and cultural values play the greatest role in an individual's life, and in the life of their community. And indeed, faith and cultural supports are a widely-accepted element of culturally-competent care for persons in the last stages of life. This exists simultaneously as a legal requirement, a moral imperative, and as a medical consideration: the failure of health care providers to acknowledge, understand, and manage sociocultural variations in the health beliefs and behaviors of their patients may impede effective communication, affect trust, and lead to patient dissatisfaction, nonadherence, and poorer health outcomes, particularly among minority populations.[5] Specific beliefs and practices may also influence decision-making about personal care; the suitability of life-sustaining treatments; the desire to seek medical assistance in dying; the availability of services related to medical assistance in dying; the management of pain and the provision of nourishment; as well as personal feelings of comfort, spiritual wellness and overall well-being. It is vital that health care providers approach care in a manner that is aware, respectful, and inclusive of these underlying beliefs, and of the way such beliefs shape patient needs, preferences, and choices.

One of the central challenges in achieving this standard is the considerable variability and extent to which faith and cultural needs are met across different settings, as well as the distinguishing characteristics and practices of the different faiths and cultures themselves. Canada is a diverse, multi-religious country that aspires to recognize a broad and inclusive definition for religious, cultural and spiritual practices. For the provision of health care in the last stages of life, formulating a modern, unified approach to issues of faith and culture requires the perspectives of a broad array of faith-based community and cultural leaders.

This paper therefore adopts an independent, qualitative research methodology to explore current practices across Ontario in the provision of cultural and faith-based supports in relation to care in the last stages of life. This proceeds in five parts. The paper begins by defining key terms in the "last stages of life" and delineating between related and intersecting concepts including "faith", "spirituality", "ethnic origin", "palliative care", and "informed consent", among others (Part II). The paper goes on to provide an overview of how faith and culture intersect with the provision of health care, distinguishing the beliefs and practices of various major faith groups (Part III). The next section outlines key legislative and professional regulatory frameworks, as well as various best practice models and existing hospital and community-based programs. This includes research conducted and data obtained that details the palliative and pastoral services available to patients at 19 of the busiest hospitals in Ontario (as identified by data obtained from Canadian Institute for Health Information) (Part IV, and Appendix C). The authors then present qualitative findings based on interviews with 17 faith leaders and health practitioners from the Greater Toronto Area and Southwestern Ontario (Part V, and interview questions at Appendix D). The paper concludes with recommendations to enhance the quality of care for a diverse, multicultural population contending with the last stages of life (Part VI).

One primary finding of this study provides a broad-based understanding of care during the last stages of life in Ontario and the choices available to patients from diverse backgrounds. It is our hope that a thorough examination of the choices available to patients from diverse backgrounds, as well as an in-depth understanding of the ethno-cultural values informing their choices, will assist palliative and primary care teams in providing more culturally-competent care.

A second recurring theme identified by this paper is how faith and cultural beliefs shapes how Ontarians choose and direct their care in the last stages of life. These same beliefs may diverge from expected medical interventions and standards of care, imposing an apparent – and potentially antagonistic – barrier between patient and health practitioner. This is particularly true given the historical emphasis on the provision of acute- and critical-care treatment within hospital settings. Even today, some 41% of deaths in Ontario took place at one of 155 public, private or specialty psychiatric hospitals, rather than in long-term care, a hospice, or at home.6 This also applies to patients with more protracted illnesses, like cancer, who represent the majority of palliative care patients.[7] According to a 2011-2012 study, approximately 39% of cancer patients in Ontario died in acute-care hospitals.[8] This is markedly higher than in other countries such as the Netherlands (31%) or the United States (29%).[9] The significant proportion of patients dying in hospitals speaks to the practical necessity of making faith and cultural services accessible in both traditional community settings and within major health care institutions.

A third theme of the paper elucidates the legal perspective. Legal rights supporting the observation and accommodation of faith and spiritual practices in health care settings are grounded in a diversity of sources, from the *Canadian Charter of Rights and Freedoms*[10] to Ontario's *Human Rights Code*[11] and a variety of professional practice directives. Awareness of these obligations is often a first and significant step for health providers to support patients – and their families and wider communities – to live their rights and to help resolve disputes where opinions diverge. As a society, the broader aim is to provide palliative care patients with the information and choices that best serve them, which can be achieved through a comprehensive understanding of the options available for end-of-life care. With the assistance of religious and cultural institutions, physicians and caregivers in Ontario can provide culturally-competent care that respects the values of diverse patients and aids in enhancing care and comfort during the last stages of life. This paper seeks to provide clarity on those values within the context of health care law in Canada.

Out of these themes, the paper proposes the following recommendations to better incorporate faith and spiritual belief as culturally competent practices in the last stages of life in Ontario. These include:

1) Increasing awareness and clarity among health practitioners about patient rights to access and practice religious and cultural beliefs under the *Charter of Rights*, Ontario's *Human Rights Code*, and various professional practice directives

2) Increasing awareness and clarity among adherents to a faith or cultural group about variations within their system of beliefs and practices. Attention to faith and cultural differences should be individualized to each person, and one must not assume that a patient belongs to a cultural monolith.

3) The need for greater uniformity among palliative care services across the province to better normalize access to, and accommodation of, various faith and cultural practices, and thus achieve a more holistic model of patient-centered care for all

4) The need for greater access to culturally-competent health care throughout health care institutions in Ontario. This would ensure a commitment from health care providers and caregivers to better understand patient needs.

5) The integration of faith and cultural preferences into the formal education curricula of health care teaching institutions. A graduating doctor or nurse should have a basic idea of the nature of various religions and their general requirements, preferences and practices.

6) Institutions should provide a variety of tools and resources for health practitioners to apply in their patient care, including readily accessible online reference materials.

7) As some institutions in very multi-religious regions of the province have done, create a better network of multi-faith and cultural leaders so hospitals, LHINs, and individual practitioners can work closely and get support from faith leaders when needed.

8) Institutions should implement a structured approach to documenting the spiritual, cultural, and religious values and preferences of their patients and their families, as some institutions have done with the Chielo process.

9) Pastoral Care Education programs need to formally invite faith leaders and lay followers to join, and "chaplaincy" programs should evolve

from what were once specific (Judeo-Christian) faith-based supports to multi-faith spiritual support services.

10) Legislation governing the Consent and Capacity Board needs to be reformed to give medical expertise on the prevailing standard of acceptable and appropriate care a weight equivalent to that given to a patient's final wishes. There should also be greater clarity around the patient's right to refuse medical treatment. Furthermore, for patients who involve faith or community leaders in their care, the legal parameters of these leaders' involvement at the end-of-life should be elucidated. This is especially important with respect to the issue of informed consent where faith leaders counsel patients on the compatibility of medical treatment options with cultural and faith traditions.

11) Health care institutions should provide essential supportive resources like private prayer rooms for faith- and spiritual-based end-of-life practices. Public hospitals and community-based palliative care hospitals should also assist patients with accessing private prayer rooms. If a patient cannot physically access a prayer room, hospitals should provide palliative care patients with assistance in scheduling on-site hospital visit with community and faith leaders.

II. KEY TERMS AND CONCEPTS

Prevalent in the discussion of end-of-life care are a number of concepts and terms that may have different and deeply personal meanings to each individual. A brief explanation of key concepts and terms is provided below.

A. Last Stages of Life, Palliative Care, and End-of-Life Care

The Law Commission of Ontario's (LCO) project, *Improving the Last Stages of Life*, considers the role of the law in fostering quality of life for persons who are dying and those who support them. Their goal is to recommend law reforms that are concrete, precise, and responsive to the experience of Ontarians in the last stages of life.[12]

The "last stages of life" is the broad and inclusive term used by the LCO to capture this experience of dying as a process or a continuum of events, whether as a result of terminal illness, chronic conditions or serious frailties that could progress until the end

of life. Some such persons may have little time left to live, while others may transition through the dying process for an extended period of years. The LCO's definition of "last stages of life" is unique. Their objective in selecting this term is to distinguish the experience of *persons who are dying* – as a particular stage in life – from established models of care that may be beneficial during the dying process, most notably palliative and end-of-life care.[13]

This broad and inclusive term contrasts with the specificity of "palliative care" and "end-of-life care." The World Health Organization provides the following definition of palliative care:

> Palliative care is a care regimen that aims to improve the quality of life of patients and their families facing the problem 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.[14]

Palliative care has a number of elements and individual patient care may encompass all or only a select number of the following:

- relief from pain and other distressing symptoms;
- affirmation of life and the regard of dying as a normal process;
- neither hastening nor postponing death;
- integration of the psychological and spiritual aspects of patient care;
- provision of a support system to help patients live as actively as possible until death;
- provision of a support system to help the family cope during the patient's illness and in their own bereavement;
- a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- possibly used in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and including those investigations needed to better understand and manage distressing clinical complications.[15]

This distinguishes "palliative care" from "end-of-life care." End-of-life care refers to care provided to persons whose death is likely imminent.[16] Persons at the end of life are typically in the advanced stages of a life-limiting condition, are in their last weeks or days of life and may require intensive services. The terms "end-of-life care" and "palliative care" are often used synonymously in the literature; however, they are

distinguishable. End-of-life care is only one aspect of palliative care. Palliative care is a philosophy of care and it encompasses a broader range of treatments and accompaniments throughout the dying process.[17]

For the purposes of this paper, the authors will rely on the "last stages of life" as the umbrella term inclusive of the experiences of persons who are dying, distinguishing "palliative" and "end-of-life" care where relevant to the discussion.

B. Faith and Creed

The Oxford English Dictionary provides a simple definition of faith as either: a) the strong belief in God or the doctrines of a religion, based on spiritual apprehension rather than proof, or b) a system of religious belief, as in the "Christian Faith."[18] For the purposes of this paper, the authors invoke "faith" as encompassing both aspects of this definition.

This inclusive definition of "faith" is additionally read to incorporate the concept of "creed" as defined by the Ontario Human Rights Commission (OHRC). Creed is not defined in *Ontario's Human Rights Code*, but the Commission provides some guidance based on the jurisprudence of various courts and tribunals, considering creed to include "religious beliefs and practices," as well as "non-religious belief systems that, like religion, substantially influence a person's identity, worldview and way of life."[19] The OHRC has further identified several relevant characteristics in determining "creed," namely that it:

- Is sincerely, freely and deeply held
- Is integrally linked to a person's identity, self-definition and fulfilment
- Is a particular and comprehensive, overarching system of belief that governs one's conduct and practices
- Addresses ultimate questions of human existence, including ideas about life, purpose, death, and the existence or non-existence of a Creator and/or a higher or different order of existence
- Has some "nexus" or connection to an organization or community that professes a shared system of belief.[20]

(For an extended legal analysis of Ontario's *Human Rights Code,* see Part IV.B.)

This more expansive definition of "faith" with "creed" offers the benefit of including Aboriginal and Indigenous belief systems which may not comfortably fit within narrower

definitions of "faith," as well as other belief systems, and even the lack of a system of belief.

C. Spirituality

Spirituality can be a more complex term to define than faith / religion as it goes beyond established organizations or recognized communities of belief. Contemporary definitions tend to treat spirituality as more personal and something people define for themselves "largely free of the rules, regulations, and responsibilities associated with religion."[21] Spirituality was not historically distinguished from religiousness until the rise of secularism in the 20th century. As attitudes toward organized religion change,[22] a growing number of people categorize themselves as spiritual but not necessarily religious or connected to an organized religion. For this group, spirituality has been individualized and secularized, and is "entirely different from its original meaning."[23]

D. Culture

Culture is understood differently in various academic disciplines.[24] It is a fluid and nebulous concept which can overlap with and include notions of religion, spirituality, and creed. In pluralistic societies like Canada, many cultures can co-exist. Cultures across the globe have different practices regarding the last stages of life, and this can play an important role in providing appropriate care. When dealing with peoples' practices and preferences, the following definition of culture may be useful:

> A way of life common to a group of people, including a collection of beliefs and attitudes, shared understandings, and patterns of behavior that allow those people to live together in relative harmony, but that set them apart from other peoples. […]These practices also produce behavior that falls within a range of variation the members consider proper and acceptable.[25]

Although this definition is not comprehensive, it helps illustrate how beliefs, attitudes, and behaviour may be used in care decisions.

E. Culturally-Competent Health care

Culturally-competent health care has a broad range of definitions. According to the Registered Nurses Association of Ontario, cultural competence "ranges on a continuum from eliminating the negative end of destructiveness (racism and abuse) to a positive end, where cultural diversity is valued and has the potential to create innovative,

transformative opportunities that maximize health, economic and social benefits."[26] More specifically, this may involve an understanding of the different ways a culture can influence patient behaviour in a clinical setting, so that proper communication can take place and excellent clinical outcomes are achieved.[27] Cultural competence requires a commitment from health care providers to "understand and be responsive to the different attitudes, values, verbal cues, and body language that people look for in a doctor's office by virtue of their heritage".[28] This does not mean that health care providers must speak the same language as their patients or share the same cultural heritage. Rather, culturally-competent care requires that the "underlying values of inclusivity, respect, valuing differences, equity and commitment" should govern all interactions, policies, and practices in a health care setting.[29] As these values are also Canadian values, in essence, culturally-competent care is a unifying model.

F. Ethnicity

"Ethnicity" is another flexible term often used to describe a nexus of traits intersecting around race, culture, and nationality. The OHRC considers the term to refer to shared cultural history or nationality, and notes that it often overlaps with "ethnic origin," a prohibited ground of discrimination in the *Code*.[30] The *Code* considers "ethnic origin" to encompass a wide range of characteristics, including ancestry, and that one ethnic group might be distinguished on the basis of cultural traits such as language or shared customs around family, food, dance, and music.[31]

G. Race and Racialization

Race is a social, not a scientific, construct. The phenomenon of racism persists on the basis of misguided beliefs that perceive physical characteristics as determining a person's views, activities and worth, and which are used as a basis for discrimination. The most obvious physical characteristic is skin colour. However, the OHRC has also identified a number of related areas that may contribute to the racialization of a person or group of people: language, accent or manner of speech, name, clothing and grooming, diet, beliefs and practices, leisure preferences, places of origin, and citizenship.[32]

The social process racialization is defined as the "process by which societies construct races as real, different and unequal in ways that matter to economic, political and social life."[33] The OHRC outlines how, in addition to physical characteristics such as skin colour

that may distinguish a person with respect to their race, other characteristics are also "racialized." These include:

- language
- accent or manner of speech
- name
- clothing and grooming
- diet
- beliefs and practices
- leisure preferences
- places of origin
- citizenship [34]

All of these grounds are to be considered when a human rights complaint with regards to racial discrimination is made.

Where race is referred to in this paper, it is either in the context of informant interviews or in the context of how certain sections of Ontario's population may be racialized by health practitioners and other Ontarians.

H. Indigenous Peoples and Spirituality

Indigenous peoples in Ontario include a wide range of diverse groups that make any generalizations about "Indigenous Spirituality" a challenge.

The United Nations *Declaration on the Rights of Indigenous Peoples* does not define "Indigenous" but states that "Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions."[35] The OHRC defines "Indigenous" as including status, non-status, Indian, Aboriginal, Native, First Nation, Métis and Inuit.[36]

Recognizing this diversity of practices, the OHRC declines to define "Indigenous Spirituality" due to its "diversity and Indigenous peoples' right to define and determine this for themselves."[37] Nevertheless, while the OHRC observes that Indigenous Spirituality "can vary significantly among different First Nation, Métis and Inuit groups and individuals, and across different regions,"[38] there are some commonalities. Generally speaking, Indigenous Spirituality is understood as a "way of life" (or

worldview) centered on a relationship with the Creator, the land and "other beings and forms of life."[39]

Importantly, there is a statutory basis to recognizing Indigenous Spirituality. In May 2016, the Government of Canada formally adopted the UN *Declaration on the Rights of Indigenous Peoples.*[40] Additionally, Ontario's Human Rights Code creates a duty to accommodate indigenous beliefs and practices.[41] (See also the discussion below in Part IV.A – B).

When discussing "Indigenous Spirituality," this paper will refer to the spiritual beliefs and practices that Indigenous peoples identify as being "traditional" or "customary," including more recently developed practices and syncretic innovations.[42] This is not meant to exclude any aspect of Indigenous Spirituality that Indigenous individuals choose to adopt.

I. Informed Consent and Substitute Decision-Making

Medical decision-making in the last stages of life can raise challenges for patients, their caregivers, and substitute decision-makers (and family members) alike. Several pieces of legislation define this consent and capacity regime in Ontario.

The *Health care Consent Act* (HCCA) is the leading legislation.[43] It sets out explicit requirements for obtaining consent and a tribunal-based adjudicative mechanism where disagreements arise. Under the HCCA, a health practitioner may not commence treatment unless the patient or their substitute decision-maker (SDM) has provided informed consent.[44] This consent may be given orally, in writing or "may be express or implied" depending on the clinical circumstances.[45] The elements of valid consent are:

1. The consent must relate to the treatment.
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud.[46]

The HCCA codifies the common law test that informed consent requires disclosure of matters that a reasonable person would require in order to make a decision on treatment.[47] It further specifies these "matters" as including:

1. The nature of the treatment.

2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.[48]

Capacity with respect to treatment is present if the person is able to understand the information that is relevant to making a decision about the treatment, and is able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.[49] This does not apply if the health practitioner is of the opinion that there is an emergency, defined as a patient experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm.[50]

Other legislation provides a complimentary framework for determining the capacity and requirement to consent to personal assistive services and admission to long-term care in Ontario. Under the *Ontario Long-Term Care Homes Act, 2007* (LTCHA), a long-term care resident has the "right to have his or her participation in decision-making respected."[51] Personal assistive services fall under the purview of the patient's "right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs."[52] Having said this, a long-term care patient may refuse treatment or care as he or she has the right to "participate fully in the development, implementation, review and revision of his or her plan of care,"[53] and also to "give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent."[54]

A clinician's determination of incapacity to consent to treatment can be challenged by the patient by appealing to the Consent and Capacity Board (CCB), an adjudicative tribunal created to rule on such disagreements.[55] CCB panelists may include health care practitioners, lawyers, and members of the general public.[56] The CCB may confirm the health practitioner's finding or may determine that the person is capable with respect to the treatment, and in doing so may substitute its opinion for that of the health practitioner.[57]

Conflicts may arise when SDMs make decisions on an incapable person's behalf. If a SDM wishes to refuse consent to treatment, he or she must do so in a way that is consistent with prior capable wishes expressed while the patient was capable. If the SDM is unaware of any such wishes from the person, then he or she must consider the incapable person's best interests.58 These considerations must take into account:

- the values and beliefs that the incapable person held when capable and that the SDM believes he or she would still act on if capable;
- whether the treatment is likely to improve the incapable person's condition or well-being, prevent his or her condition or well-being from deteriorating, or reduce the extent to which, or the rate at which, his or her condition or well-being is likely to deteriorate;
- whether the incapable person's condition or well-being is likely to improve, remain the same, or deteriorate without the treatment;
- whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her;
- whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.[59]

Conflict may also arise when a SDM and a patient's medical team disagree on a course of treatment or plan of care. In Ontario, the CCB adjudicates intractable conflicts with families. Health care providers may apply to the CCB to determine a SDM's compliance with the rules of substitute decision-making (a so-called "Form G" application).[60] Criteria used to adjudicate the issue are primarily the established prior wishes of the patients, and if this is unknown, then the best interests of the patient.[61]

Under the HCCA, a physician must first formulate a "treatment plan" based on a patient's diagnosis and then obtain "consent or refusal of consent in accordance with the [HCCA]."[62] In cases where a patient lacks or is alleged to lack capacity, two types of disagreement can occur once a treatment plan is proposed to a SDM. In the first case, the SDM may refuse treatment. In that case, the physician may feel that this decision is not in the best interest of the patient or does not reflect their previous wishes, and appeal to the CCB. In the second case, the SDM may disagree with the treatment plan and demand an alternate plan from the responsible medical professionals.

The case of *Friedberg v. Korn* illustrates some of the conflicts that can occur in the setting of conflicts with families with respect to end-of-life care and traditional Jewish values.[63] The patient was in a vegetative state and had previously granted her SDM power of attorney to remove life support if she ended up in such a state. The attending physician applied to the CCB to determine if her patient had expressed prior capable

wishes about her care at the time she signed a power of attorney for personal care, which stated the following:

> I hereby instruct that if there is no reasonable expectation of my recovery from physical or mental disability, I be allowed to die and not be kept alive by artificial or heroic measures. I do, however, instruct that medication be mercifully administered to me to alleviate suffering even though this may shorten my remaining life.[64]

The *Substitute Decisions Act* (SDA) allows for a power of attorney to be valid if the grantor is capable it at the time of execution, even if the grantor is incapable of personal care at the time.[65] The patient's children challenged the power of attorney on the basis that it did not reconcile with her religious beliefs. At the hearing, two rabbis presented conflicting perspectives on the matter. The patient's rabbi claimed that the patient's adherence to Orthodox Judaism meant that she followed more traditional values, which claimed that it was not up to the individual to decide if the quality of one's life is worth living – it was only up to God. Although the rabbi testified that there was no obligation to prolong life in Orthodox Judaism, he stated there was nothing undignified about the patient's condition. The act of removing life support in this context was equivalent to the act of murder. The rabbi even questioned the patient's mental state for failing to adhere to Judaism while writing her power of attorney, as she was a practicing Orthodox Jew.

Notably, the patient did not consult her rabbi while preparing this power of attorney. Despite this, the CCB still found in favour of the patient's power of attorney, which was written in clear, unequivocal language, and requested to end her life if she had to be kept alive by artificial means. The CCB decided autonomy and choice of the individual, irrespective of how these decisions might be perceived in retrospect in the context of religious beliefs, should be upheld.

On review by the Superior Court of Justice, however, the power of attorney was overturned. The Court reviewed a number of factors, including the patient's religious values. The patient's beliefs, which infused every aspect of her life, raised serious doubts about whether she understood the contents of the power of attorney.[66] Combined with other extrinsic factors, such as inconsistencies in the power of attorney itself, and the patient's language difficulties, the court found that the CCB had made an error in law.[67]

III. FAITH, CULTURAL PRACTICES AND CARE IN THE LAST STAGES OF LIFE

A. General Intersections between Faith, Culture and Care

A patient's identified practices and beliefs relating to culture and faith can create several different kinds of challenges when such norms differ from those of a health practitioner, particularly around the last stages of life in general and end-of-life care in particular.[68]

To begin with, the relationship between religion and modern health care can be a source of concern as "religious beliefs and practices are commonly criticized for their potential negative effects on health and well-being".[69] Yet at the same time people call upon "religious resources" as among the methods they utilize to cope with life stress and illness. Patients who regularly attend religious services indicate (in particularly high percentages) that their caregivers should discuss spiritual aspects of their illness.[70] There is recognition of the importance of spirituality and religion as a significant influence on human health and behavior.[71]

In part this is directly related to the fact that patient attitudes toward end-of-life care may be influenced by religious or spiritual concerns. For improved physician-patient communication it is necessary for health care providers to clarify a patient's religious affiliations, spirituality, tradition and culture as these desires may affect treatments and outcomes.[72] Religious and cultural groups are not monolithic; patients can bring "to the medical encounter different languages, explanatory models concerning the cause and treatment of illness, religious beliefs, and ways of understanding the experience of suffering and dying."[73] Many issues arise due to differences in language and the style of communication of both the patient and the physician. Communication barriers can cause a bidirectional misunderstanding and create "unnecessary physical, emotional, and spiritual suffering".[74]

Friction may also arise where the patient and health practitioner have different understandings of the physician's role in the process.[75] Religion and spirituality can cause a lack of faith in the physician, which in turn may cause a lack of adherence to the treatment regime.[76] Some cultures believe that "knowing the truth is harmful to the patient, [and so] a physician who persists in telling them the direct "truth" may be perceived as cruel, uncaring, and ignorant."[77] Such "truth-telling" can therefore actually

engender mistrust between health provider and patient, and even contribute to the patient's withdrawal from medical care altogether.[78] This can also create a sense of hopelessness in the patient if they misunderstand the physician's reason for telling them the news directly, rather than going through the family.[79] While patients and families may judge the propriety of a health care provider's actions harshly in the context of faith or cultural expectations, heath care providers are nevertheless governed by requirements to elicit a patient's informed consent.[80]

Further barriers between Indigenous patients and health practitioners may exist due to the traumatic, multi-generational experience of the residential school system. It is imperative that the health care practitioners be aware of these underlying feelings, as interaction with the patient may be deeply influenced by this history. Non-Indigenous health care providers with little knowledge of this damaging history may come to believe common stereotypes about Indigenous patients or their family members.[81]

Another key issue concerns differing beliefs about the role of the family in decision making. In some cultures, the family is heavily involved in decision-making; disagreements and conflict can arise with health providers, particularly when family members try to override the decisions of a capable patient, or go against the previously-stated wishes of a patient.[82] A lack of of collaboration with the patient and their family can create dissatisfaction with care by all parties involved.[83]

Patients and family members may also believe that there is inequality in the provided care. Experiences of societal discrimination based on faith or cultural identity may lead individuals to lose belief in the equity of medical care.[84] A failure to understand these perceptions of inequity rooted in faith and cultural identity can cause a loss of trust between a patient and their caregiver, causing an "increased desire for futile aggressive care at the end of life."[85]

Emergency and life sustaining treatment can also raise friction between the provision of medical care and personal faith and cultural beliefs. Religious patients or families may insist on life-prolonging measures perhaps even against physicians' advice, and religious coping has been associated with increased preference for cardiopulmonary resuscitation, mechanical ventilation, and hospitalization near death.[86] These beliefs can include belief in miracles and seeking guidance from God. In one trauma-related study, more than half of the respondents believed that God could heal a critically-injured patient even when the physician stated that the situation was medically futile. Religious

adherents may similarly choose particularly aggressive or interventionist therapies because they believe that God could use the therapy to provide divine healing, or they hope for a miraculous cure while intensive medical care prolongs life.[87] Some religious patients with cancer were less likely to understand the definition of a "do-not-resuscitate order" and were more likely to think it was morally wrong.[88] They were also less likely to have a living will and more likely to desire life-sustaining measures.[89]

In light of these considerations, it is unsurprising that research conducted in the US suggests that training in cultural competency "continues to be an identified need for hospice nurses, social workers, family practice physicians, psychiatrists and other health care providers."[90]

B. Specific Faith and Cultural Practices in End-of-Life Care

Bülow's study of the views of the world's major religions on questions of end-of-life care notes five major areas where religious beliefs intersect with critical questions concerning end-of-life care.[91] These include: the permissibility withholding a life-sustaining treatment; withdrawing a life-sustaining treatment; withdrawing artificial nutrition; administering a treatment that may result in unintentionally shortening life while alleviating patient suffering (the so-called "double effect"); and the permissibility of euthanasia.[92] Table 1 below summarizes different religion's views on end-of-life practices.

Table 1: Different Religion's Views on End of Life Practices:[93]

	Withhold	Withdraw	Withdraw Artificial Nutrition	Double Effect	Euthanasia
Catholics	Yes	Yes	No	Yes	No
Protestants	Yes	Yes	Yes	Yes	Some
Greek Orthodox	No	No	No	No	No
Muslims	Yes	Yes	No	Yes	No

Jewish Orthodox	Yes	No	No	Yes	No
Buddhism	Yes	Yes	Yes	Yes	No
Hinduism	Yes	Yes	N/A	N/A	Some
Sikhism	Yes	Yes	N/A	N/A	Some

The following is a brief and general overview of the approaches of major religious groups present in Ontario to end-of-life. These descriptions are intended as guidance only, as a few short paragraphs cannot capture the sheer variety of religious belief and experience.

1. Christianity

There is no one doctrine or set of beliefs and practices concerning end-of-life and death given the variety of groups that identify as Christian. The sections below outline the views of a selection of major sects of Christianity.

2. Catholicism

Based on the Church's official published positions, the withholding or withdrawal of therapy which may impose disproportionate discomfort is permitted. The Church is less comfortable with withdrawal of nutritional support of patients in a persistent vegetative state. Pain alleviation, even if it has the unintended side-effect of shortening life, is also permitted. Bülow considers this an acceptance of the "double effect" of certain treatments.[94]

The specific rites and beliefs of Catholics concerning death may be summarized as follows:

- Prayers and communion as requested by patient and/or family.
- The Sacrament of the Anointing of the Sick if requested.
- Extreme (meaning final) unction may also be performed.
- These rites must be conducted by a priest.
- After death, the body is to be treated with respect.

- Autopsies are permitted for legal inquests or scientific research.[95]

3. Protestantism

Protestantism is largely consistent with Catholicism on the issue of withdrawal of treatment that imposes hardship on the patient. However, the various Protestant sects differ in their attitude toward euthanasia. Bülow summarizes these views as follows:

> Most Protestants are comfortable with the present wide array of life-sustaining therapies, but if there is little hope of recovery, most will understand and accept the withholding or withdrawal of therapy. One example of the diversity within Protestantism is the question of euthanasia. The Evangelical Lutheran church in Germany has developed advance directives for end-of-life choices but rejects active euthanasia, whereas theologians in the reformed tradition, e.g. in the Netherlands, defend active euthanasia.[96]

There are no universal practices in terms of burial versus cremation. Many leave this choice to the deceased or their family. For example, Anglicans have quite a structured death ritual involving the administering of the sacrament of unction near death. Funerals are performed in a Church. These services may be led by ordained or laypersons. Burial or cremation is permitted. In comparison, Baptists have very few set rituals outside the common belief in Jesus Christ and his promise of eternal life to believers.[97]

4. Greek Orthodoxy

The Greek Orthodox Church does not have a defined position on end-of-life care, but condemns every act that does not prolong life.[98] Both Greek Orthodox and Catholic Churches have explicit prohibitions against "active euthanasia." The death rites and beliefs of the Orthodox Church are oriented toward the belief in eternal life. The coffin of the deceased is returned to their home so that they may make a final visit. The deceased is buried; cremation is forbidden as the body must return to the earth in order to rise again for final judgment.[99]

5. Judaism

There are three Jewish denominations of note: Reform, Conservative and Orthodox. All share the belief that food and fluids are regarded as basic needs and not treatment. Withholding these is considered euthanasia.[100] A patient deemed competent but refuses treatment, including food and fluid, is to be encouraged — but not forced — to change

their mind. This is more flexibly applied when food or fluids may cause suffering or complications.[101] To touch a person who is dying may, among some branches of Judaism, be considered an act to precipitate death, and hence a sin.[102]

As with Christian sects, there is an acceptance of the double effect,[103] that is, palliative care provided to the patient that may inadvertently hasten death. The acceptance of both withdrawal of useless treatment and the application of palliation, with its inadvertent side effects, recognizes that no matter what medical interventions take place, there is ultimately a time to die.[104]

Specific Jewish rites in and around the time of death include:

- The body must not be left unattended from death until burial.
- The burial should take place as soon as possible, preferably within 24 hours after the death or as soon as the family can be gathered.
- Jews are opposed to most autopsies.
- The body must be buried not cremated.
- Amputated limbs must be buried, not destroyed.[105]

6. Islam

In Islam, the philosophical intent of treatment is to prevent premature death, but not at any cost. Withholding treatment is only acceptable when it will in no way improve the patient's situation. It can never be done to hasten death, but only to prevent what Bülow calls "overzealous treatment."[106]

The issue of euthanasia is seen as a violation of Allah's will relating to matters of life and death. As such, assisted dying falls outside the scope of acceptable end-of-life practices for Muslims.

Some of the following practices may be considered important rites around death and dying. Before death:

- The patient must confess sins and beg forgiveness.
- He or she should recite (with the help of others) the Islamic Creed or Shahadah – "the first pillar of Islam."

- A Muslim near the dying person should recite some chapters from the Quran, especially *Surah Ya-seen*, and ask God for Mercy and Forgiveness for the dying person.
- Privacy and same-gender care for girls and women is required, if possible.[107]

After death:

- The individual's eyes should be gently shut, his or her mouth closed with a bandage running under the chin and tied over the head, and his or her arms and legs straightened.
- The family washes and prepares the body, then turns it to face Mecca.
- Only relatives or friends may touch the body, and unless required by law, there should be no post-mortem; the body should be disturbed as little as possible.
- The surrounding people can grieve and shed tears but are forbidden to wail, beat the breast, slap the face, tear their hair or garments, or complain.[108]

7. *Hinduism*

Hindus believe that the spirit of the person who dies remains for several days until religious ceremonies are performed. Hindus prefer to die at home, as close to mother earth as possible (usually on the floor or the ground). The *Gita* is recited to strengthen the dying person's mind and provide comfort so that he or she may begin the final journey.[109]

Married women's nuptial threads or amulets on the neck or arms indicating special blessings should not be removed until after death. Then, anything that binds the body (such as a belt or ring) is removed, paving the way for the soul's free journey to infinity.[110]

The following rituals and traditions are observed in the Hindu faith:

- No one should have any attachment to the dead body.
- The family washes the body.
- The oldest son arranges for the funeral and cremation before daybreak.
- Embalming or beautifying the body with artificial decorations is strictly forbidden.

- The body must be attended until cremation.
- The name of Rama is chanted, or the *Gita* is read continuously in the presence of the body.
- A post-mortem of the body is not favoured.
- Cremation takes place on the day of death.
- The ashes are usually scattered over holy waters.[111]

8. *Sikhism*

Sikhs believe in the rebirth of the spirit into new lives until the spirit achieves final salvation. The specific death rites of Sikhs generally conform to the following practices:

- The body is bathed, dressed and cremated.
- In case of a father's death, the oldest son must be present at the cremation and is subsequently recognized as the new head of the household.
- The floor is washed and covered with white sheets; people take their shoes off outside the room.
- A brief service for relatives is held with hymn singing.
- Lamenting is not in order, but members give thanks to God for the deceased's life.
- Afterward, a service is held at the home or temple, with continuous reading from the Guru Granth Sahib. This lasts approximately 48 hours. [112]

In addition to these practices, Bülow highlights how both Hinduism and Sikhism are guided by a duty-based approach to ethical health care decision-making, rather than a strictly rights-based approach. Bülow explains that the shared belief in karma drives the desire for a "good death" as opposed to a "bad death", to thus ensure a good rebirth rather than a bad one:

> The way you die is important. A good death is signified by old age, having said one's goodbyes and all duties having been settled. Bad death is violent, premature, in the wrong place (not at home or at the river Ganges) and signified by vomit, faeces, urine and an unpleasant expression. Death in an ICU seems to be fall into the category of a bad death. [113]

Bülow goes on to explain how these beliefs intersect with some rather practical matters: a "do-not-resuscitate order" is generally seen as a way to achieve a peaceful (good) death free of mechanically sustained life (bad); organ transplantation is generally well

received; and euthanasia is strictly tied to the hastening of a "good death" rather than experiencing a "bad death."

9. Buddhism

The two main Buddhist sects (Theravada and Mahayana) have very similar beliefs around death and dying. Life is seen as a journey and death is not a final end, but merely one of a series of births and rebirths that allows the practitioner the opportunity to transition to a higher level of existence. Buddhists are encouraged to contemplate death and to recognize it throughout their lives as something inherent to existence and as a constant companion through life. Buddhists are taught three death awareness practices: that all death is certain, that the timing of death is uncertain, and that the only thing that can help at the time of death is mental and spiritual development.[114]

A Buddhist's state of mind near death is important as it may affect the nature of their rebirth; they should have thoughts of love and compassion as they transition to the end. Loud wailing and emotional outbursts may disturb a dying person's thoughts and are discouraged; families are often encouraged to let go of their relative, as emotional clinging denies the inevitability of death. The death environment should be made as peaceful as possible, preferably in the person's home; if a hospital stay is inevitable, accommodations should be made to create as peaceful a setting as possible, such as by letting the family set up an altar, bring flowers, etc. Tibetan (Mahayana) and some Theravada practitioners may read from the Tibetan *Book of the Dead.*[115]

In Theravada Buddhism, there are no specific objections to autopsy, and no specific practice of leaving the body for an undisturbed period of time. Burial or cremation can happen quickly or after a few days. Mahayana Buddhists may wish to leave the body undisturbed for up to three days, as a way to help the departed soul through an intermediate stage before transitioning to the next life.

10. Indigenous and Aboriginal Culture

Indigenous cultures are not monolithic, and as in any culture different individuals can have stronger or weaker connections to Indigenous cultural identity. This is particularly true given the historic experience of forced assimilation of Indigenous peoples in Canada. It is important to note that traditional Indigenous beliefs can coexist with Christian beliefs, without rejection or disrespect. Many Indigenous patients may wish to

have end-of-life rituals that come from their Christian faith in addition to their ancestral cultural traditions.

In the decision-making process, family members may call upon community members, elders or healers for support, as there is a great respect for wisdom, experience, and knowledge about spiritual matters and traditional medicines from the elders within the community.

During the end-of-life process:

- A person identifying with Indigenous and Aboriginal culture may require a room away from other patients where they can honour their traditional beliefs and practices.
- Traditional healers may use "healing circles and traditional sacred medicines such as sage, cedar, tobacco or red willow shavings, and sweet grass" in last rites rituals.
- Smudging ceremonies, involving the burning of sacred tobacco, are common practices.
- Some Aboriginal and Indigenous cultures will also prescribe the wearing of a medicine pouch.
- Certain plants and artifacts that are considered sacred to the practitioner and should not be touched or removed.
- Traditional singing or drumming may occur.
- Burial also needs to take place within 24 hours of death.
- During preparation for burial the body must never be left alone.
- After the funeral, it is important to undertake the purification of the hospital room as well.[116]

IV. FAITH AND CULTURAL PRACTICES IN LAW AND LEADING MODELS OF CARE

A. Freedom of Religion and Equality under the Charter of Rights and Freedoms

This section seeks to provide an overview of how the *Canadian Charter of Rights and Freedoms*[117] (the "*Charter*") applies to the provision of health services towards the end

of life. The Charter contains several provisions directly relevant to end-of-life decision-making. Section 7 guarantees "the right to life, liberty and security of the person," which has been found to arise in a number of circumstances in the health sector. More directly relevant to faith and cultural supports, however, is Section 2(a), which provides for freedom of conscience and religion. This is a central focus of this paper as it relates to consent and treatment decisions. Further, Section 15 provides equality rights for a number of enumerated and analogous grounds requiring equal treatment before the law and equal protection, which may be relevant to delivery of end-of-life care services.

1. Charter s. 32

As a preliminary matter, it is important to delineate how the *Charter* affects the provision of health services. Technically, the *Charter* applies only to the relationship of the government with the people. Section 32(1) of the *Charter* lists its application exclusively to Parliament, government, and the provincial legislatures. However, this also includes all actions by the government, including the bodies it creates through statute. The *Charter* can therefore regulate private relationships, since it applies to any statute governing those relationships, such as those governing the provision of health care by health care institutions and professionals.

These issues have been extensively litigated.[118] Courts have found that simply because an institution is independent of the government does not necessarily mean that the *Charter* will not apply, especially where the state has created an administrative structure, through a legislative scheme, in order to promote an important governmental policy.[119] Where the government chooses to provide publicly-funded health services, and provides considerable guidelines and policies on how to do so, there is an important governmental role, even if this care is delivered by private institutions.[120] In the provision of any health-related services in end of life care, the Charter is therefore likely to be an important and primary consideration.

2. Charter s. 2(a)

Section 2 of the *Charter* lists certain "fundamental freedoms" applicable to all persons in Canada. Section 2(a), the first of these, protects "freedom of conscience and religion." One of the first cases interpreting this Section was *R. v. Big M Drug Mart Ltd.*, assessing the constitutionality of the *Lord's Day Act*, which prohibited commercial activity on Sundays.[121] Despite the historical origins of the practice including secular purposes, the current Act conflicted with the freedom of religion under Section 2(a) as it provided

penal sanctions for the failure to observe a religious holiday. The Court tied the concepts behind Section 2(a) with Section 27, the interpretation clause of the Charter that promotes the preservation and enhancement of a multicultural heritage.[122] The case emphasized the importance of governmental action being free of religious content, even if there was some secular content, and the importance of protecting religious minorities.

Although most of the subsequent 2(a) cases deal with religious minorities, some deal with the limits of Christian practices as well. Perhaps paradoxically, when a similar provincial law was challenged the following year in *R. v. Edwards Books and Art Ltd.*,[123] the day of rest was characterized as a mandatory civic holiday without a penal sanction. Although it still violated Section 2(a), it was properly saved under the reasonable limits in Section 1 as it was carefully designed to achieve its purpose of having a shared civic holiday.[124] Here the Court indicated that the *Charter* does not require legislatures to eliminate every miniscule state-imposed cost that may be associated with the practice of religion, and the Charter only seeks to prohibit burdens or impositions on religious practice that are non-trivial in nature.[125]

The plurality of beliefs encountered in a diverse and multicultural society is potentially limitless, but the Court has designed a way to identify which specific beliefs engage Section 2(a). In *Syndicat Northcrest v. Amselem*, the Court was dealing with the use of small, temporary religious structures on balconies of a condominium during the Jewish holiday of Sukkot, which apparently violated the condominium's by-laws. The Court developed a two-part test for whether Section 2(a) rights are engaged: whether there is a sincerely-held belief, and whether that practice or belief is connected to religion.[126] The sincerity of a belief is assessed on a low threshold, because courts should not be testing an individual's private and personal beliefs in a judicial context.[127] This practice or belief does not have to be endorsed or authorized by any religious official, as belief is highly individualized. Instead, what is relevant is whether the person believes that they should follow a practice or belief based on their faith, because the courts or the state should not attempt to resolve differences in religious dogma.[128] The Court decided that the aesthetics of a condo board policy in this case should not interfere with the religious practice of building a temporary structure on balconies.[129] Notably, the Court did not adopt Justice Binnie's dissent that the *Charter* should not apply given the private nature of the dispute.[130]

In other circumstances, the Court has provided limits or an analytical framework as to how Section 2(a) should apply. In *Alberta v. Hutterian Brethren of Wilson Colony*, the Court reviewed Alberta's *Traffic Safety Act*, which contained a photo requirement for licenses.[131] The Court acknowledged that this requirement infringed on the Section 2(a) beliefs of the Wilson Colony of Hutterian Brethren, who did not believe in photographs, but this infringement was justified based on reasonable limits under Section 1. A universal photo requirement was necessary to minimize the risk of fraud and ensure each license was only used by a single person.[132] The Court in *R. v. N.S.* developed an analytical framework instead to assess the right of a complainant in a sexual assault case who wore a face veil (*niqab*), instead of creating a blanket prohibition or automatically finding a Charter violation.[133] The Court determined that the competing right of an accused to cross-examine a witness and to a fair trial should be reconciled on a case-by-case basis if no accommodation can be achieved.[134] Accommodation of religious beliefs, therefore, does not always include systematically providing comprehensive concessions, but instead often requires careful analysis that considers context, while still maintaining human rights principles.

Limitations on Section 2(a) have also been observed in the health context. In *B. (R.) v. Children's Aid Society of Metropolitan Toronto*, the Court assessed the claim of Jehovah's Witness parents who did not believe in blood transfusions due to their religious beliefs.[135] Their child had been born prematurely, and experienced a change in medical status at the age of one month, which the physicians believed would endanger the child's life. Although much of the Court's divided opinion focused on the Section 7 right to life, liberty, and security of the person, the majority decision by Justice La Forest held that the legislative scheme allowing for the state to protect the child was saved under Section 1 despite the fact that it "seriously infringed" the parents' freedom under Section 2(a) to choose medical treatment that was in accordance with their faith.[136] Chief Justice Lamer emphasized that the priority of Section 2 rights over other *Charter* rights, including Section 7, are apparent by their very characterization as "fundamental freedoms."[137] Justice Iacobucci wrote that a Section 1 analysis was not needed, because Section 2(a) of the *Charter* does not allow for the imposition of religious practices that threaten the health, safety, and life of a child.[138] He added that the breadth of freedom of belief was necessarily constricted through the freedom to act on those beliefs, especially since this child has never even had the opportunity to express any agreement with these beliefs, and may never live long enough to exercise her constitutional rights.[139]

The imposition of faith or religious practices by the government, or institutions deemed to be closely related enough to the government, was recently reviewed in *Mouvement laïque québécois v. Saguenay (City)*.[140] The practice of a public prayer prior to municipal council meetings was found by a human rights tribunal to violate the Section 2(a) rights of an atheist resident. The Court emphasized that freedom of belief also includes freedom to not believe, which is an essential feature of the state's duty of religious neutrality.[141] Promoting a multicultural and multi-religious landscape also requires the state to avoid making professions of faith or adopting or favouring one religious view over another.[142] The Court rejected that the province's history, tradition, and religious heritage justified the use of the Christian prayer.[143] The appropriate approach is where the state neither favours nor hinders any particular religious belief system and demonstrates respect for religious beliefs, as well as those who have no beliefs at all.[144] Where an individual's freedom of conscience is impaired in the health care context by an institution relying on these traditions and heritage, this may be considered an infringement of a Section 2(a) right, depending on the facts at hand. These will be important developments in the future application of Section 2(a).

The framework used to determine whether a Section 2(a) *Charter* right has occurred has developed further in administrative law. Administrative tribunals, which govern numerous aspects within the health sector, are conferred significant amount of autonomy given their specialized nature and the expertise of the tribunal members.[145] Because these tribunals already employ a Section 1 reasonable-limits analysis in their decision-making, there is no need on judicial review to conduct an additional analysis of these limitations.[146] This judicial framework was recently employed in the Ontario Court of Appeal decision in *Trinity Western University v. Law Society of Upper Canada,*[147] where a Community Covenant of a religious university was used to exclude graduates from admissions to practicing law in Ontario. Although the Court of Appeal acknowledged that the university's Section 2(a) rights were engaged, the Law Society's decision was reasonable and did not violate the duty of state neutrality because the decision was consistent with its statutory obligation to act in the public interest.[148] The decision did not prevent the practice of religious belief, but instead denied a public benefit because the impact of the religious beliefs in the school's Community Covenant on the LGBTQ community.[149] The religious values of health institutions, especially where they conflict with other *Charter* rights and statutory obligations, are therefore an important consideration in any policy development for end of life decision-making.

3. *Charter s. 15*

Section 15 of the *Charter* is one of the most important provisions in the discussion of integrating religious and cultural supports into end-of-life care because it relates to equality rights. Section 15(1) guarantees equality under the law and equal protection "without discrimination based race, national or ethnic origin, colour, religion, sex, age or mental or physical disability." All of these grounds were in the 1960 *Canadian Bill of Rights*,[150] with the exception of mental and physical disabilities, which helps illustrate the changing nature of our understanding of discrimination between 1960 and 1982. Since the advent of the *Charter* this understanding has advanced even further.

Although we refer to the list in Section 15(1) as "enumerated" grounds of discrimination, the case law has extended this list further to other grounds which are analogous enough to the characteristics found in the *Charter* itself. The end result is that there are other grounds which are protected by the *Charter* that are not found explicitly in its text.[151] The concept of "analogous grounds" was first introduced in the case of *Andrews v. Law Society of British Columbia*.[152] The Court tied the concept of discrimination to the creation of distinction, either through an action or a failure to take into consideration any differences.[153] A violation of Section 15 would occur only when this distinction was shown to be discriminatory based on an enumerated or analogous ground.[154] Further, in determining whether something was an analogous ground, the Court looked at whether the distinction is an irrelevant personal difference, similar to those in Section 15(1), but also in human rights legislation.[155] The purpose for stamping out such discrimination is to protect vulnerable groups in society that may not have adequate protection by elected officials, especially where those distinctions create or reinforce patterns of discrimination.[156] The *Andrews* approach was later used in *Canada (Attorney General) v. Ward*[157] to refine the notion of analogous groups as including those with innate or unchangeable characteristics, whose members voluntarily associate for reasons of human dignity, and groups associated by voluntary status due to their history.[158] These characteristics were then applied in *Egan v. Canada*[159] to extend the definition of spouse to same-sex individuals. Although sexual orientation is not included in the *Charter* explicitly, these subsequent cases have found them to be so similar to the enumerated grounds that they should also be included. Health institutions developing policies to avoid discriminatory behaviour in health services should therefore use caution when employing the explicit enumerated list in the *Charter* alone, and should be aware that newer analyses for Section 15 rights may emerge in the future.

More recently, in *Law v. Canada* ,[160] the Court considered whether the discriminatory conduct imposes a burden or withholds a benefit in a way that promotes stereotypes, or promotes a view that an individual is less worthy of recognition or value as part of Canadian society.[161] This narrowing of discrimination rights focused on dignity focused on personal autonomy and self-determination, considering the physical and psychological nature of dignity through unfair treatment that is insensitive to the needs, capacities, and merits of different individuals.[162] Dignity is a critical consideration in the deeply personal context of end-of-life care.

In developing this emphasis on dignity, the Court relied heavily on both *R. v. Morgentaler* [163] and Chief Justice Lamer's dissent in the assisted-dying decision *Rodriguez v. British Columbia (Attorney General)*.[164] Despite references in Morgentaler originating in the context of Section 7, this dissent in *Rodriguez* recognized the strong right to bodily integrity and personal autonomy in the medical context.[165] The majority in *Rodriguez* declined to delve into the full scope of Section 15 in the context of assisted dying, and instead found any infringement be saved by Section1.[166] Similarly, when the Supreme Court of Canada later found in *Carter v. Canada (Attorney General)*[167] that the prohibition on assisted dying did violate Section 7, it refrained from analyzing whether it also violated Section 15.[168] Instead, the development of Section 15 arose in other cases. The focus on dignity in Law produced inconsistent results, as was observed in the divided decisions in *Gosselin v. Quebec (Attorney General)*[169] and *Canadian Foundation for Children, Youth and the Law v. Canada (Attorney General)*.[170]

In *R. v. Kapp*,[171] the Supreme Court noted difficulty with the Law formulation, as even with contextual factors the abstract and subjective notion of human dignity is confusing and difficult to apply.[172] The Court in *Kapp* reverted back to an *Andrews*-type analysis, using only a two-part test as to whether a law creates a distinction on an enumerated or analogous ground, and if that distinction perpetuates a disadvantage through prejudice or stereotypes.[173] The purpose of Section15 is to ensure substantive and not just formal equality, meaning the promotion of a society where all are secure that they are equally deserving of concern, respect, and consideration.[174]

Following *Corbiere v. Canada (Minister of Indian and Northern Affairs)*,[175] a decision relying on comparison with a "comparator group" to determine whether discrimination had in fact taken place, [176] the Supreme Court moved to a broader, contextual approach, in *Withler v. Canada (Attorney General)*.[177] The contextual factors identified in Law are to be applied in order to create substantive equality, but not as a

requirement or a prescriptive list.[178] Since *Withler*, claims of analogous grounds of discrimination are evaluated contextually, on a case-by-case basis. Although this may create less predictability in equality claims, it potentially affords greater flexibility and provides claimants with greater latitude as to how to advance these claims.

Within the *Charter* itself, there is a recognized exception to the prohibition against discrimination, found in Section 15(2). This provision allows for laws, programs, or activities which seek to ameliorate or lessen the disadvantages that groups identifying with grounds listed in, or analogous to those listed in, Section 15(1) face in Canadian society. This exception does not violate the spirit of Section 15, but in fact reinforces it, as part of the purpose the prohibition against discrimination in Section 15(1) is to remedy historical disadvantages.[179] The appropriate way to understand Section 15(2) is to see if a program is focusing on a discriminated group, without reference to the effectiveness of such program.[180] The understanding of Section 15(2) was more fully fleshed out when the Court revisited this section in *Kapp*. Here, the Court devised a two-part test for Section 15(2) claims. First, the program must have a remedial or ameliorative purpose. Second, the program should target a disadvantaged group based on enumerated or analogous grounds.[181] Courts will review a program to see if it is truly ameliorative, even if a statute explicitly claims that it is, by looking at whether there is a correlation between a program and a disadvantaged group.[182] The disadvantages intended to be addressed by Section 15(2) are any vulnerabilities, prejudice and negative social characterization.[183] The general vulnerabilities faced by patients at the end of life, as well as the challenges faced by religious and cultural minorities, would make ameliorative programs focused on addressing these areas one of the programs intended by this subsection.

B. Ontario Human Rights Code

Like the *Charter*, the Ontario *Human Rights Code* requires equal treatment in the provision of services, including health care services—as well as in employment, contracts, vocational associations, and housing accommodation, without discrimination on the grounds of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability.[184] The OHRC has developed a number of policies to assist in the interpretation of the Code. Although these policies are not binding on tribunals or the courts, they are typically seen as highly persuasive by legal authorities.

There is no hierarchy of human rights, meaning no right supersedes, or is superseded by, another right. No right is absolute, as all rights can be limited by the rights of others. When there is an apparent conflict between two sets of rights, the OHRC *Policy on Competing Human Rights* requires consideration of each situation in context and seeking of solutions, in a formal or informal process, in a good-faith manner that aims to respect both sets of rights as much as possible.[185]

There is a limit on the duty to accommodate if undue hardship is shown based on cost, health or safety, but this is a high threshold. It may also be limited where there is significant interference with the legal rights of others.[186]

The duty to accommodate applies to hospitals and clinics as well, and also protects physicians and other health care providers who have sincerely-held beliefs. Where conscience and the sincerely-held creed or religious beliefs of a physician conflict with that of their patients, some consideration is required. The *OHRC Policy on Preventing Discrimination Based on Creed*187 provides a framework for some of these issues, as does the CPSO in its policy on *Professional Obligations and Human Rights*.188 A physician's right to religious freedom will need to be balanced with a patient's *Charter* right not to suffer discrimination or right to life, liberty, and security of person, among others. Freedoms can be constrained to protect public safety, order, health, morals or the fundamental rights and freedoms of others.[189]

C. Professional College Policies and Chaplain Services

1. *The College of Physicians and Surgeons of Ontario*

As mentioned briefly above, the CPSO policy statement on *Professional Obligations and Human Rights* states that physicians must:

- Act in the best interests of their patients, and insuring all patients receive equitable access to care, especially if a patient is from a vulnerable or marginalized population.
- Communicate effectively and respectfully in a manner that supports patient autonomy in decision-making, and insures they are informed at all times about their medical care.
- Properly manage conflicts, especially if values differ, always placing the patient's interest in a paramount position.

- Apply these principles equally to patients and those seeking to become patients.[190]

Physicians can limit the care they provide to patients in cases where they are not competent to provide care. This is not considered discrimination if this information is conveyed to the patient as soon and as respectfully as possible, and the patient is referred to an alternate practitioner. Physicians cannot terminate their relationship with patients on any of the grounds protected by the *Ontario Human Rights Code*.

As such, the CPSO requires physicians to respect patient dignity at all times in communicating objections clearly and sensitively, and informing patients that their objection is for personal rather than clinical reasons. They must ensure access to care by providing information on clinical options, and must not withhold information even if it conflicts with their beliefs. They need to make an effective referral, meaning that "a referral made in good faith, to a non-objecting, available, and accessible physician, other health care professional, or agency. The referral must be made in a timely manner to allow patients to access care." Refraining from providing the service should have no significant impact on the patient's legal rights and health care services.[191] Finally, a physician is expected to provide care in an emergency where it is necessary to prevent imminent harm, even if it conflicts with their beliefs.

2. *The College of Nurse of Ontario*

The College of Nurses Ontario (CNO) does not have an explicit policy on human rights, though references to continuity of care and obligations to arrange alternate care are scattered throughout several guidelines, namely "Refusing Assignments and Discontinuing Nursing Services,"[192] "Culturally Sensitive Care,"[193] and "Professional Standards."[194]

According to these guidelines, nurses demonstrate regard for client well-being and maintain professional commitments by:

- using their knowledge and skill to promote patients' best interests in an empathetic manner;
- putting the needs and wishes of clients first;
- identifying when their own values and beliefs conflict with the ability to keep implicit and explicit promises and taking appropriate action;

- advocating quality client care; and
- making all reasonable efforts to ensure that client safety and well-being are maintained during any job action.[195]

"Abandonment" occurs when a nurse has accepted an assignment and discontinues care without:

- getting the patient's permission;
- arranging a suitable alternative or replacement service; or
- allowing a reasonable opportunity for alternative or replacement services to be provided.[196]

A nurse who discontinues services without meeting the above conditions could be found guilty of professional misconduct.

3. Chaplaincy and Spiritual Care Providers

The Rev. Maness provides a helpful history of the terms "chaplain" and the word "chapel" as originating in early Christianity. Originally the term arose in reference to the "cappellani", priests who guarded the sacred cloak (or "cappa") of St. Martin of Tours.[197] Throughout the centuries, chaplains have taken on a number of roles, including particularly important functions as religious escorts for the Frankish kings through the Dark Ages and into the medieval era. Modern incarnations can involve a religious minister of any religion, including a priest, pastor, rabbi, imam, or lay representative, and are usually attached to a secular institution such as a hospital, prison, school, military academy, police department, or university.

In the Canadian health care setting, chaplaincy programs are accredited by the Canadian Association for Spiritual Care (CASC), a now-secular body that itself evolved from church-based pastoral care societies in the Maritime provinces.[198] Its mandate is "to prepare persons through competent supervision for ministries of pastoral care, counselling and education." [199] Typically, spiritual care workers apply to a Clinical Pastoral Education program, a multi-unit course requiring the equivalent of 12 weeks of full-time instruction, and is open to clergy, theology students, and laypersons with theology training.[200] Instruction is offered at general and psychiatric hospitals, as well as correctional centers, with each center connected to a theological college, and each instructor certified by the CASC. Military chaplains are trained under a separate regime in the Canadian Armed Forces.[201]

Previous requirements that spiritual care workers be members of the Christian clergy have been dropped across Canada, mirroring other jurisdictions around the world.[202] CASC requirements still refer to Christian concepts such as ministries and divinity degrees, though our research uncovered some institutions that made attempts to move away from Judeo-Christian terminology. Chaplains are required to hold a masters-level degree in divinity or theology, which may present a barrier to faith traditions that lack accredited teaching institutions in Canada. Theological schools in Ontario are overwhelmingly Christian in origin and character. Some accredited pastoral care teaching sites assess an applicant's educational background and assess equivalency; the Canadian Multifaith Federation now does equivalency assessments for applicants of all faiths to join these teaching programs.

Research conducted on hospital chaplaincy programs in the United States notes a "vague and persistent uncertainty" around hospital-funded spiritual care programs, as there is an awareness that these professionals are the most financially vulnerable as "spiritual care programs are not essential to hospitals in the same way as scientifically based health care professionals".[203] In 2008, the Association of Professional Chaplains (APC), a US-based advocacy commission, reported that they received 10-12 requests per year for help during the downsizing or elimination of funded spiritual care programs or chaplain positions.[204] Another article states that:

> Hospital chaplains lack the professional security that many other health care disciplines enjoy. Their job descriptions are relatively vague when compared to their more technologically-based colleagues. The procedures that effective pastoral care requires in any particular instance often are less specific, enjoy less consensus and generate less easily measurable results than many medical and surgical procedures.[205]

Interview subjects and sector informants indicated that most often these positions were paid through hospital budgets; however, specific information was not forthcoming in the interviews/surveys conducted. Angela E. Schmidt (2013) conducted in-depth interviews and identified funding sources for Ontario hospital chaplains.[206] The information provided in her doctoral research speaks to how, in Ontario, "the majority of hospital chaplains (80%) are funded through the hospital operating budget and that 16% of the total FTE [full time employee] are paid through the chaplain's religious denomination (with no contribution by the hospital)."[207]

In order to better understand the practical application of the program, we spoke to a representative at William Osler Health System, which operates two hospitals in the

Toronto area. Half of the patient population comes from a non-Christian background. The term "chaplain" has been replaced with "Spiritual Health Therapist," and a one-year training residency program, headed by a Buddhist, is open to anyone with the prerequisite requirements. [208] Notably, the institution issues course credits through the Toronto School of Theology, a Christian ecumenical consortium of historic divinity schools tied to the University of Toronto.[209] Every patient admitted to Osler is asked if they want to be visited by spiritual health therapists, and accommodations to involve faith leaders of different faiths are facilitated frequently.

D. Summary of Leading Practice Tools

The following section provides a few leading examples of the models and guidelines health care providers may use to help navigate end-of-life issues with their patients in culturally-appropriate ways.

1. Giger-Davidhizar and Huff Cultural Assessment Model

This model considers six components relevant to end-of-life care including "communication, space, time, environment control, social organization, and biological variation".[210] It is important for health care providers to apply knowledge gained from conceptual and theoretical models of culturally-appropriate care to individuals who are culturally diverse in order to provide culturally-competent care. Models like these enable us to "understand an individual's cultural heritage, beliefs, attitudes and behaviors."[211] For a breakdown of this model, please see Appendix A.

2. The Checklist to meet Ethical and Legal Obligations

As discussed earlier, the provision of end-of-life care that is consistent with a patient's values and beliefs can be rife with potential conflicts. One attempt to add clarity and certainty is an organized approach to try to capture and document the wishes of the patient. The *Checklist to Meet Ethical and Legal Obligations to Critically Ill Patients at the End of Life* (ChELO) was developed by a group of ethicists based at William Osler Health System and London Health Sciences.[212] It sets out an organized list of questions to families and SDMs that is used with all patients admitted to intensive care settings at Osler. It is used to document the prior wishes and values of the patient, the depth of their feelings towards religion, and what they might have thought if they lived in a prolonged state of being unable to interact or communicate. There are some indications that this approach has reduced ethical and legal errors that might have occurred in obtaining consent for withdrawing or withholding futile care.[213]

3. The ABCDE Model

Kagawa-Singer and Blackhall have adapted the mnemonic "ABCDE" tool to assist health care providers in avoiding the pitfalls of stereotyping in relation to "attitudes, beliefs, context, decision-making, and environment."[214] While this tool is developed for clinicians, it may prove useful for policy makers as well as it allows them to see places where policy development can further enhance service provision for all Ontarians. Integrating this tool into Ontario hospitals and health care facilities should be considered. More detailed information about this model is available at Appendix B.

4. Multifaith Information Manual

The Canadian Multifaith Federation (CMF) has created "The Multifaith Information Manual," which provides information on management of religious diversity. Now in its fifth edition, the manual "addresses such issues as: basic beliefs of faith groups; ceremonial objects and dress; sources of prayers and scriptures; mode of worship; structure and denominations; rituals, mode of dress & modest requirements; dietary requirements; beliefs and practices regarding death; and symbols".[215] Order forms are available on the CMF's website.

5. Professional Information on Health care Facility Websites

During our discussions and surveys with medical professionals and in our qualitative research (see below at sub-section E.2), some participants discussed the need for more resources to better provide services to patients. They would like to have more training, best practice examples and contact with community and religious leaders who can offer assistance by answering questions to complex culturally related problems so they can provide better health care services.

Hamilton Health Sciences has gathered resources and links for their service providers. Unfortunately, the information is somewhat out-of-date and several links broken.[216] Nonetheless, this is a proactive approach that should be replicated by other institutions. This will allow medical professionals take a proactive approach to cultural competence and patient care.

Similarly, the Hospital for Sick Children also strives to provide culturally-competent care. Orientation materials for nursing students provide guidelines that help students understand the importance of being culturally-competent.[217] They are taught how to

apply "principles of respect, openness and mutuality to culturally unique families as you would with families of the same or similar background as you."[218]

E. Examples of Hospital-Based Support Services and Programs

1. Canadian Multifaith Federation

There is a long-established history of government support for multi-faith services in the health care setting. One leading example of this is the Canadian Multifaith Federation (CMF).

The CMF has been assisting institutions in providing faith and cultural support in varying contexts, including end-of-life care, for over 44 years.[219] The initiative was born out of a March 1972 meeting that brought together the provincial government with the Ontario Provincial Interfaith Committee Chaplaincy (OPIFCC) to explore the provision of a consistently high-level of spiritual and religious care to the general population.[220] OPIFCC struck a committee in the late 1970s to provide advice and support, as well as regional coordination of chaplaincy services, in each region of the province. A staff person was hired to support the screening of chaplain candidates and conduct assessments of spiritual religious care programs within local institutions.[221]

This partnership was affirmed and renewed in 1992 when the OPIFCC signed a memorandum of agreement between it and the three Ministries of Health, Corrections and Social Services, who provided operational funding. This arrangement persisted for the next 20 years, with over $493,000 in funding provided by the province.[222] This funding ended in 2013.[223] Since then, the newly-named Canadian Multifaith Federation (CMF) has not changed its core mandate despite the loss of government funding. The CMF aims to work with agencies and organizations in Ontario, including hospitals, "to promote timely provision of adequate and appropriate spiritual and religious care for persons in care".[224]

The CMF has also offered services through a group of regional bodies called Regional Multifaith Committees (RMC), which aim to improve the quality of religious services and spiritual care in government facilities. One of the central aims of these committees is to educate by providing government facilities with sensitivity training.[225]

The CMF is often called upon by various health care institutions and government agencies for valuable advice. Public, not-for-profit and academic sectors, as well as members of the general public, also regularly seek the valuable information the CMF provides.[226]

The CMF provides interested parties with a Multifaith Competency Certification, which ensures spiritual and religious care providers have sufficient knowledge and experience to provide and coordinate spiritual care services. The certification is a prerequisite for spiritual and religious care positions in public-private, not-for-profit, and academic institutions.[227] The CMF also conducts competency interviews throughout the province to determine candidates' knowledge and skills to work in a multi-faith environment. After successful completion of certification, candidates will receive a recommendation and certificate that attests to their competence from the organization.[228]

2. *Hospital- and Community-based Faith Services and Partnerships*

In our survey of leading Ontario hospitals, we found great variability in the information available to patients about the palliative and pastoral, and cultural services provided at those facilities. We chose 19 of the busiest hospitals in Ontario based on data collected by Canadian Institute for Health Information.[229] We reviewed the websites for each of these hospitals to see what faith and cultural information was made available to patients. We also sent a set of standardized questions to administrators at each hospital about the palliative, pastoral and cultural services they provide. In addition to the summary below, Appendix C provides a complete table of the facilities we surveyed along with the information and services they make available to patients.

While roughly half of the facilities did not have any significant information about faith and cultural services on their websites, the rest presented varying degrees of detailed information. A few facilities put us in touch with their palliative care directors and clinical ethicists, including St. Michael's Hospital, Humber River Hospital, Trillium Health Partners and William Osler, who presented us with much of the data presented here. We also spoke with some palliative care-providing physicians directly to learn of faith and cultural supports available to their patients.

We found a striking variability across these facilities in terms of availability of multicultural spiritual support, and even basic palliative care itself. For example, some facility websites did not provide any public information available about their palliative care programs (or whether they had such programs at all), so it would be difficult for a

member of the public to determine whether culturally-competent palliative care was available. In contrast, other websites had detailed and downloadable "take-aways" like patient information handouts.

Facilities were also distinguished by the on-site services they support. We found that some standout institutions support the provision of services by chaplains from a variety of faiths. Some deliver spiritual care from a non-denominational perspective and help facilitate involvement of spiritual-care advisors from particular religions and belief systems if patients request them. The Ottawa Hospital has a special Aboriginal cancer group which "honours the Aboriginal path of well-being." William Osler has a multi-faith program headed by a Buddhist that has renamed chaplains as "Spiritual Health Therapists."

We also found evidence that the training of health professionals in faith and cultural traditions is uneven, with very little formally taught to medical or nursing trainees about specific faiths. One geriatrician we spoke to frankly stated that in his ten years of formal training, there was no specific review of religious or cultural practices of the local patient population. This appears to be the predictable outcome given that there seems to be no uniform guideline across the province that regulates or encourages hospitals to provide culturally- and religiously-sensitive care. Where excellent programs exist, they seem to be driven by individual communities and motivated professionals. As we have outlined above, there is a legal requirement for institutions to accommodate religious requirements short of undue hardship. It appears to us that the variability of services on the ground may be falling short of this standard.

In addition to the services facilitated by health care institutions, there are also a number of independent multi-faith organizations in Ontario. They are less well-known and utilized as they have not previously enjoyed the formal support or recognition by the government of Ontario. These organizations can and should be utilized by health care institutions as resources of faith leaders who can provide service and assist medical professional in providing culturally-competent health care.

An example of such a partnership working successfully is the Toronto And Region Islamic Congregation (TARIC) Islamic Centre and the Humber River Hospital. The goal of TARIC is to provide "dynamic leadership in serving the Muslim community by establishing facilities and organizing programs that meet their needs while actively reaching out to all non-Muslim Canadians". [230]

The Chairman of the TARIC Islamic Centre, Mr. Haroon Salamat, says that TARIC has been working closely with the Humber River Hospital Chaplaincy program since 2001. Humber River Hospital has a formal "Local Volunteer" program.[231] When requested by Humber River Hospital, TARIC also recruits and screens volunteers for this program.

The goal is to offer emotional support to patients by visiting one-on-one. The program TARIC allows members of the congregation to visit the hospital and provide spiritual support to patients. The community works in partnership with the local hospitals to introduce and register volunteers and provide hospital passes, giving them easy access to most units and patients.

> *We have a good relationship with the hospital ourselves … Many volunteers have passes to go through the wards and visit the sick.*
>
> — Haroon Salamat, Chairman of TARIC Islamic Centre

Interviews with health care providers and religious leaders revealed that health care institutions are also creating relationships with individual leaders within communities or with religious leaders within the provincial context. These relationships are not necessary formalized or compensated.

3. Long-Term Care Facilities that Focus on Culture

Ontario is home to many culturally-focused long-term care (LTC) and palliative care facilities. One example of this is the Yee Hong Centre for Geriatric Care, formerly the Chinese Community Nursing Home for Greater Toronto. It was created in 1987 because of "lack of emotional support and difficulty in communicating for Chinese seniors within mainstream medical facilities".[232] At the time of its founding, the community considered it imperative for their aging population to be able to live in comfort and dignity in their remaining years, and only a nursing home attuned to the values and traditions of the Chinese culture could achieve that. For example, Chinese seniors may prefer congee rather than toast and cereal for breakfast and rice rather than pasta for supper. To provide culturally-specific support, many of the staff support and volunteers are from the Chinese and Japanese communities. The organization's mandate is to "provide leadership and vision in developing culturally and linguistically appropriate services for seniors of Chinese origin."[233]

LTC facilities like Yee Hong provide excellent culturally-specific health care. These institutions can be viewed by non-culturally specific institutions as models of service delivery.

V.   THE EXPERIENCE OF FAITH LEADERS AND HEALTH PROVIDERS

A. Methodology

This independent research explores current practices in Ontario surrounding cultural and faith-based support with relation to end-of-life care. The final sample population included a total of 17 participants, all of whom work in the Greater Toronto Area and Southwestern Ontario. Seven are medical professionals: four medical doctors and three registered nurses. A total of six faith leaders were interviewed: one from the Islamic faith, two from the Jewish faith, and three from Christian denominations. Interviews also included four cultural leaders: one from each of an Indigenous, Muslim, Sikh and Hindu community. It is important to note that each of the health practitioners interviewed have personal connections to faith and culture. One registered nurse's work focuses on Chinese and Japanese cultural groups, while one physician and one nurse are practicing Muslims. Another physician lived in India and brought his understanding of different cultures to his work.

Individual experiences with faith-based and spiritual care in relation to end-stages of life were explored through semi-structured interviews. Interviews were conducted over the phone and audio-recorded to allow for more comprehensive analysis. The research inquiry inquired about a range of issues, including participant:

- experiences with access to faith-based supports for patients in the last stages of life, and/or for their friends, family and community members
- experiences with health care facilities providing resources on faith-based and culturally competent care
- knowledge concerning professional policies and legislation relating to faith and cultural accommodation in the provision of care in the last stages of life, and
- opinions surrounding the need for future professional policies and legislation relating to faith-based and culturally competent care, and in relation to medical assistance in dying.

A complete record of the questions asked in the semi-structured interviews is available at Appendix D.

The data set has been interpreted and discussed based on the principles of thematic analysis. The purpose of thematic analysis is to delineate, examine, and track themes embedded within the data.[234] These patterns are then explored and enriched with subsequent data.[235] Accordingly, our research identified several key themes which are each outlined and discussed below. Collectively, these themes make it clear that a more comprehensive approach is needed to better provide faith-based and culturally competent care in the last stages of life. These findings in turn support the recommendations made in the final section of this paper.

B. Major Themes across Stakeholder Experiences

The overarching notion that there is a need for a more comprehensive approach to end-of-life care (which considers holistic individual needs, including culture and religion), was supported by five key themes identified during one-on-one interviews with cultural leaders, religious leaders, and medical professionals.

These themes identified the need to:

1. Recognizing a greater role for faith and culturally competent care in the last stages of life
2. Implementing consistent faith and culturally competent care policies across all facilities and denominations
3. Facilitating diversity in faith and cultural beliefs rather than enforcing strict doctrinal adherence
4. Improving education and training among health care providers to achieve more holistic care
5. Better engaging faith and cultural communities when developing law and regulations

It is important to note that in identifying the key themes arising from one-on-one interviews, it became apparent that cultural and religious concepts could not be easily delineated. These conversations were closely knit together but, overall, gave rise to the same core concepts.

1. Recognizing a greater role for faith and culturally competent care in the last stages of life

One of the most powerful themes arising from individual interviews was the need for better, more patient-centered care in the last stages of life. Those interviewed highlighted the need for a strong understanding of cultural competency in health care and the integration of faith and cultural needs. The notion of what good palliative and end-of-life care encompasses was one that participants emphasized in particular, indicating that the focus could not solely be on physical needs but rather take on a more holistic appearance and address spiritual and social needs as well.

> *Palliative care involves the physical being; it involves the psychological being, the spiritual, the religious; it involves the person; it involves the family, the community. Every one of us is going to die. This is a shared human experience and most important to everyone.*
> —Faith Leader

Although Ontario health care providers accept the idea that harmonizing cultural and faith-based care into the service is crucial, there is nevertheless a disconnection with how those services are being provided. Although some of these services are being provided, they are not being administered equitably across the province.

Our research also indicates a substantial gap in terms of knowledge surrounding the various cultures and faiths and how to access these communities when a patient is requesting support. Furthermore, basic competency in understanding and applying principles of cultural sensitivity emerged as another area of concern. For example, one participant from the Jewish community described sensitivities surrounding the use of feeding tubes, an issue that many health care practitioners may not be aware of.

> *Certainly culturally, especially when there is a Holocaust survivor in the Jewish tradition, it is very emotional.*
> —Faith Leader

It is these types of sensitivities that reinforce the need for health care providers and practitioners to be made aware of and trained to deliver care in a culturally-competent way. It is important for care providers to have an understanding of culture that helps them anticipate and respond effectively to needs, and to be able to communicate with patients and families in a respectful manner when situations arise where culture and/or belief may influence how a patient wishes to be cared for. One medical doctor stated, "Now we need to educate and inform each other of the importance of how that culture

actually matters." A registered nurse working in a long-term care home serving primarily the Chinese and Japanese seniors gave the following example of when cultural desires conflict with best practice:

> *When you talk about attention from a cultural standpoint versus what may be what the literature would point to, as I understand, for the Chinese generally speaking dying with a full stomach and well-hydrated is a desire. In their view it is what would be valued. However, if we look at the literature we know that as human beings, as you come closer to death, the need for nutrition, the need for hydration is inefficient. So to force someone to eat, to insert a feeding tube when they are closer to end of life, to hydrate them extensively really would not be in the name of comfort. So that is a tension we have experienced and a topic that has needed to be discussed.*
>
> —Health care Professional

In general, most faith and cultural leaders found that institutionalized health care settings were fairly open-minded and cooperative when they were present to provide care to a patient near end of life. A majority found that they were welcomed and supported. That said, there was an indication that *cultural and faith-based care was not given as much consideration as they should be*. Faith and cultural leaders often felt that their *role and participation in care during the last stages of life was not well understood by the system as a whole*. In general, this was felt to be a shortcoming and a disservice to those patients with strong spiritual roots.

> *My concern would be around where spiritual care… how our health care system doesn't really value spiritual care for patients.*
>
> —Faith Leader

> *A take on this is there must be some clarity in the medical institution, that if spiritual care and religious care is an essential part of the healing process, it must be given within all reason equal priorities.*
>
> —Faith Leader

Even health care workers themselves described this notion. For example, the following quotation is from a practicing registered nurse:

> *Spiritual care and faith-based care is somebody's way of life. It is how they know themselves and how they know how to interact with others. When you take that away from them you are just dealing with the body, and possibly the mind. But everything else is not there; we are not dealing with a person as a whole. In the medical world we say we are providing total care, you know, we are providing holistic care. It is not holistic if spiritual*

> *and faith-based care, and particularly even when looking at spiritual and faith-based care, when you are not looking at the culture that this client is presenting with, or the client is telling us he is a part of or feels strongly with.*
>
> —Health care Professional

2. *Implementing consistent faith and culturally competent care policies across all facilities and denominations*

Accessing cultural and faith-based supports tended to be described as an "ad hoc process." There was no consistency in terms of patients being asked about *their belief system* and furthermore, in many circumstances, the *onus fell on the families to find and access a faith leader* if they felt it was necessary. For those faith-based supports that are well known and easily accessible, the *bias is toward Christian denominations*. For example, one Catholic priest described the fact that there are Catholic resources in almost every hospital:

> *Every major hospital in the GTA has a Catholic chaplain associated with it… easy solution to contact the Catholic chaplain. Many are in the hospital every day, visiting or delivering the Eucharist.*
>
> —Faith Leader

The *lack of formal policies* surrounding cultural and faith-based care within hospitals further reflects the shortcomings in understanding of the importance of culturally-sensitive and faith-based care for patients in the last stages of life. Furthermore, *inconsistencies exist across institutions* in terms of access for faith leaders to patients in various units of hospitals. For example, while most participants stated they never encountered issues gaining access to a patient in order to provide spiritual support, one imam noted having been denied access to a patient in the intensive care unit.

We asked participants about specific legislation that could be adopted to support faith-based and spiritual care by asking them if they "are there any traditions held within your community that support end-of-life decision-making, including contemplating changes in future legislation? If not, why?" We probed further, asking if they felt that "there are any accommodations that need to be made in human rights legislation to support access to faith-based support during end-of-life care?"

In many cases, participants were not able to cite the specific legislation that protects or mandates this type of support. Most participants felt that *it was not necessary to develop formal policies*, but rather the need to promote culturally-sensitive spiritual care was part of good health care and awareness of human rights legislation.

> *No, I don't think so. I don't think the need is necessary at this stage. The way things are right now most people have adequate protection, from the hospital and the doctors and from other people who may be putting other pressures on them. I think the system is adequate as it is now. Now when they do bring in the legislation concerning assisted death, that opens up a new can of worms.*
>
> —Health care Professional

An important nuance identified in the interviews is that it was not an issue of access so much as of understanding. A majority of those interviewed felt that hospitals were open and willing to accommodate faith and cultural needs and allow faith leaders to participate in patient care. In fact, one participant from the health care profession voiced concern that creating and mandating policy would turn such care into "another ticky box" which would diminish the depth and sensitivity with which it needs to be addressed. However, in other cases participants felt very strongly about the need to create good legislation and policy around faith-based care:

> *A legislation that I would like to see, and I am going to say this as strongly as I can, is the faith and appropriate implementation of culturally sensitive faith-based care to clients when they need it and when they ask for it.*
>
> —Cultural Leader

Creating policy would, however, help ensure that families and staff are given adequate information on what resources are available to them. There was concern that although there were faith and cultural supports and networks available, the problem arises that many people are just not aware of them or how to access them.

Another indication that there is indifference to spiritual care in the health care system is the *tendency for chaplaincy services to be the first hit when budget cuts are implemented*. Several participants expressed concern surrounding this pattern and the fact that they are *seen as non-essential services*, which is not how they are conceived by those patients who rely on these services. In many instances, hospitals do not even have a full-time chaplain or spiritual care representative available. For example, one chaplain described the situation as follows:

> *One of the shocking things that is happening, is how chaplaincy services in hospitals are being shut down. That is just shocking and is causing huge damage in my opinion and in the opinion of any faith tradition.*
> —Faith Leader

In addition, a reverend articulated the situation in the following manner:

> *So, it almost feels that spiritual care components, the wellness and the holiness of life is being removed. And I know that it is being done for monetary reasons.*
> —Faith Leader

3. Facilitating diversity in faith and cultural beliefs rather than enforcing strict doctrinal adherence

The role of religious and cultural leaders in spiritually-oriented support for patients in the last stages of life, and particularly near the end of life, tends to *be supportive rather than directive*. This was a feature seen across all faith and cultural communities consulted. Almost all individuals interviewed described taking on a listening role with the goal of *allowing the patient to come to terms with their prognosis* and resolve any unfinished business prior to their death. Furthermore, these individuals also emphasized *providing support to the families* of the loved one.

> *My role as a faith leader is to listen and to help those who are struggling with illness, who are approaching the end of life and their families to find meaning and a sense of God's presence in the midst of those experiences… To allow them to explore the things, and put into words those things that will help those they leave behind to move forward.*
> —Faith Leader

> *The goal is to bring some calm and peace to the individual so that they feel that people are caring for them and that there is hope. And of course, there is the religious aspect to it, to give them the belief that there is always hope for redemption for any misdeeds that they may have committed to the past. And to ask for forgiveness from God almighty.*
> —Cultural Leader

In many cases faith leaders are trained in counselling and in addition to supporting terminally-ill patients and their families, they take it upon themselves to support health care practitioners.

> *We are trained in counselling and in understanding how to help people to get through some really difficult times. We often go to family meetings*

> *with physicians in order to support families through this. We provide support to staff, opportunities to engage in reflecting on what the work situation is like for them, in dealing with a difficult family, or maybe a young death has taken place and some of the staff are having difficulty with that. Anything and everything.*
>
> —Faith Leader

A majority of faith leaders indicated that they would never abandon an individual if choices were made regarding their end-of-life care that conflicted with the belief system. This further emphasized the notion that a faith leader's role was more supportive rather than trying to direct the patient in making certain choices that align with the belief system. The following excerpts from various faith communities illustrate the homogeneity of this standpoint across different faiths.

> *It is not up to me to tell someone yes you should do it, or you don't do it.*
>
> —Faith Leader

> *Just because they have made that choice it's not like you lock them in a room until they go and don't go see them again. That's not the case.*
>
> —Faith Leader

> *Never would any of us do, I think presume, to tell anyone or their family what they should do in terms of their care that they receive.*
>
> —Faith Leader

In general, it seems that spiritual care from faith and cultural leaders is characterized as primarily patient-centered. When discussing what these types of conversations looked like, a majority of participants indicated that they were steered by the patient who is nearing end-of-life, and the approach should be as gentle and respectful as possible.

> *Usually the conversation is more or less steered by the individual*
>
> —Cultural Leader

For example, in Indigenous communities, conversations about the end of life are generally begun by the individual, when ready. Rarely would elders take it upon themselves to approach an individual. Again, conversations are steered by the individual and ultimately the choices surrounding their care are their own.

> *We don't have the right, they have to make up that decision on their own… Only they have that right because it is their life. So we don't push anything on them… So respecting a person's decision. You may not agree with it, but you need to respect it..*
>
> —Cultural Leader

In cases where a decision is made that is contradictory to the norms of the belief system an individual identifies with, most faith leaders said they would still provide support for the patient and their family. Some indicated that they may try to inform the individual that the choice goes against their religion, and to provide information to try to steer them back to a path of piety. For example:

> *We would try to use as much as possible our knowledge of Islam, to bring the individual to what we consider the right path.*
>
> —Faith Leader

> *Our tradition has never really been to say, "you cannot do this," it is sort of helping people discern where God wants them to go.*
>
> —Faith Leader

The role that faith and cultural leaders play with regards to end-of-life care is one that is unlikely to be, and arguably cannot be, carried out by health care practitioners. The notion that spiritual care needs to be supported by a dedicated individual was captured in the following comment:

> *I feel unfortunately we do not have anyone dedicated to providing spiritual, religious and faith based care too our clients. I think it is really important to dedicate that role to someone. Just because, the roles we are all playing they are so, they quite vast as it is and we are having a hard time just being able to fill our particular role. And the added spiritual and faith based care is not something that I feel that anyone is capable to offer right now.*
>
> —Health care Professional

An individual with training in the area of spiritual care is better able to provide holistic faith-based support for those near end-of-life. Health care practitioners already carry enormous responsibility and often are very time constrained. The specialized training that many faith leaders undergo and their connections within their faith community better position them to both provide comprehensive spiritual support and, furthermore, to rally together additional faith resources for patients requesting support.

4. *Improving education and training among health care providers to achieve more holistic care*

As previously discussed, an "awareness gap" has been identified that limits the influence of cultural and faith-based knowledge on the delivery of end-of-life care. The *need* to

understand the role of culture and faith in providing end-of-life care was emphasized by a majority of participants. In order to address this issue, there is a *need for better training opportunities for care providers with regards to these issues including orientation to available community resources.* For example, in order to provide good care, one cultural leader from the Sikh community felt that "it is very important for the hospital to know the religion and support them accordingly." This lack of understanding contributes to patients, especially those belonging to minority groups, suffering, as they are not receiving care which adequately supports their spiritual needs. Similarly, an imam described the need for more awareness in order for staff to be prepared to handle requests from members of a faith community.

> *All institutions have care providers. Hospitals, nursing homes. They all need orientation, in-services, on various faiths. Just the facts. So that staff is aware to accommodate when such a need is requested.*
> —Faith Leader

Currently, it seems that there is little, if any, formal training with regards to cultural and religious sensitivities for health care providers. When one medical doctor was asked about his knowledge of training in this area his response was, "Nothing in Canada, you just have to use your own knowledge." Another physician described the current landscape in understanding cultural and religious influences within the medical field:

> *Nobody really takes you aside and says what are the fundamental beliefs of Judaism and what is it in the end of life a Jewish patient would want. That I think we have not taken the time to truly educate or frankly relieve to each other what the uniqueness of the various cultures and religions are. We all focus on the food, and focus on the celebration of their religious holidays, but we don't really understand what that religion is. That is not taught.*
> —Health care Professional

One member of a religious community stated, "institutions need to make it a point that part of the orientation is ethnic-sensitive training." Along these lines, it became apparent that there is an *openness* to, even interest in, learning about culture and religion, and how these factors influence the provision of care.

> *What I have witnessed is an improved awareness of it… People are a lot more open and interested. We just don't get enough focus on education of it.*
> —Health care Professional

However, the *gap exists in finding the resources to provide such training*. It was noted that the *faith communities are willing to work with the hospitals* to offer such training; furthermore, it was suggested by some medical professionals that faith communities could provide these types of training opportunities:

> *I think definitely there needs to be education for all the health professionals on the unique aspects of faith-based care. Faith-based end-of-life care. And, the ones who could do it best are frankly the religious leaders of that community.*
>
> —Health care Professional

Another suggestion from a medical professional was to create a team of individuals responsible for faith education:

> *What we need is interfaith teams, that can be established, that can educate everybody that works there about respect, and recognition.*
>
> —Health care Professional

It seems that both cultural and faith communities want to be engaged and are willing to help with increasing awareness surrounding their practices; in fact, many are already doing so. An example was given of one Muslim community that has created a well-established volunteer program in which members of their faith are registered with hospitals and able to make rounds, providing spiritual support to patients from their own faith and others.

> *Many volunteers have passes to go through the wards and visit the sick.*
>
> —Cultural Leader

A representative from an Indigenous community described providing advice to hospitals on how to set up a smudging room that would provide a space for completing end-of-life ceremonies for members of their community. That being said, this is not standard hospital procedure. This representative also articulated the need for hospitals to be trained more in cultural sensitivities, especially those of Indigenous people.

Increasing awareness of culture and faith through better training of care providers creates an opportunity to improve end-of-life care for patients from all communities. *Strengthening the handshake between the faith communities and health care institutions* through creating mutual understanding of practices and sensitivities is one area for consideration.

> *There is a lot of agencies that don't know about culture. So, the more they know about our culture, the more they can be respected. So that means things will be done in a good way.*
>
> —Cultural Leader

5. Better engaging faith and cultural communities when developing law and regulations

When faith and cultural leaders were asked about whether or not the government had reached out to them for consultation on legislation surrounding end-of-life care, very few said they had been contacted. Despite huge variation in beliefs and opinions on certain legislation, the various faith groups do engage with one another in these discussions. Interestingly, on several occasions participants indicated that despite conflicting beliefs, *religious institutions like churches dialogued with one another*. Furthermore, they felt that there was an assumption that each faith was an isolated entity.

> *The faith communities do talk to each other and all understand each other.*
>
> —Faith Leader

Although a majority of participants stated that they believed their communities had never been consulted by the government, a handful had engaged in conversations with government bodies surrounding proposed legislation. Nonetheless, the overall feeling was that *consultations were limited to the larger more visible religious groups*, such as the Catholic Church. The smaller minority groups are seldom sought out for these types of conversations. A representative from a non-Christian faith group was particularly concerned with this fact.

> *No one from any government body consulted or approached us for our opinions on this matter. Which is also surprising… they use statistics to provide service. But if there is not enough of a number we do not get service. That results in people suffering.*
>
> —Faith Leader

There was a unanimous desire from the *various faith and cultural communities to be consulted by the government.*

> *So there is a kind of a unified religious voice that is crying in the wilderness, you might say. Seeking to be heard and listened to. Whether it will or not, I don't know. It is not just a single issue Roman Catholic idea here. It is a very galvanized attitude among faith leaders around this whole issue.*
>
> —Faith Leader

Furthermore, there was recognition of the fact that this is a *complex issue due to the growing number of faith communities* seen in Southwestern Ontario and that the role which faith plays in society has continually been shifting. Interviewees frequently sought to clarify how conversations with and about these groups is not to stand in the way of legislation, but rather be involved and engaged in meaningful discussion. Having an awareness of the legislative history may be useful as, often, it is the faith and cultural leaders that are on the front line supporting patients near end-of-life. For example, a representative of the Islamic community indicated that the community has no intention to lobby against the government with regards to the assisted-death legislation, but they will have to live with it.

> *We don't agree with it but that doesn't mean we will stand in the way of any other community who wants it. We think it is wrong but that is from an Islamic point of view. We would not go to any kind of extreme to lobby to the government and try to stand in their way. They have to do it. We would have to live it.*
>
> —Faith Leader

Similarly, others stressed a desire to be heard by the government and to participate in the dialogue. These feelings underlie the perceptions of these individuals that they were much closer to the situations discussed by the government than the government was.

> *I think the government needs to listen better. To listen to the experience of faith-based people who are in the environment, in the world which they are talking about, much more than them.*
>
> —Faith Leader

> *The government needs to have an open-minded attitude toward listening, and I would dare say, to dialogue with these religious communities. Not to have a conversation with them but to dialogue with them. And dialogue means a lot more than simply a conversation. Dialogue means that you will sit in partnership, and listen, and try to understand and respond accordingly. Both parties have to do those. The church has to listen to the government, of course it does. But the government in turn must listen to the churches and it isn't. It isn't doing that at all.*
>
> —Faith Leader

C. Experiences with Faith and Cultural Accommodation in Practice

In most of the interviews conducted with religious leaders and spiritual care providers, participants stated that hospitals and other institutions were accommodating of various

cultural and religious practices and allowed for easy access to patients by members of various cultural and religious communities. In general, a majority of faith leaders described hospitals being cooperative and having no issues accessing patients in need of faith-based or cultural support. When asked about whether or not he had ever encountered any barriers in accessing hospitalized patients, a member of a religious community stated:

> *Personally no, I've never. Generally speaking all hospitals are happy to have pastoral care workers mix and mingle among patients in their hospitals … generally speaking those accesses are pretty unlimited.*
> —Faith Leader

The respondent further articulated that in cases where individuals are denied access, namely to ICUs, "most pastors will give the most respect to the institutions" and that "there is usually a purposeful reason for that."

In our interviews, a story was shared about an Indigenous community, where an institution went beyond the required standards to accommodate a smudging ceremony, considered an important part of end-of-life practice. For example, one hospice was supportive and accommodating of a smudging and pipe ceremony even after the fire alarms were set off.

> *When I went in to hospice they allowed to smudge [the] body, and the smoke alarms went off and they were quite okay with it. It was very nice that they allowed us to do all of this.*
> —Indigenous Leader

In another instance, a hospital created a custom room specifically for use during smudging and pipe ceremonies.

> *Some hospitals I have dealt with, have made room for us to perform smudging ceremony or conduct pipe ceremony.*
> —Indigenous Leader

In another case, a representative from a cultural long-term care facility described changing the institution's policy relating to the removal of the bodies of recently-deceased residents from the premises, in order to be more culturally competent. In the past, bodies were removed exclusively via the basement loading dock. Members of the Palliative Care Committee discussed this practice and determined that:

We are sending our deceased who have lived in this home for, some like 5, 10 years out a loading dock. So, we all agreed that there was a need to change that practice and have our deceased go out respectfully… either out a front or back door, but not out a loading dock.

Upon further investigation, they found that part of the reason the practice had developed was rooted in strong cultural influences: it was bad luck to take a body out through the front door, and there was a lot of fear and discomfort surrounding "the body." However, the Resident and Family Councils both unanimously agreed that the options should be front or back door exits, not the loading dock. It became apparent that most of the discomfort was actually from staff members, who also had very strong cultural ties. In the end, the policy was changed to accommodate a respectful exit for the deceased through either from the front or back door, not the loading dock.

Our research indicates that where faith leaders and cultural or spiritual care providers are integrated into the process, they are being supported. Where support in Ontario's framework is required is to health care providers. Several participants working in the health care field alluded to the notion that there was a lack of standard procedure and/or policies surrounding how to handle faith and cultural requests from patients nearing end-of-life. This theme was touched on by participants from various sectors of the health care system, including those working in hospitals and long-term care. For example, one nurse working in primary care observed:

> *It is a fractured, medically based non-cultural system. In my experience….it is very medically driven, it is based on symptoms only. Let's just deal with the symptoms. A lot of times it involves sedation.*
>
> —Health care Professional

Another nurse working with a marginalized population commented that she would find requests for spiritual and end-of-life care incredibly difficult to manage, as there is a lack of resources to assist her.

> *Often just at a loss of words we don't know where to begin to try and provide that type of service.*
>
> —Health care Professional

Similarly, several other participants alluded to the fact that there was a need for resources to help them navigate these situations. For example, one physician working in a GTA hospital stated that most physicians are not aware of resources because policies

within the hospital are relatively ambiguous. Furthermore, in many cases it was suggested that faith resources were often biased towards Catholic or Christian services.

> So, most of the physicians will not even have an idea about this. It is kind of vague.
> —Health care Professional

> And you don't have something or someone, or service, or something mainstream or systematic that we are able to provide everybody. I wish there was a list of services that we can all say we are able to provide or client.
> —Health care Professional

A majority of the medical professionals interviewed suggested the need for more resources to help them provide patients with access to faith-based supports. One medical doctor stated that "people are a lot more open and interested. We just don't get enough focus on education of it."

This individual suggested the establishment of interfaith teams to help educate clinicians on faith and cultural practices that may impact how care is provided.

> *What we need is interfaith teams, that can be established, that can educate everybody that works there about respect, and recognition.*
> —Health care Professional

Along the same lines, one nurse felt that it was necessary to dedicate a specific role to faith and cultural support, as the demand of clinical practice does not allow for time to address spiritual and faith needs of patients near end-of-life. Furthermore, even knowing how to access this type of care for such a vast range of cultures and faiths is an immense undertaking. Again, it requires an individual committed to knowing this information and how to connect an individual to those types of services.

> *I feel unfortunately we do not have anyone dedicated to providing spiritual, religious and faith-based care to our clients. I think it is really important to dedicate that role to someone. Just because the roles we are all playing they are so, they quite vast as it is and we are having a hard time just being able to fill our particular role. And the added spiritual and faith-based care is not something that I feel that anyone is capable to offer right now.*
> —Health care Professional

D. Proposals to Improve the Integration of Faith and Cultural Accommodations and Supports into Ontario's Health care Framework

As discussed throughout this section, culturally-competent health care is important to providing good palliative and end-of-life care. Figure 1 shows a model that supports the qualitative data we collected in our interviews.

Figure 1: Summary of Findings on How to Integrate of Faith, Spiritual & Cultural Accommodation/ Supports into Ontario's Framework

The need for cultural competence in health care

- There needs to be better training for health care providers with regards to religious and cultural sensitivities

- This includes giving faith and culture more respect with regards to the role it plays during end-of-life care

- There is an openness and desire to learn among health care practitioners

There is a need for consistent policies supporting culturally-sensitive, faith-based and spiritual care for all denominations

- Policies in institutions are "ad-hoc" at best, or not transparent, leaving staff and medical professionals unsure of support systems

- Increase visibility of other faiths so there is less precieved bias towards Christian denominations' support systems

How to Integrate Faith, Spiritual & Cultural Accommodation/Supports into Ontario's Framework

Institutions need to provide more resources to faith-based, spiritual and cultural supports

- Dedicated personnel, interfaith teams and more resources should be allocated to providing spiritual, religious and faith-based care to paitnets

- Provide resources and tools that health care practioners can utilize and accesss

- Resouces can also be allocated in terms of space for last rites and faith, spiritual, and cultural practices

There is a need for government to engage with all faith and cultural groups if legislation changes

- There is increasing complexity due to the growing number of faiths present in Canada, and not all faiths are being engaged

As discussed elsewhere in this paper, institutions need to practice culturally-competent health care. Medical professionals we interviewed indicated that better training is required for health care providers on religious and cultural sensitivities. Many medical professionals we interviewed discussed the fact that they were open to learning more about faith, spiritual, and cultural care. When medical professionals understand cultural competence, they will more likely give faith and culture more respect with regard to the

role it plays during end-of-life care. This will have an overall effect on the service patients will be given.

Another shortcoming our research alludes to is the need for consistent policies supporting culturally-sensitive faith-based and spiritual care for all denominations. When we spoke to religious and cultural leaders they were unaware of policies that institutions they supported had. Medical professionals we interviewed also were not aware. Our survey results indicate that hospitals do indeed have policies, but they are not properly promoted to all front-line service-delivery personnel. This makes the policies seem "ad-hoc" and medical professionals unsure of support systems. Transparent policies would help create a more culturally-competent team.

There was also a discussion around the need for institutions to provide more resources to faith-based, spiritual, and cultural supports. This could be in the form of dedicated personnel or interfaith teams that can support front-line service-delivery staff. Some service providers and religious leaders felt that support systems are more focused on Christian denominations. Institutions do not necessarily support smaller faith denominations. Some institutions also have resources (tools) on their websites to support medical professionals. Our research above speaks to a few of these tools that can be easily accessed by practitioners.

Lastly, if the government decides to legislate, it is important to engage with all faith and cultural groups, as there is a complexity due to growing number of faiths seen in Canada, with not all groups being engaged.

VI.   FINDINGS AND RECOMMENDATIONS

If one word was chosen to describe the provision of faith-based and culturally-competent services for patients in the last stages of life in Ontario, including for palliative and end-of-life care, it would be "transitional." The integration of faith and cultural supports into quality care in the last stages of life in Ontario presents a number challenges for policy makers and health care providers and practitioners. Spiritual care and culturally-competent health care in palliative and end-of-life care may often be an afterthought, and may not be systemically addressed by many health care providers and facilities. There appears to be no systemic directive or guideline to do so, despite a growing body of legislation and case law demonstrating that these issues cannot be ignored.

The predictable if unfortunate result may be increased and unnecessary conflicts between health care providers and patients that could be avoided. Many of these conflicts are also individualized, rather than addressed systemically. This blind spot is reinforced by conflict resolution mechanisms like the Consent and Capacity Board which adjudicate only over individual cases, and generally through the lens of health care law which may not adequately address issues of faith and cultural accommodations. Additionally, the advent of legislation permitting medical assistance in dying creates further challenges and potential conflicts between the faith and cultural rights of the medical community and patients, resulting in overlapping rights and responsibilities that may take time and further legislative or adjudicative guidance to resolve.

Based on our research, policy makers would be well-advised to consider the following as they contemplate the integration of religious and cultural supports into palliative and end-of-life care in Ontario:

1) Increasing awareness and clarity among health practitioners about patient rights to access and practice religious and cultural beliefs under the *Charter of Rights,* Ontario's *Human Rights Code*, and various professional practice directives

2) Increasing awareness and clarity among adherents to a faith or cultural group about variations within their system of beliefs and practices. Attention to faith and cultural differences should be individualized to each person, and one must not assume that a patient belongs to a cultural monolith.

3) The need for greater uniformity among palliative care services across the province to better normalize access to, and accommodation of, various faith and cultural practices, and thus achieve a more holistic model of patient-centered care for all

4) The need for greater access to culturally-competent health care throughout health care institutions in Ontario. This would ensure a commitment from health care providers and caregivers to better understand patient needs.

5) The integration of faith and cultural preferences into the formal education curricula of health care teaching institutions. A graduating doctor or nurse should have a basic idea of the nature of various religions and their general requirements, preferences and practices.

6) Institutions should provide a variety of tools and resources for health practitioners to apply in their patient care, including readily accessible online reference materials.

7) As some institutions in very multi-religious regions of the province have done, create a better network of multi-faith and cultural leaders so hospitals, LHINs, and individual practitioners can work closely and get support from faith leaders when needed.

8) Institutions should implement a structured approach to documenting the spiritual, cultural, and religious values and preferences of their patients and their families, as some institutions have done with the ChELO process.

9) Pastoral Care Education programs need to formally invite faith leaders and lay followers to join, and "chaplaincy" programs should evolve from what were once specific (Judeo-Christian) faith-based supports to multi-faith spiritual support services.

10) Legislation governing the Consent and Capacity Board needs to be reformed to give medical expertise on the prevailing standard of acceptable and appropriate care a weight equivalent to that given to a patient's final wishes. There should also be greater clarity around the patient's right to refuse medical treatment. Furthermore, for patients who involve faith or community leaders in their care, the legal parameters of these leaders' involvement at the end-of-life should be elucidated. This is especially important with respect to the issue of informed consent where faith leaders counsel patients on the compatibility of medical treatment options with cultural and faith traditions.

11) Health care institutions should provide essential supportive resources like private prayer rooms for faith- and spiritual-based end-of-life practices. Public hospitals and community-based palliative care hospitals should also assist patients with accessing private prayer rooms. If a patient cannot physically access a prayer room, hospitals should provide palliative care patients with assistance in scheduling on-site hospital visit with community and faith leaders.

Throughout this paper, we have looked at how best to integrate religious and cultural supports into quality care in the last stages of life in Ontario. We have provided a snapshot on the topic by reviewing specifying used terms, reviewing the law and professional best practices and policies, and looking at how facilities and health care professionals are currently providing faith-based and culturally-competent health care. Faith and cultural supports are an accepted element of care for persons who are approaching death, as well as for their family members and the broader communities to which they belong. Not only is this a legal requirement, but it is a moral and medical one as well, as culturally-sensitive and inclusive models of care provide better medical outcomes.

A recurring theme of our research is for an acceptance and acknowledgement of the importance of faith and cultural beliefs as vital components in shaping how Ontarians choose and direct their care at the end of life. However, these beliefs also act as unexpected barriers to health care providers providing the best services for Ontarians as they approach death. It is important for faith and cultural leaders to work alongside medical professionals to provide culturally-competent health care, as it is in the patient's best interest.

Faith-based and culturally-competent care is a unifying model that encompasses the values of inclusivity, respect for diversity, equity and commitment that should govern all interactions in a health care setting. The need for health care practitioners to become more sensitive to the unique needs of their patients and the values that inform their opinions regarding treatment is of utmost importance in an increasingly diverse society. As the values that form the basis of culturally-competent care are also Canadian values, a renewed focus on faith and cultural supports should be viewed as an integral part of what makes the Canadian health care experience unique.

APPENDIX A: GIGER-DAVIDHIZAR'S AND HUFF'S CULTURAL ASSESSMENT MODELS[236]

Components	Assessment Questions for the Health care Provider to Consider	Sample Scripts
Communication (Note: If the patient's and family's education levels are unknown, a good rule of thumb is to present information at a 6th - 8th grade level. Also minimize the use of medical jargon.)	• What are the usual and customary communication patterns and practices? For example, the Cambodian Sampheah greeting (placing hands together like praying at chest level and bowing to the person) is more than just a way of saying hello, but it is also a sign of respect, which is central to Cambodian culture. • How do the patient and family expect to be communicated with on death and dying issues? • Who will be the decision-maker in the family regarding health care issues? • Who will be the spokesperson for the family? • Are there certain terms that are used to describe illness or terms or subjects that are taboo? • What traditional explanations may be used to	▪ *Your condition is very serious. Some people like to know everything that is going on with their illness. What would you like? How much do you want to know?"* (Note: If the patient does not want to know or only wants the information given to the family, remain flexible by letting the patient know, *"If you change your mind about wanting information I will be glad to talk with you and answer any questions."* ▪ *"Do you make your own decisions about your care, or do you want someone else to make those decisions (who specifically)?"* ▪ *"Since ___ will be making decisions about your care, is it ok for me to talk to them about your illness and your situation?"* ▪ For the patient who asks that the discussion be with the family: *"Do you want to be there when we talk?"* ▪ To seek clarification from the family: *"I want to make sure that I am being clear in explaining your father's condition and treatment options to him. Could you please tell me what you understand about your father's situation and his treatment options?"*

	explain a terminal illness?	
	• Does the family freely ask questions or voice their concerns?	
	• Are there gender and age rules governing interpersonal interaction?	
	• Are there trust issues between the health care provider and the patient and family? Are there trust issues if the patient and provider are not the same gender?	
	• Would the patient or family be more comfortable with a provider of the same ethnic group as themselves?	
	• What types of non-verbal cues are observed with the patient and family?	
	• What seem to be major barriers for the patient and family in the use of health care services?	

APPENDIX B: ABCDE TOOL FOR ACCESSING CULTURAL/RELIGIOUS INFLUENCE IN PATIENT DECISION MAKING[237]

	Relevant Information	**Questions/Strategies**
Attitudes (of Patients & Families)	What attitudes do this ethnic group in general, and the patient and family in particular, have toward truth telling about diagnosis and prognosis? What is their general attitude toward discussions of death and dying? How reflective are their practices of traditional beliefs and practices?	Educate yourself about attitudes common to the ethnic groups most frequently seen in your practice (see References). Determine attitudes of your patient and their family. For example, is there a symbolic meaning of the particular disease.
Beliefs	What are the patient's and family's religious and spiritual beliefs, especially those relating to the meaning of death, the afterlife, the possibility of miracles?	"Spiritual or religious strength sustains many people in times of distress. What is important for us to know about your faith or spiritual needs?" "How can we support your needs and practices?" "Where do you find your strength to make sense of this experience?"
Context	Questions about the historical and political context of their lives, including place of birth, refugee or immigration status, poverty, experience with discrimination or lack of access to care, languages spoken, and degree of integration within their ethnic community	Religious and community organizations may be able to provide general information about the relevant group (see below, "Environment"). Ascertain specific information by asking the following: "Where were you born and raised?" "When did you emigrate to the United States, and what has been your experience coming to a new country? How has your life changed?" "What language would you feel most

		comfortable speaking to discuss your health concerns?" Life history assessment: "What were other important times in your life and how might these experiences help us to understand your situation?"
Decision-making style	What decision-making styles are held by the group in general and by the patient and family in particular? Is the emphasis on the individual patient making his or her own decisions or is the approach family centered?	Learn about the dominant ethnic groups in your practice (see References): How are decisions made in this cultural group? Who is the head of the household? Does this family adhere to traditional cultural guidelines or do they adhere more to the Western model.
Environment	What resources are available to aid the effort to interpret the significance of cultural dimensions of a case, including translators, health care workers from the same community, community or religious leaders, and family members?	Identify religious and community organizations associated with the ethnic groups common in your practice (consult with hospital social workers and chaplains).

APPENDIX C: RESEARCH ON HOSPITAL POLICY

Findings on the hospital information- The Accessibility of palliative care information for families

Research conducted:

- For this research we contacted 19 hospitals to better understand the following information
- Initially we research on website to find If information on end of life or palliative care was available on the hospital to see how accessible the information was and if there was policy we could find with relative ease
- We also canvassed the websites for a point of contact to whom our team could speak to regarding palliative care and end of life polices/practices within the hospital

What we found:

- Many of the hospital's did have information regarding end of life, palliative care services, or policies regarding there hospital.
- For instance The Ottawa Hospital website has information about their hospital's services, assistance on the end of life and palliative care services. They also have provided a phone number and a room to where families can go to for help. What is interesting to note is that the Ottawa Hospital website in the Aboriginal Cancer Program, the hospital has worked with the "First nations, Inuit and Metis people" (https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgrmCS/Programs/CancerProgram/PRGM/AboriginalCancerProgram) to implement practices which " honours the Aboriginal Path of Well-being" (https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgrmCS/Programs/CancerProgram/PRGM/AboriginalCancerProgram)
- In another example -The Mount Sinai Hospital website has specific information on their own palliative care center. However when you further investigate resources for patients your search engine requires a log in and user name to access this.

From the 19 hospitals that were approached for canvassing and for further contact I received the following responses for assistance to speak to Doctors or Ethicists:

London Health Sciences Centre (LHSC)	Family medicine/ Palliative Care Program	http://goo.gl/0jKEJ1	Human resources Robert Sibbald, Clinical and Organizational Ethicist, London Health Sciences Centre Dept of Family Medicine, Schulich School of Medicine and Dentistry, Western University robert.sibbald@lhsc.on.ca	Satisfactory Typing in phrases into LHSC search engine palliative we found this: http://goo.gl/0jKEJ1
Kingston General Hospital (KGH)	32 page booklet available online Your Guidebook to Cancer Care	http://bit.ly/1TkrEGl	Sandra Carlton JOINT VICE PRESIDENT & CHIEF HUMAN RESOURCES OFFICER carltos1@kgh.kari.net	Unsatisfactory no direct contact information on palliative care department for KGH. Typing in phrases into KGH search engine palliative we found this: but

				booklet and press releases. http://bit.ly/20gLRvq See press release: Local partnership to improve access to palliative care http://bit.ly/1XFCk2r
Southlake Regional Health Centre	The Cancer Centre Team http://bit.ly/1W72ueZ	http://bit.ly/1sHteqt	Point of contact- Dr. Harlod Yuen hyuen@southlakeregional.org Director of Palliative care Debbie Walsh dwalsh@southlakeregional.org	Satisfactory, when searching information on palliative care, but no contact number or email provided on the website.

Out of 19 respondents we received answers to our questions from the following hospitals:

William Osler Health System (WOHS)	Supportive Palliative Care	palliative care inpatient units at Brampton Civic Hospital and at Etobicoke General http://goo.gl/QK6gCD Palliative Care Program-outpatient http://bit.ly/27J0kGn	Paula Chadwick PAULA.CHIDWICK@williamoslerhs.ca	Satisfactory- (WOHS), when searching information on palliative care Also see other materials for patients and families http://goo.gl/9soVBx http://goo.gl/fQXWpJ
Trillium Health Partners	Palliative Care information is available, but not for public access	https://goo.gl/89PqMq	Dianne Godkin PhD Senior Ethicist Regional Ethics Program	Information is not available for public access important information

St. Michael's Hospital	Palliative Care Unit	http://goo.gl/vdmlZC	Peter Thompson Peter Thompson's profile photo thompsonp@smh.ca	Satisfactory, when searching information on palliative care

Findings on the hospital information- The Accessibility of palliative care information for families

Hospital Name	**Program or Department Name**	**Website**	**Contact:**	**Ease of finding information**
Mount Sinai	Tammy Ladner Center for Palliative Care	http://www.tlcpc.org/	info@tlcpc.org	Satisfactory, when searching information on palliative care
University Health Network	E.W. Bickle Centre for Complex Continuing Care	http://goo.gl/qzTLXf	maid@uhn.ca	Satisfactory, when searching information on palliative care. UHN also provided Pdf documents to help families, available online http://goo.gl/7sJ02r
Hospital for Sick Children	Paediatric Advanced Care Team	http://goo.gl/TxlhcY	Adam Rapaport – Director of Paediatric Advanced Care Team adam.rapoport@si	Satisfactory, when searching information on palliative care, Info is accessible and has detailed info on the available contacts.

			ckkids.ca pact.info@sickkids.ca jenny.loor@sickkids.ca	http://bit.ly/2595vQV
St. Michael's Hospital	Palliative Care Unit	http://goo.gl/vdmlZC	Peter Thompson Peter Thompson's profile photo thompsonp@smh.ca	Satisfactory, when searching information on palliative care
Sunnybrook Health Sciences Centre	Palliative care consult team	http://goo.gl/l2r57n	questions@sunnybrook.ca.	Satisfactory, when searching information on palliative care Palliative care consult team Also found under the Sunnybrook Hospital website. Brochure information also available for families http://goo.gl/cqLFF6
William Osler Health System (WOHS)	Supportive Palliative Care	palliative care inpatient units at Brampton Civic Hospital and at Etobicoke General	Paula Chadwick PAULA.CHIDWICK @williamoslerhs.ca	Satisfactory- (WOHS), when searching information on palliative care Also see other materials for patients

		http://goo.gl/QK6gCD Palliative Care Program-outpatient http://bit.ly/27J0kGn		and families http://goo.gl/9soVBx http://goo.gl/fQXWpJ
Markham Stouffville Hospital	Palliative Care Unit	http://www.msh.on.ca/palliative_care	ljoyce@msh.on.ca - media	Satisfactory- contact information is accessible, when searching information on palliative care
London Health Sciences Centre-	London Regional Cancer Program	http://goo.gl/SWpn8m	robert.sibbald@lhsc.on.ca Robert Sibbald, Clinical and Organizational Ethicist, London Health Sciences Centre Dept of Family Medicine, Schulich School of Medicine and Dentistry, Western University robert.sibbald@lhsc.on.ca	Satisfactory, contact information is accessible, when searching information on palliative care LRCP Palliative Care Services 519-685-8500 ext. 57930 & ext. 57918 Palliative Medicine Outpatient Clinic for Oncology Patients Every Friday from 1 p.m. to 5 p.m. London Regional Cancer Program

				A referral is required from a family physician, surgeon or oncologist. For more information call New Patient Referral at 519-685-8600 ext. 58602
London Health Sciences Centre	Children's Hospital-Palliative Care	http://goo.gl/9hYkbX	robert.sibbald@lhsc.on.ca	Satisfactory, contact information is accessible when searching information on palliative care
St. Joseph`s Health care London	Palliative Care	http://bit.ly/1YJyhAr	http://bit.ly/1WHagNb parkwoodaccess@sjhc.london.on.ca	Satisfactory, contact information is accessible Also found this on hospital website http://bit.ly/1qzsSjM hospital policy
Southlake Regional Health Centre	The Cancer Centre Team http://bit.ly/1W72ueZ	http://bit.ly/1sHteqt	Point of contact-Dr. Harlod Yuen hyuen@southlakeregional.org Director of Palliative care Debbie Walsh dwalsh@southlakeregional.org	Satisfactory, when searching information on palliative care, but no contact number or email provided on the website.
The Ottawa Hospital	Outpatient Supportive and Palliative Care Clinics	https://goo.gl/yMzx07 https://goo.g	HumanResRecepGen@toh.ca	Satisfactory- contact information is accessible on website after typing in the search engine

		l/DMkM7T		palliative care
	Inpatient Supportive and Palliative Care Consultation Team			
Humber River Hospital	No specific department, but policy is provided	http://www.hrh.ca/000628#Do	http://www.hrh.ca/WereListening	Typing in phrases into HRH search engine palliative care nothing came up. After entering end of life policy, we found this: http://www.hrh.ca/000628#Do Also note booklet for families is not working. Detailed information on the funeral homes provided, support groups, but no specific religious groups chaplain provided
Trillium Health Partners	Palliative Care information is available, but not for public access	https://goo.gl/89PqMq	Dianne Godkind PhD Senior Ethicist Regional Ethics Program	Information is not available for public access important information
Mackenzie Health Richmond Hill	No information other than this on the hospital	http://goo.gl/snKM51	publicaffairs@mackenziehealth.ca	Difficult after trying key search words: end of life, palliative care, death. We were able to find one web page

	website: Chronic Disease and Seniors Health - Inpatient Palliative Care			with no other information regarding a contact or a department http://goo.gl/snKM51
St. Joseph`s Health care Hamilton	Information on this hospital website titled: General Internal Medicine	http://bit.ly/ 1NCzau9	Human Resources recruit@stjoes.ca	Difficult looking for search engine. No direct contact information on palliative care department. Not clear on issues of palliative care on hospital website. We were only able to find this information http://bit.ly/1TkhKVf "The Reveal of a New Palliative Care Suite".
Niagara Health System	Information on this hospital website titled: Palliative Care	http://www. niagarahealt h.on.ca/en/p alliative-care	Human Resources hrrecruit@niagarah ealth.on.ca	Satisfactory- Information is available to anyone. No direct contact information on palliative care department, http://bit.ly/240fUss
London Health Sciences Centre (LHSC)	Family medicine/ Palliative Care Program	http://goo.gl /0jKEJ1	Human resources Robert Sibbald, Clinical and Organizational Ethicist, London Health Sciences	Satisfactory Typing in phrases into LHSC search engine palliative we found this: http://goo.gl/0jKEJ1

			Centre Dept of Family Medicine, Schulich School of Medicine and Dentistry, Western University robert.sibbald@lhsc.on.ca	
Kingston General Hospital (KGH)	32 page booklet available online Your Guidebook to Cancer Care	http://bit.ly/1TkrEGl	Sandra Carlton JOINT VICE PRESIDENT & CHIEF HUMAN RESOURCES OFFICER carltos1@kgh.kari.net	Unsatisfactory no direct contact information on palliative care department for KGH. Typing in phrases into KGH search engine palliative we found this: but booklet and press releases. http://bit.ly/20gLRvq See press release: Local partnership to improve access to palliative care http://bit.ly/1XFCk2r
Health Services North- Sudbury	Not available	Hospital website http://bit.ly/1NCI8HD	Communications dlessard@hsnsudbury.ca	Unsatisfactory and difficult after trying key search words: end of life, palliative care, death. No information

				available
Timmins and District Hospital	Palliative Care	http://bit.ly/1Vehu9O	generalinquiries@tadh.com	Unsatisfactory, very limited information and not helpful for anyone see websites: http://bit.ly/27JeMhq http://bit.ly/22iuHPY

APPENDIX D: SUBJECT INTERVIEW QUESTIONS

Religious Groups

1. How do [faith] leaders within your belief system approach the subject of end of life care?

Probes:
Have you noticed any specific attitudes from [faith] leaders, regarding end of life care and support?
Is end of life discussed openly and comfortably within your belief system?

2. Can you highlight some of the key areas that [faith] leaders may look to address with individuals near the end of life?

Probes:
What are the ways in which your belief system perceives those with medical issues or declining physical or cognitive abilities?
How are persons with disabilities perceived?

3. Are members of your belief system generally satisfied with the type of support [faith] leaders provide? Does it have a tendency to help them make decisions regarding their end of life options? Do you think there is a possibility of potentially hindering or inhibiting their ability to make a decision?

Probes:
Are the faith values held by you personally, or by the community at large, every used to influence or change the mind of patients you are dealing with?

4. Are there any traditions held within your belief-system that support end of life decision making, including contemplating changes in future legislation? If not, why?

Probes:
How willing would [faith] leaders, in your tradition, be in working with existing institutions and organizations, especially if these emerging policies appear to be at odds with their beliefs?

5. Have you had any experience with end of life care? Can you tell me a little bit about what that looked like?

Probes:
What kind of things did you touch on?
Do you feel that you influenced the decisions the patient made about their care?
Was the patient's prior expressed wishes and desires properly respected in this process?
Would there be ways to better ensure that they were? Were family members involved?

6. Have you had first-hand experience dealing directly with a health care institution during end of life support of a member of your community/loved one.
   a. Did you encounter any difficulties and/or barriers in providing faith-based support for the individual?
   b. Do you feel that sufficient information and resources were provided to help you navigate through the process?

Probes:
Was the institution accommodating towards your needs [the person's needs]?
Was the process easy to navigate through?
What kinds of resources did they provide?

7. Do you feel that health care institutions should have consistent policies on accessing faith-based organizations outside of on-site chaplaincy services when dealing with end of life circumstances?

Probes:
What types of things do you think these policies should cover?
Are you aware of any current policies and procedures?

8. Do you feel there are any accommodations that need to be made in human rights legislation to support access to faith-based support during end of life care?

Assisted Death Questions:

1. How do you [think faith leaders] feel about the proposed assisted death legislation?

Probes:
Do you think most faith leaders are aware of the legislation?
Are they paying attention to it? (i.e.; is it being brought up)

2. Are faith leaders open to supporting patients that are considering assisted death, even if their traditions do not allow for this decision?

Probes:
If not, how would you go about disengaging yourself from the situation?
Do you feel that it would be your duty to persuade them to change their mind?

3. What would be your suggestion on how faith leaders might navigate cases where patients are considering and/or wanting to move forward with an assisted death? Have you ever had to counsel a member of your faith on this?

Probes:
Would there still be opportunity for faith leaders to support these individuals?
Do you feel a faith leader can still support family members and how might that look?

Cultural Groups

1. How do leaders within your community approach the subject of end of life care?

Probes:
Have you noticed any specific attitudes from individuals in your community, regarding end of life care and support?
Is end of life discussed openly and comfortably within your community?

2. Can you highlight some of the key areas that [faith] leaders may look to address with individuals near the end of life?

Probes:
What are the ways in which your community [culture] perceives those with medical issues or declining physical or cognitive abilities?
How are persons with disabilities perceived?

3. Do individuals in your community ever seek out end of life consultations by [faith] leaders? When they are carried out, what is it that they hope to achieve? In other words, what would be an individual's overall goals during these types of conversations?

Probes:
Are there things that you prefer not to discuss?
Are other family members usually involved?

4. Are members of your community generally satisfied with the type of support [faith] leaders provide? Does it have a tendency to help them make decisions regarding their end of life options? Do you think there is a possibility of potentially hindering or inhibiting their ability to make a decision?

Probes:
Are the faith values held by you personally, or by the community at large, every used to influence or change the mind of patients you are dealing with?

5. Are there any traditions held within your community that support end of life decision making, including contemplating changes in future legislation? If not, why?

Probes:
How willing would [faith] leaders, in your tradition, be in working with existing institutions and organizations, especially if these emerging policies appear to be at odds with their beliefs?

6. Have you had any experience with end of life care where a faith leader was involved? Can you tell me a little bit about what that looked like?

Probes:
What kind of things did the faith leader touch on?
Do you feel that they influenced the decisions the patient made about their care?
Was the patient's prior expressed wishes and desires properly respected in this process?
Would there be ways to better ensure that they were? Were family members involved?

7. Have you had first-hand experience dealing directly with a health care institution during end of life support of a member of your community/loved one.
    a. Did you encounter any difficulties and/or barriers in accessing faith-based support for the individual?
    b. Do you feel that sufficient information and resources were provided to help you navigate through the process?

Probes:
Was the institution accommodating towards your needs [the person's needs]?
Was the process easy to navigate through?
What kinds of resources did they provide?

8. Do you feel that health care institutions should have consistent policies on accessing faith-based organizations outside of on-site chaplaincy services when dealing with end of life circumstances?

Probes:
What types of things do you think these policies should cover?
Are you aware of any current policies and procedures?

9. Do you feel there are any accommodations that need to be made in human rights legislation to support access to faith-based support during end of life care?

Assisted Death Questions:

1. How do you think [faith] leaders feel about the proposed assisted death legislation?

Probes:

Do you think most faith leaders are aware of the legislation?
Are they paying attention to it? (i.e.; is it being brought up)

2. Are [faith] leaders open to supporting patients that are considering assisted death, even if their traditions do not allow for this decision?

Probes:
If not, how would you go about disengaging yourself from the situation?
Do you feel that it would be your duty to persuade them to change their mind?

3. What would be your suggestion on how faith leaders might navigate cases where patients are considering and/or wanting to move forward with an assisted death? Have you ever sought counsel for a member of your community on this?

Probes:
Would there still be opportunity for faith leaders to support these individuals?
Do you feel a faith leader can still support family members and how might that look?

Medical Professionals

1. When it comes to end of life care, do you feel that there is adequate support for patients, including consideration of their spiritual needs?

Probes:

If a faith leader is not present, are the patients traditions/beliefs considered in their care?

Are they given enough information to help them make decisions regarding their end of life options? Is the approach used always helpful, or can these values/beliefs be superimposed on to the patient instead?

Can faith/value traditions provide greater meaning to a life within a palliative care setting?

2. What kind of chaplaincy services are provided by your organization for patients in palliative care?

Probes:
In your opinion, how might a palliative patient's spiritual needs be better met?
Is there a place for spiritual needs in palliative care at all?

3. Have you ever encountered specific requests, from patients near end of life, for faith or culturally based support? If yes, how did you respond to the request? If not, can you comment on how you would handle such a request should it ever arise?

Probes:
Are there standard procedures for handling these types of demands?
Are you aware of any resources available within your institution?
If you were not able to provide any resources, do you know who within your organization you could ask?

4. Have you ever been in a situation where an individual's belief system became a barrier to providing care near end of life?
    a. How did you go about navigating the situation?
    b. Did you have any previous training on how to handle a situation where a belief-system was preventing you from providing best care?

Probes:
How/when did you know that their belief had become a barrier to care?
Were there any supports to help you manage the situation?

5. Are you aware of faith or cultural-based supports that your institution provides to patients near end of life?
    a. Have you ever encountered any difficulties and/or barriers in accessing faith-based support for a patient?
    b. Do you feel that sufficient information and resources are provided to help patients navigate through the process?

Probes:
Is the institution you work for accommodating towards patients requests/needs?
Is the process easy to navigate through?
What kinds of resources do they provide?

6. Do you feel that health care institutions should have consistent policies on accessing faith-based organizations outside of on-site chaplaincy services when dealing with end of life circumstances?

Probes:
What types of things do you think these policies should cover?
Are you aware of any current policies and procedures?

7. Do you feel there are any accommodations that need to be made in human rights legislation to support access to faith-based support during end of life care?

Assisted Death Questions:

8. How do you feel about the physician-assisted death legislation?

Probes:
Do you support the legislation? If not, do you mind sharing why?

How would you respond to a patient's request to terminate their life? Is your decision influenced in any way by your own values/beliefs?

9. Do you have any experience with faith leaders and what they think of the proposed legislation?

10. Have you ever counselled a patient that was in favour of death? What advice did you give him/her?

Probes:
Do you feel that it would be your duty to help them change their mind?
If you do attempt to influence their perspectives, do you rely on medical information, social information, values/beliefs, or all of the above?

11. What would be your suggestion on how medical professionals might navigate cases where patients are considering and/or wanting to move forward with an assisted death?

12. Would there still be opportunity for medical professionals to support these individuals and their families regardless of their own opinions of physician-assisted death?

13. Are you open to supporting patients that are considering assisted death, even if the patients or your own traditions do not allow for this decision?

Probes:
If not, how would you go about disengaging from the situation?
What other supports might you suggest?
Would your views on this change or evolve if you were exposed to different perspectives from your own belief system?

ENDNOTES

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[1] The authors adopt definitions for these terms consistent with the Law Commission of Ontario's Last Stages of Life Project. These terms are defined later in this paper at Part II, "Key Terms and Concepts." See also the Law Commission of Ontario, *Improving the Last Stages of Life: Discussion Paper* at Appendix A "Glossary of Terms" (forthcoming, April 2017), to be available online: http://www.lco-cdo.org/en/our-current-projects/improving-the-last-stages-of-life/ ("LCO Discussion Paper").

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[7] Canadian Cancer Society, *Right to Care: Palliative Care for all Canadians* (2016), 3. Online: https://www.cancer.ca/~/media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en (last accessed March 13, 2017).

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[9] Note 8, 4.

[10] *Charter of Rights and Freedoms*, being Part 1 to *The Constitution Act, 1982,* enacted as Schedule B to the *Canada Act 1982* (UK), 1982, c 11.

[11] *Human Rights Code*, R.S.O. 1990, c. H.19.

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[13] LCO Discussion Paper, note 1.

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[17] This discussion is drawn from the LCO's Discussion Paper, note 1, Appendix A "Glossary of Definitions."

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[22] Brian J. Zinnbauer and others, "Religion and spirituality: Unfuzzying the fuzzy" (1997) Journal for the Scientific Study of Religion 549, 549.

[23] Koenig, note 21, 284.

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[32] OHRC, note 30, section 3.h.i "Race."

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[34] OHRC, note 30, section h "race and related grounds."

[35] United Nations, *Declaration on the Rights of Indigenous Peoples*, G.A. Res. 61/295, U.N. Doc. A/RES/61/295 (Sept. 13, 2007), 46 I.L.M. 1013 (2007), art. 33(1). Online: https://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwj735Cjl9bSAhWr1IMKHWHRB_MQFggcMAA&url=http%3A%2F%2Fwww.un.org%2Fesa%2Fsocdev%2Funpfii%2Fdocuments%2FResA_RES_61_178.doc&usg=AFQjCNF2HYs-XeoDl553XXX4w2MpZa88XA&sig2=97ndVafc18ECcPP5WE1lww (last accessed March 13, 2017).

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[37] Note 36.

[38] Note 36.

[39] Note 36.

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[49] HCCA s. 4(1).

[50] HCCA s. 25(1) and s. 18(4).

[51] *Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8, s. 3. (LTCHA).

[52] Note 51.

[53] Note 51.

[54] Note 51.

[55] HCCA s. 32(1).

[56] HCCA s. 73. See also *Mental Health Act*, R.S.O. 1990, c. M.7 s. 39(13-14) (MHA).

[57] HCCA s. 32(4).

[58] HCCA s. 21(1).

[59] HCCA s. 21(2).

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[67] *Friedberg*, note 63, paras. 73, 102, 104

[68] Phyllis R. Coolen, "Cultural Relevance in End-of-Life Care" (EthnoMed.org, May 1, 2012). Online: https://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care (last accessed March 13, 2017).

[69] William R. Miller & Carl E. Thoresen, "Spirituality, religion, and health: An emerging research field." (2003) 58:1 American Psychologist 24, 32 (Miller).

[70] Miller, note 69, 26.

[71] Miller, note 69, 26.

[72] Charles L. Sprung and others, "The importance of religious affiliation and culture on end-of-life decisions in European intensive care units" (2007) 33:10 Intensive Care Medicine 1732, 1734.

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[74] Kagawa-Singer, note 73, 2995.

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[76] Kagawa-Singer, note 73, 2994.

[77] Kagawa-Singer, note 73, 2994.

[78] Kagawa-Singer, note 73, 2994.

[79] Kagawa-Singer, note 73, 2995.

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[83] Kagawa-Singer, note 73, 2994.

[84] Kagawa-Singer, note 73, 2995.

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