Examining the "Black Box" of Spirituality in Ontario Advance Care Planning Resources: A Multimodal Critical Discourse Analysis

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Dedication

To the strongest web of family support and love a person could ever hope for—my wife Kimberly and my children Renée, Oliver, and Drew.

Thank you for your incredible love and support along every step of this journey.

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Abstract

This thesis responds to a two-fold problem observed in the literature regarding spirituality and bioethics: that spirituality in Advance Care Planning (ACP) has been inadequately explored in the Ontario context, and that any comprehensive examination of the multidimensional and complex "black box" of spirituality in ACP must also address the interwoven themes of death and values, as well as the undercurrents of conflict in bioethics regarding spirituality's inclusion. This thesis responds to this problem by examining the Advance Care Planning Ontario (ACPO) website utilizing a Multimodal Critical Discourse Analysis (MCDA) approach rooted in the paradigm of Critical Discourse Analysis/Critical Discourse Studies (CDA/CDS) focusing on the main research question: how is spirituality situated in resources found on the ACPO website? This study was undertaken in two parts: first, an analysis of the website using MCDA tools of inquiry inspired by Machin and Mayr (2023); and second, a coding process using Braun and Clarke's (2022) reflexive thematic analysis focusing on both discourses related to spirituality, death, and values; and also the ideological assumptions observed in these discourses. Findings suggest spirituality being situated peripherally and vaguely with little articulation of its diversity. Additionally, a discourse of immanence regarding spirituality, values, and death was observed with a focus on physical aspects of ACP with little opportunity for engagement on transcendent spiritual themes in decision-making. Ideological assumptions observed impacting spirituality's situatedness included secular, instrumental, rational, utilitarian, individualistic, and medical-legal assumptions—leanings that may exclude diverse ways of knowing and limit inclusion of diverse spiritualities in ACP. Future recommendations include a central and integral role of spirituality in all its diversity, a fuller acceptance of multidimensional aspects of death and dying central to many spiritualities, and the development of opportunities for spiritually integrated value reflection in ACP processes that invite deeper reflection regarding transcendent themes.

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Abbreviations

ACP: Advance Care Planning

ACPO: Advance Care Planning Ontario

CCB: Consent and Capacity Board

CDA/CDS: Critical Discourse Analysis/Critical Discourse Studies

CDA: Critical Discourse Analysis

CDS: Critical Discourse Studies

CPR: Cardiopulmonary Resuscitation

DNR: Do Not Resuscitate

EOL: End-of-Life

FAQ: Frequently Asked Questions

GOC: Goals of Care

HPCO: Hospice Palliative Care Ontario

MCDA: Multimodal Critical Discourse Analysis

R/S: Religious and Spiritual

Reflexive TA: Reflexive Thematic Analysis

SDM: Substitute Decision Maker

Chapter 1

Background

1.1 Introduction to Chapter 1

1.1.1 Brief Overview of the Entire Dissertation

I begin this interdisciplinary dissertation by offering a larger map of the entire journey ahead to help provide some overall context to my research before focusing specifically on Chapter 1. I propose here that this dissertation adds to the body of knowledge regarding the relationship between spirituality and Advance Care Planning (ACP) in Ontario by utilizing a unique methodological approach that results in eight recommendations for resources on the Advance Care Planning Ontario (ACPO) website. These recommendations flow from my identification of eight unique discourses and eight ideological assumptions underpinning the ACPO website. In examining the complex and multidimensional "black box"[1] of spirituality in Advance Care Planning (ACP) resources in Ontario, I take a Multimodal Critical Discourse Analysis (MCDA) approach that is grounded in the paradigm of Critical Discourse Analysis/Critical Discourse Studies (CDA/CDS). Acknowledging both the inadequacy of research focusing on spirituality in ACP within Ontario, as well as the complicated dynamics within the field of bioethics regarding spirituality's inclusion that is noted in the literature, I critically examine the Advance Care Planning Ontario (ACPO) website in this thesis with a focus on the situatedness of spirituality as well as the discursive and ideological assumptions that may underpin this positioning. Chapter 1 provides a background to my study that includes an outline of some key contextual factors and a summary of the problem I am addressing with my research questions including my main question: how is spirituality situated in resources found on the

[1] I gratefully acknowledge this reference of spirituality as a "black box" needing examination to Ammerman (2013).

ACPO website? Chapter 2 provides a literature review focusing on both the interwoven domains of spirituality, death, and values; as well as the key bioethical themes of autonomy, informed consent, substitute decision-making, and ACP. Chapter 3 focuses on methodology and outlines the MCDA approach I take that is rooted in the paradigm of CDA/CDS, as well as the coding process I take utilizing reflexive thematic analysis. This chapter also provides an outline of key theoretical concepts that are central to this approach including notions of discourse, ideology, power, critical perspectives, and the social domain. Chapter 4 addresses the critical findings of my examination of the ACPO website as well as my own self-reflexivity. Finally, I close the dissertation with a discussion in Chapter 5 that returns to my research questions while providing additional reflection on implications and future recommendations. Having painted a picture of the broader landscape of this dissertation as a whole I turn now to providing an overview of Chapter 1 and the ground I will cover in the chapter ahead.

1.1.2 Overview of Chapter 1

I begin this chapter by providing a background to my research that positions this interdisciplinary[2] topic within my home disciplines of bioethics[3] and theology[4]. Beginning with a brief theoretical outline of the bioethical concepts of informed consent and Advance Care

[2] My thesis is rooted in the interdisciplinary notion that complex social issues require multidimensional perspectives to address the "contested space" between disciplines (Repko & Szostak, 2021, p. 4). In my interdisciplinary work, I will connect bioethics and theology with key theorists including Sulmasy (2006), Pellegrino and Thomasma (1988), and Sommerville (2000) who function on the borders of bioethics and theology.

[3] It is important to pause at the outset of this thesis to differentiate terminology regarding ethics. Collier and Haliburton (2021) suggest *Biomedical ethics,* commonly referred to as *bioethics,* is an expression of *applied ethics,* that also utilizes *theoretical ethics* to explore issues regarding, "the body, with the practice of medicine, and with technological developments that have implications for human beings and how we live" (p. 3). While both are widely used, I will utilize the term *bioethics* throughout this paper in congruency with both the Canadian perspective of Collier and Haliburton, and the disciplinary preference of Saint Paul University where I study.

[4] I explore my own approach to theology later in this section in the perspective of the researcher. But I share briefly that my theology echoes Lonergan's transcultural approach (1972/2017) and Gregson's (1985) interpretation of Lonergan's theology that extends theology broadly into the domain of spirituality as "a clear meeting point of the many world's religions" (p. xv). While not a "Lonergan thesis", per say, I am rooted in this transcultural spirit, speaking of theology in language that is inclusive of a broadly accessible spirituality.

Planning (ACP), I will make an interdisciplinary connection between bioethics and theology utilizing the work of Sulmasy (2006)[5], Pargament (2007),[6] and Pellegrino and Thomasma (1988).[7] Here I will suggest that attention to the domain of spirituality[8] is not only an obligation in health care but deserving of prominence—including intentional integration in value reflection and prioritization within ACP resources. Providing context to my broader study, I will then outline six key contextual factors in the current landscape that influence spirituality's integration into ACP based on a scan of bioethical research and my own experience in healthcare. The factors I will discuss include death-denying discourses in medicine; health care's widespread exclusion of spirituality; the challenge of defining spirituality; the diversity of spiritual belief in the present age; the tensions between individual and social expressions of spirituality; and finally, the conflict existing in the broader field of bioethics regarding spirituality.

After outlining these six contextual factors, I will provide a summary of the two-fold problem being addressed in my research. The first part of the problem is that the "black box"[9] of spirituality in ACP has been inadequately explored in the Ontario context. The second part of the

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[5] Sulmasy's (2006) theologically-informed work as both a physician and bioethicist provide a key theoretical bridge between the disciplines of theology and bioethics—a bridge that will be highlighted later in this chapter.

[6] I will draw widely on Pargament's (2007) work throughout this thesis. Their work in the discipline of psychology on defining and integrating spirituality has been pivotal in both psychology and adjoining health disciplines.

[7] The landmark work by Pellegrino and Thomasma (1988), *For the Good of the Patient,* will be foundational to this thesis because of its ability to ground the practice of bioethics in the good of the *patient*, rather than that of *medicine*.

[8] This is the first mention of spirituality in this thesis—a domain that is central to my work. A full discussion of the academic struggle to define spirituality will happen in Chapter 2. For now, it will be helpful for the reader to know that my usage of the terms "spirituality" and "spiritual" will encompass all spiritual expressions including religion. A full rationale will be provided in my literature review. Additionally, while some describe spirituality as a dimension or domain (Pargament, 2007), or a category, concept, or word (Sheldrake, 2013), I will utilize "domain" in congruence with the palliative care orientation of Puchalski et al. (2014) who suggest spirituality as one of the "domains of care" (p. 11). It is this clinical context that best frames my perspective on spirituality.

[9] As noted above, I draw on Ammerman's (2013) metaphor of the "black box" of spirituality in this thesis to help articulate the complex and mysterious notion of spirituality. In addition to the common notion of flight recording equipment on planes should a crash occur, Marco (2021) outlines a diversity of other meanings of the "black box" across disciplines including the mystery of technology, using the example of a cellphone where the phone functions with intricate inner workings but to the common user it is a mystery—they have "no clue as to what exactly they are and how they work" (p. 13). Marco also notes many other disciplinary meanings of the "black box" including Dennett's (1991) philosophical meaning in the context of the human mind and the mystery of consciousness. In my purposes in exploring spirituality in ACP, the "black box" suggests a kind of mystery, complexity, and hiddenness.

problem is that considering the complexity of the domain of spirituality, and the social undercurrents of conflict regarding spirituality's exclusion in the field of bioethics, a comprehensive examination of spirituality in ACP must be undertaken—an examination that must consider both the complexity and multidimensionality[10] of the spiritual domain that is interwoven with concepts of death and values, as well as themes of power and the potential ideological[11] assumptions that may be embodied in discourses[12] within ACP resources. After exploring what this deeper exploration of spirituality might entail for bioethics by drawing on a theological approach to philosophy,[13] I finally extend this complex and layered problem to the social aspects of power[14] and explore how these dynamics might be intertwined with discourse and ideology in ACP resources. I will then briefly introduce the research methodology of Multimodal Critical Discourse Analysis (MCDA)[15] before addressing my rationale for taking this approach. Next, I articulate my perspective as the researcher and finally outline the academic

[10] The multidimensional quality of spirituality will be explored in the literature review in Chapter 2, drawing on the work of Miller and Thoresen (1999) and Pargament et al. (2013) when exploring definitions of spirituality.
[11] Ideology will play a central role in this thesis but as Blommaert (2005) notes, the meaning of this term is a "terminological muddle" (p. 161). I will discuss more fully in Chapter 3 but will share at this point that I appreciate Blommaert's view of ideology as being seen in two distinct ways—a specific category of representations with well-known largely political "-isms"; and secondly, ideology as a "*general* phenomenon" (p. 158, italics theirs). It is this latter view that will frame my research and specifically a definition by Machin and Mayr (2023) of ideology as "an overall world view that reflects the interests of the powerful in society" (p. 37). I will discuss more in Chapter 3.
[12]The concept of discourse is also featured prominently in this thesis and I am keenly aware of a plethora of understandings. Wodak and Meyer (2016) note the term discourse has "been subject to a hugely proliferating number of usages in the social sciences" (p. 3). I address their meanings in Chapter 3. But for now, I share the definition of discourse I use by Machin and Mayr (2023) as being "broader frameworks of interpretation" (p. 36).
[13] The disciplines of theology and philosophy are often intertwined. Schumacher (2015) provides the example of Aquinas who bridged Aristotelian thought with faith and articulates a more formal notion of "theological philosophy" where theology and philosophy "each informs and enables the purposes of the other" (p. 21). In a less formal relationship, I will carry this same spirit, drawing on a theologically informed philosophy utilizing Taylor, Tillich, and Lonergan to help bridge these disciplines in responding to the complex contemporary context.
[14] Power is a significant theme in discourse analysis and will be dealt with in greater detail in Chapter 3. I will distinguish the concept here not as a kind of force, but what Machin and Mayr (2023) suggest as "privileged access to social resources" (p. 36) that "provides authority, status and influence" (p. 36) that aligns with ACP processes.
[15] MCDA is also known by some in the field as Social Semiotics or "SocSem" as Catalano and Waugh (2020) suggest. I will outline the nuances of this in my methodology in Chapter 3. But for now, it may be helpful for the reader to know that I have chosen the approach of Machin and Mayr (2023) to use MCDA because of its ability to explore multimodally and that it allows space for other critical discourse approaches like textual analysis that is featured prominently in my thesis. A full outline of the methodological approach of MCDA within the paradigm of critical discourse analysis/critical discourse studies (CDA/CDS) will be outlined in detail in Chapter 3.

and social relevance of this study. A summary of my research questions and objectives ends the chapter.[16] I begin with a background to the topic.

1.2 Background to the Topic

1.2.1 Bioethical Background to ACP

Having provided an introduction to my dissertation, I begin this next section by outlining a brief background to my interdisciplinary topic involving bioethics and theology, starting with the domain of bioethics where my topic of ACP is situated. Foundational to Western health care is the bioethical principle of *respect for autonomy*.[17] Defined by Beauchamp and Childress (2019) as "a norm of respecting and supporting autonomous decisions" (p. 13), the concept is rooted in the philosophical work of both Immanuel Kant and John Stuart Mill—an incorporation of Kant's notion of individual control of one's choices in accordance with a moral standard, and Mill's concept of freedom to act based on one's convictions (Purtilo & Doherty, 2011). The principle of *respect for autonomy* is expressed in the field of medicine through the doctrine of informed consent that suggests the inclusion of both "autonomous authorization of a medical intervention" (Beauchamp & Childress, 2019, p. 120) and an institutional framework that exercises "conformity to the social rules of consent" (p. 120). While personal autonomy and one's informed consent to medical procedures are well-established expectations in health care, a challenge arises in contemporary medicine when one is unable to make a self-determined choice because of incapacity. With one study finding that 47% of hospitalized patients over the age of 65 being incapable of making decisions (Geros-Willfond et al., 2016), the present reality is that a significant number of serious medical decisions in the future will likely rely on a decision not

[16] It is worth noting that this chapter integrates excerpts from my formal *Research Proposal* approved by my dissertation committee and expanded upon within this context with greater detail.

[17] To provide a background, I offer only a brief outline of the bioethical notions of respect for autonomy, substitute decision-making, and ACP in this section. A fuller treatment will be included in Chapter 2 with my literature review.

immediately self-determined by a patient, but rather, through a form of substituted decision. Considering both this likelihood of one's future incapacity to make decisions and also the increased number of treatment decisions facing patients because of technological advances (Lutz et al., 2018), increased responsibility is likely to fall on a substitute decision-maker (SDM)[18] to know what an incapable loved one would choose in any given situation.

Making a medical decision on behalf of another has proven to be laden with challenging dynamics. Landmark legal cases in the 1990s demonstrated significant complexity regarding the SDM and human rights, resulting in new legislations that attempted to create clarity for an SDM (Lutz et al., 2018). One of the legislations that emerged during this time was the *Health Care Consent Act of Ontario, 1996* that sought to outline for Ontarians the role of the SDM should one be incapacitated. This Act declared that those making decisions on another's behalf must base their decision on "the incapable person's best interests" which are determined by one's knowledge of the "values and beliefs that the person knows the incapable person held when capable…[and]…any wishes expressed by the capable person with respect to treatment" (Health Care Consent Act of Ontario 1996, c. 2, Sched. A., s. 21(2)). The onus would be on the SDM to be able to authentically know their loved one's values, beliefs, and wishes (Brudney, 2009) and to be able to "don the mental mantle of the incompetent" as one judge suggested (Beauchamp & Childress, 2019, p. 140). But to shoulder this kind of moral responsibility in decision-making the SDM requires a clear understanding of another's values and beliefs that are articulated in advance to appropriately respond in any number of potential medical scenarios that may arise.

[18]This is the first time I will use "SDM" in this thesis. As noted by Purtilo and Doherty (2011) terms like surrogate, proxy consent, or substituted judgment are all used in the literature to describe decisions for incapable individuals. I use the term SDM in alignment with the *Health Care Consent Act of Ontario, 1996* with the exception of direct quotations from sources that prefer the use of "surrogate" or other terms.

ACP emerged as a movement in the 1990s in response to this increasing need for the SDM to know the expressed values, beliefs, and wishes of a loved one (Lutz et al., 2018).[19] ACP sought to provide a framework for individuals to discern, articulate, and document their beliefs and values regarding potential medical choices in the future, while equipping the SDM with the adequate knowledge needed to make a future medical decision on their behalf if needed.[20] An SDM would be able to effectively don the mental mantle of the incapable person with a sense of knowledge of their wishes. Globally, ACP programs have become widespread in what Howard et al. (2021) call "Large-scale ACP initiatives" (p. 710) that exist to support individuals to share their values and beliefs with an SDM to prepare for future incapacity. Ontario initially took part in Canada's national ACP movement that crystallized in the development of the *Speak Up* program that was developed in 2010 (Howard et al., 2021) before focusing on a specifically Ontario-based version of the program under the banner of Advance Care Planning Ontario (ACPO). It is the ACP resources found on the ACPO website that will be examined in this thesis.

1.2.2 A Theological Connection to ACP

It is at this juncture where the bioethical thread of my research begins to intertwine with the other main discipline in my interdisciplinary research—theology. On one hand, I am aware of the unique medical themes in ACP that seek to provide an adequate bioethical context for individuals to reflect on their values, beliefs, and wishes regarding future decisions, including breathing troubles, pain management, critical illness, life-support, and the future trajectory of one's current health challenges. On the other hand, I am also aware of another category of deeply

[19] Formal definitions of ACP are varied and will be explored in the literature review in Chapter 2. But a helpful summation for the reader suggests ACP is: "a process of supporting decision-making by informing, empowering, and enabling" (Thomas, 2018, p. 3). I will expand on various understandings of ACP in Chapter 2.

[20] Aligning with the *Health Care Consent Act of Ontario, 1996*, an individual can either accept the legislatively assigned SDM as chosen hierarchically or choose their own SDM. ACP processes in Ontario include resources to allow for the choosing of an SDM outside the hierarchy and also the process of naming values, beliefs, and preferences. To narrow the scope of my study I will only be examining the latter.

human and existential—what I will later name as spiritual[21]—themes present in ACP processes that intersect with one's deepest values and beliefs, grounding one's very decisions. It is this second domain of the human person that inspires my research curiosity. Considering that the health care community is asking individuals to imagine the sober possibility of grievous medical scenarios that could potentially lead to decisions regarding their own death, I wonder if our ACP processes encompass the "fullness"[22] of what is at stake in these conversations? Do our resources invite the depth of individual human reflection on values and beliefs that these potentially sober themes might deserve? Do they allow for what Taylor (1989) refers to as "strong evaluations" (p. 14) to make decisions inspired by one's unique moral orientation?

Hence, the bigger question in ACP really becomes—what qualities of value reflection might these sobering themes truly deserve? It is here where I draw on the work of Sulmasy (2006) to help articulate this connection between medicine, death, and this emerging sense of the spiritual. Referencing an Emily Dickenson poem,[23] Sulmasy asks whether we know what human meaning stirs beneath the knife of the surgeon (p. 5). And the answer Sulmasy provides, drawn from experiences in medicine and philosophy, is that stirring underneath the surgeon's knife is the "richness, power and, mystery" (p. 6) of life. It is this word "life" that is critical for Sulmasy in that it encompasses this fullness of human experience—including the uncertain frontier of death. Sulmasy remarks that "Life holds within it the seeds of death…Life is defined over and against Death—the ultimate expression of our finitude" (pp. 6 - 7). And with this, the notion of

[21]In connecting the existential domain to spirituality, it may be helpful for the reader to know that the transcultural lens I take to spirituality is grounded in a theological/anthropological approach to spirituality that echoes the work of both Lonergan (1972/2017) and Schneiders (2003) who see the human spirit on a quest. This approach enables a broad accessibility cross culturally. This will become clearer in Chapter 2 where I will explore this at greater length.
[22] Charles Taylor uses the word "fullness" to express a moral and spiritual shape to life where "life is fuller, richer, deeper, more worthwhile, more admirable, more what it should be" (Taylor, 2007, p. 5) and where "we orient ourselves morally or spiritually" (p. 6). I will utilize this word to articulate this same depth in ACP reflection.
[23] The excerpt shared is: "Surgeons must be very careful; When they take the knife! Underneath their fine incisions; Stirs the Culprit—*Life*!" (Dickenson, 1998, as cited in Sulmasy, 2006, p. 3).

serious illness is transported out of a single medical incision and into the vast existential territory of life that includes human mortality and all that goes with that. Sulmasy concludes by suggesting that the sobering theme of death is always looming in medicine: "sickness and pain are the foretaste of death… Behind every twinge of pain, beneath every wave of nausea, and within every drop of blood, the shadow of death is lurking" (p. 63). It is this palpable presence of death in illness that inspires a number of high stakes[24] questions regarding life's orientation: "troubling questions of a transcendent nature – questions about meaning, value, and relationship" (p. 17). And while some may be at peace with the thought of transcendence and what may be beyond life, Yalom (2009a) describes many patients facing anxiety around death with some being "staggered by the enormity of eternity" (p. 13) and others experiencing the "horror of their entire personal world vanishing" (p. 13). I observe in these expressions both a deep-seated fear of death, and also an existential opportunity for what Yalom calls an "awakening experience" (p. 31) where thoughts of death can present rare opportunities to define one's life and values. This notion is not unlike Taylor's (2007) observation that our unique experiences in life can inspire a sense of fullness and direction where "Our highest aspirations and our life energies are somehow lined up, reinforcing each other" (p. 6).[25] At this point, I hope the reader is beginning to see the spirit of my project that is emerging—that there is a fullness underneath illness, where thoughts of death can inspire questions of ultimate values, self-transcendence, and ultimate meaning. And these questions can potentially sprout opportunities to clarify and potentially prioritize values while bringing one's strongest evaluations into focus to help make future medical decisions

[24] I will use this phrase "high stakes" at different points in my thesis regarding death to suggest the many existential and spiritual themes that make death so significant including its finality, irreversibility, mystery, uncertainty, and the implications to one's larger web of relationships including family.

[25] These references to Yalom (2009a) and Taylor (2007) seem to suggest another benefit of ACP is a therapeutic one, inspiring a potential awakening of values and clarity that may in fact be helpful in ACP prioritization. While out of scope of this study, a future project could carry this meaningful thread further. I return to this in Chapter 5.

based on the fullest expression of one's beliefs and values. These are the qualities of reflection that are needed to address the sobering themes of life brought up in ACP processes.

This is where spirituality truly enters the conversation with ACP. Considering that Pargament's (2007) approach to spirituality includes sacred qualities of ultimacy, boundlessness, and transcendence, it is not difficult to see how one might frame the depth of human questioning arising in illness as being spiritual. These questions may involve what is ultimate, boundless, and transcendent. And with the presence of these deeper spiritual dimensions of life and death stirring beneath medicine, there is an interwovenness to spirituality within ACP where all of life can potentially come into focus with these larger questions. Pargament (2007) suggests there is an inextricable quality to spirituality that "is fully embedded in the fabric of life" (p. 21) that cannot be compartmentalized or addressed in isolation. Sandage and Strawn (2022) voice a similar caution in compartmentalizing one's experiences that can limit effective spiritual integration in therapeutic settings (p. 6). And if this interwoven quality of one's spirituality is true for all of life, it is also embedded in the work of health care[26] as well. Extending this thinking further, Sulmasy (2006) concludes that spirituality is not only intrinsic to the field of medicine but a moral obligation for clinicians to address in care. Other proponents of integrating spirituality in medicine take it even further than just the mere inclusion of spirituality in health care but actually suggest establishing it as a top priority. Pellegrino and Thomasma (1988) suggest that an Aristotle-inspired focus on the "good of the patient" (p. 73) means not just addressing the spiritual in patient care but privileging it for the fullest possible good of the patient and their decisions. This kind of prominence given to spirituality in clinical care echoes

[26] A offer a note here about the use of "health care" in this dissertation. While some utilize "healthcare" as one word, I follow the lead of Collier and Haliburton (2021) whose Canadian bioethical perspective utilizes the two word "health care" in referencing systems, resources or workers. Aside from direct quotes that include references to the single word "healthcare" I will default to the example by Collier and Haliburton (2021) throughout this dissertation.

the same holistic notion put forward decades earlier by Frankl (1946/2019) in the field of psychotherapy. And in this same spirit, Puchalski et al. (2014) have focused their efforts on the intentional development of the field of spirituality and health to "reclaim medicine's spiritual roots, helping to define spirituality broadly and to build acceptance for its essential relevance to patient care" (p. 10). My current work assumes a similar position—that addressing spirituality in the fullest capacity possible is a core obligation in health care and that this obligation extends to the domain of ACP where those engaging in value reflection need the opportunity to explore values from their own fullest and deepest lens to help orient and navigate the very serious and complicated landscape of future unknown health care decisions.

1.3 Contextual Factors Influencing Spiritual Integration in ACP

Having laid out a bioethical and theological background to my research in the previous section—including my underlying understanding of the fullness of spiritual themes looming in serious illness and death, as well as medicine's obligation to address spirituality in clinical care—I am now at a point where I can begin to explore some of the significant contextual factors present in this complex discussion. Despite the bold suggestion that addressing spirituality is a moral obligation in health care, or that it should even be given prominence, the contextual dynamics around this inclusion in the field of medicine and ACP remain complicated and nuanced**.** But what makes this spiritual integration so fraught with difficulty? The answer to this question is complex and multifactorial, involving a constellation of societal influences that I will touch on briefly in the paragraphs ahead. In particular, I will focus on six contextual factors[27] that impact the integration of spirituality in medicine and ACP processes, including: the emergence of death-denying discourses in medicine; the widespread exclusion of spirituality in

[27]It is worth noting that this summary of six contextual factors is by no means an exhaustive or comprehensive list, but my attempt to outline what I have observed in my scan of research and also my experience in health care.

the field of medicine as a whole; the challenge of defining spirituality; the diversity of spiritual belief in the present age; the tensions between individual and social expressions of spirituality; and finally, the conflict in the field of bioethics regarding spiritual inclusion.[28] After briefly outlining these six factors I will articulate the research problem that arises within this multifactorial landscape.

1.3.1 The Emergence of Death-Denying Discourses in Medicine

The first contextual factor contributing to the difficulty of integrating spirituality in ACP is the impact of death-denying discourses in medicine. While some in the field of medicine embrace death as a natural part of life (Sulmasy, 2006; Puchalski et al., 2014) and others even suggest an acceptance of death in health care discourses focusing on "a good death and the correct way to die" (Northcott & Wilson, 2022, p. 155), a death-denying perspective in Western culture is broadly observed by many in the field of medicine (Sommerville, 2000; Kübler-Ross, 1969/2003). Balboni and Balboni (2019) reference "The Camouflaging of Death" (p. 94) and a "repression" (p. 99) of emotions around death in a Western medical culture that seems to seek distance from death, while also exercising a kind of compartmentalization of the event itself. In highlighting death-denying discourses found in medical culture that influence bioethics, Sommerville (2000) observes a philosophical shift with the conversion of the "mystery of death into the problem of death" (p. 13) that is needing to be solved. In a similar vein, noted death expert Kübler-Ross (1969/2003) asks a poignant question regarding our approach to death in the West: "Are we becoming less human or more human?" (p. 23). In this question, Kübler-Ross is linking death acceptance to a fuller sense of our humanness and suggesting that to banish the

[28] I note these contextual factors only briefly here to help paint a picture of the broader landscape of the factors that impact spiritual integration of ACP. I will return in greater depth to some of these themes including death denial, the challenge of defining spirituality, and the exclusion of spirituality in medicine in my literature review in Chapter 2.

topic of death means diminishing our very humanness. Ethicists Zoloth and Charon (2002) allude to a similar dynamic in their strong criticism of medical culture, imploring the ethical community to embrace death, saying "bioethics is the profession committed to facing death directly, calling out its name, and finally, unlike medicine, finding meaning in the lost places in the clinical world where death has established its dominion" (p. 29). In response to this kind of ethical pledge, to be "unlike medicine", my own curiosity leads me to wonder about the treatment of death in ACP reflection resources. Is there a similar dynamic in ACP materials in the Ontario context where death cannot be faced directly here too?[29] If death is being backgrounded, diminished, or compartmentalized in our ACP processes, is the potential opportunity to engage in the fullness of value reflection involving one's strongest evaluations rooted in spirituality also being truncated? If Berger's (1967) assessment is correct, that society is inevitably humans "banded together in the face of death" (p. 51)[30] then how are we helping clients face uncertainty and discomfort in this reality? With philosophers suggesting the centrality of death to philosophical questions across history (Ferry, 2011) and death being noted by one theorist as "the fundamental human motivation" (Becker, 1973; as cited in Northcott & Wilson 2022, p. 153), the notion of death must be considered front and centre. Further, when considering there has been little change—and even a slight increase—in the view of Canadians regarding their belief in life after death over the past three decades, from 65% in 1985, to 66% in 2015, as Bibby (2017) points out, there is still an undoubtedly mysterious and non-physicalized aspect to death that is very alive in contemporary Canadian society. Clearly our relationship with death continues to be a factor needing attention in medicine.

[29] Sommerville (2000) asks whether a fear of uncertainty may contribute to individuals desiring outcomes that are less complex. While out of scope of this thesis, the impact of uncertainty in death is worth further exploration.
[30] I owe this quote from Berger to John A. Bernau, who references this meaningful quote in their (2020) doctoral dissertation "Talk of Death: American Discourse in Three Spheres".

1.3.2 The Exclusion of Spirituality in the Broader Field of Medicine

A second contextual factor that impacts the integration of spirituality in ACP is the well-documented exclusion of spirituality in the medical field (Pargament, 2007; Balboni & Balboni, 2019).[31] Lutz et al. (2018) describe in ACP processes an "aversion to discuss all things spiritual" (p. 667) while VanderWeele et al. (2017) describe a "relative neglect" (p. 519) of the domain of spirituality in the broader health care field. And while spirituality has pockets of mainstream acceptability in medicine, including the palliative care movement (Puchalski et al., 2014; Sulmasy, 2006), others in the field observe that spirituality is "foreign to the clinical environment" (Kuczewski, 2007, p. 4); or even the metaphorical "elephant in the therapy room" (Pargament, 2007, p. 14) often left unaddressed by clinicians. But at what cost? While the field of palliative care has designated the existential, religious, and spiritual aspects as "required domains of care" (Puchalski et al., 2014, p. 11), the suggestion by many in the field is that these themes lay dormant in health care. A 2022 global report on *Spirituality in Serious Illness and Health* concludes that "deep historical connections between health and spirituality have fragmented" (Balboni et al., 2022, p. 185) and despite significant data that links spirituality to improvement in health outcomes, "such issues remain largely outside standard considerations regarding health" (p. 185). Philosophically, this is reminiscent of what Taylor (1989) suggests as disenchantment[32] in culture where "the dissipation of our sense of the cosmos as a meaningful order, has allegedly destroyed the horizons in which people previously lived their spiritual lives" (p. 17). Dupré (2004) articulates a similar impact of enlightenment thinking that continues to

[31] It is important to note here that research I will draw on uses both spirituality and religion in various forms. I am aware of the nuances of these terms and explore them in detail in Chapter 2. For now it will be helpful for the reader to know that I utilize spirituality in a way that encompasses both spirituality and religion for reasons I will address.
[32] Taylor (1989; 2007) uses this term widely in his writing to suggest secularization and a move away from the supernatural and enchanted lens. Taylor credits Max Weber for the original usage as noted in Taylor (1989, p. 17).

influence our culture in privileging reason, while Sommerville (2000) suggests medicine has become "*intolerant of mystery*" (p. 13, italics theirs). Balboni and Balboni (2019) boldly proclaim that medicine's inhospitable relationship with spirituality needs to be confronted. Regardless of notions of client-centered care and the efficacy of spirituality in the literature, there remains an implicit discomfort with spirituality's integration in the field of medicine that may impact processes like ACP that demand deeper value reflection.

1.3.3 The Challenge of Defining Spirituality

A third factor that impacts the integration of spirituality in ACP is the lack of agreement regarding a definition of spirituality. Despite its undenied popularity in culture, the serious and seemingly unsolvable question for both researchers and clinicians remains: what does spirituality actually mean? Noted by Pargament et al. (2013) as a concept that is both multidimensional and multilevel, articulations of spirituality definitions range from descriptions of them being "vague and wooly" (Carrette & King, 2004, p. 30) to being characterized by a "considerable fuzziness" (Streib & Hood Jr. Jr., 2016, p. 5). It has resulted in what Schneiders (1989) observes as a "Dense terminological confusion" (p. 687) that has come over the academic community regarding spirituality definitions. In a systematic review of the field of health care alone, McCarroll et al. (2006) found 27 "explicitly articulated" definitions of spirituality (p. 44). From a focus on anthropological approaches to spirituality (Schneiders, 2003), to transcendent oriented definitions (Reinert & Koenig, 2013), to immanent-focused definitions (Comte-Sponville, 2006), to ontological and functional categorizations (Jastrzębski, 2023) to more religiously focused definitions (Streib & Hood Jr. Jr., 2016)—Pargament et al. (2013, p. 14) conclude that no agreed upon definition is on the horizon. Sociological work by Steensland et al. (2022) echoes a similar notion suggesting "it is misguided to search for an overarching definition of spirituality that

would work transhistorically, transnationally, and transculturally" (p. 9). This undefined presence of a significant domain like spirituality with its many discourses introduces many challenges for health care. If there is no agreement on what spirituality is, how might it be authentically integrated into medical processes like ACP to help value reflection?

1.3.4 The Diversity of Spiritual Belief in the Present Age

Intertwined with the challenges of defining spirituality, a fourth contextual factor that complicates the integration of spirituality in ACP is the diversity of spiritual belief in the present age. While individual spiritual identity was once organized into tidy religious institutional categories, these binary labels of previous generations have been transformed within a dynamic culture of individual expression characterized by multiple notions of what spirituality encompasses.[33] While mainstream institutional religion once captured the orientation of spirituality for most Canadians, religious participation has shifted drastically since World War II. Bibby (2017) notes that weekly attendance at religious services by Canadians dropped from 60% in 1945, to 25% in 2000. More recent studies suggests that number slid to 16% by 2019 (Statistics Canada, 2021). And while previous generations relied on institutional religion to navigate choices and articulate spiritual values, today's Western society is characterized by many trading "the religion of their past for the spirituality of their present" (Schneiders, 2003, p. 163). This dynamism is echoed in a recent poll suggesting 34% of Canadians have made a switch to their spiritual or religious identities during their life and adhere to a religion that is different than the one they were raised; while 20% indicated being "Spiritual, but not religious" and 19% as being "Agnostic/Atheist" (Ipsos, 2017, p. 7). Commenting on these kinds of dynamics from a

[33] Bellah et al. (2008) make a strong case for individualism as a key influence, describing one character who names her belief as "Sheilaism" (p. 221) that demonstrates the centrality of individual orientation to belief for many people.

philosophical perspective, Taylor (2007) observes a culture impacted by the cross pressures of belief that "defines the whole culture" (p. 598) within what they call an immanent frame[34] that leaves individuals in a state of flux in terms of their beliefs. Elsewhere, Taylor (1989) observes a "radical uncertainty" of many lacking a spiritual "frame or horizon within which things can take on a stable significance" (p. 27). Even existential perspectives appear to be in flux in the current age as Cox (2014) suggests in their introduction to Tillich's *The Courage to Be,* that the singular Western notion of existentialism is "an endangered species" (p. xx) and has been displaced by no single philosophy but a "larger polyphonic chorus" (p. xxi) of diversity without a single reigning viewpoint. Taylor (2007) too suggests a similar theme regarding humanists with the observation that the "camp of unbelief is deeply divided" (p. 636). And when one considers the 2.2 million Canadians with Indigenous ancestry, the upwards of 450 cultural and ethnic backgrounds, the 100 religions represented in Canada (Statistics Canada, 2022b), and a record 23% of Canadians identifying as landed immigrant or permanent resident (Statistics Canada, 2022a)—an incredibly diverse and changing cultural landscape emerges with a dizzying number of spiritual discourses at play. Considering these radical changes in the spiritual landscape over the past decades, I ask the question—how has the field of medicine begun to acknowledge a culture "awash in discourse about spirituality" (Steensland et al., 2018, p. 450) and the impact this may have on ACP?

1.3.5 The Tensions Between Individual and Social Expressions of Spirituality

Interwoven with the spiritual diversity that is present in the present age is a fifth factor that contributes to the complexity of integrating spirituality in ACP—the tensions between individual and social expressions of spirituality. While much has been written about the

[34] Taylor's (2007) concepts of the immanent frame and cross pressures within modernity are extremely helpful in articulating the present age. I reference these concepts later in this chapter, along with Balboni and Balboni's (2019) focus on immanence in medicine, when I address philosophical perspectives of the researcher later this chapter.

individual turn in spirituality (Schneiders, 2003; King, 2008), it is Pargament (2007) who suggests “we cannot decontextualize spirituality” (p. 31). Steensland et al. (2022) echo this same sentiment from a sociological perspective, observing a socially situated spirituality that is “socially influenced, enabled, and patterned” (p. 4). And while society may have a strong individualistic discourse, labeled by Bellah et al. (2008) as a “dominant ideological individualism” (p. xxxii), there is a strong acknowledgement in the field that the social aspect is inextricably connected to the individual. Even seemingly individual expressions of contemporary spirituality that are expressed in books, lectures, and online discussions are rooted in a social community in one way or another (Steensland et al., 2022). From a philosophical perspective, MacIntyre (1981/2007) observes life as “more than a sequence of individual actions and episodes” (p. 204) but contextualized within a narrative unity and communal history. While many cultures celebrate a social orientation around themes of death (Sumeg, 2014) others live in the tension between an individualized spirit found in culture, and a vague sense of the role of the social. But what are the potential impacts of these tensions between the individual and the social around themes like spirituality and death? One can get a glimpse of the potential challenges when observing the research by Bandini et al. (2017) that suggests that 25% of conflict at the end-of-life surrounds the topic of religion and one’s belief in miracles, while a study by Jacobs et al. (2008) reveals 61.3% of the general public believe miraculous healing can reverse a vegetative state. Acknowledging these potential communal and perhaps intergenerational narratives at play in conflict at the end-of-life, along with the potential cultural dynamics that intersect with the complexity of health care decisions that are demanding action, one can see the conversation regarding spiritual integration becoming even more complicated.

Observing these tensions, many in the bioethical community are suggesting a socially oriented perspective is needed, including the work of Liégeois (2021)[35] who suggests "radical consideration of a relational view of ethics" (p. 1) and Marta (1997) who suggests a collective "narrative identity" (p. 202) that invites a communal response that moves beyond disconnection. This aligns with Sulmasy's (2006) suggestion that people who are ill or dying ask relational questions like: "How does this affect my relationship with others? Upon whom can I depend? Can I achieve reconciliation with my loved ones before I die?" (p. 167).[36] And community continues to be central to many cultures around the world. As Fox and Swazey (2010) suggest, "the social structure, value system, and collective sense of meaning of many societies in the world are centred around the interconnectedness and interdependence of persons, their social ties—especially their family and extended kinship relations—and their associated responsibilities and obligations" (p. 279).[37] Social discourses are very much present in spirituality as has been outlined—but how are they both being addressed and integrated within the topic of spirituality in the context of medicine and ACP?

1.3.6 The Conflict Existing in the Field of Bioethics Regarding Spirituality

Finally, the sixth and last factor I will address that contributes to the difficulty of integrating spirituality in ACP is the present conflict that exists in the field of bioethics regarding

[35]While a focus on ethics of care is outside the scope of this thesis, the work of Liégeois (2021), in particular, informs my perspective as will be noted in the perspective of the researcher that will come later in this chapter.
[36]More than just familial conflicts, other social themes intersecting with one's community include oppressive themes like colonialism, sexism, racism, and discrimination in many forms. While out of the scope of this dissertation, these other themes are factors needing additional consideration. See the excellent book *Postcolonial Images of Spiritual Care* edited by Lartey and Moon (2020) for more information.
[37]Hodge (2019) provides an additional perspective on spirituality regarding refugees and the cultural interweaving of religion and culture, the importance of family and spiritual relationships, as well as language. While the perspective of refugees is outside the scope of this thesis, this work sheds light on the centrality of social and cultural aspects and their potential influence.

spirituality.[38] While the field of bioethics was once rooted in religion, the two have undergone a kind of estrangement or separation over decades. Noting the paradigm shift, Pellegrino and D'Arcy (2011) suggest "Theological ethics and religious commitment have been systematically excluded from the secular discourse" (p. 27)—despite their importance more broadly for many clinicians and institutions. This certainly aligns with the sentiment put forward by Murphy (2012) in their landmark article that strongly suggests "bioethics should avoid any rapprochement with religion that interferes with the ability to do its normative work" (p. 3) and their remark that ethics should "keep its distance from religion" (p. 3). Here one can observe this "battlefield" (p. 239) or "field of disputed territory" (p. 244) that Stempsey (2021) articulates, and their warning: "Banning religion from bioethics is to throw out the baby with the bathwater" (p. 245).[39] The voices are strong on both sides with Crane and Putney (2012) responding to the naysayers of religious integration by inviting reconnection of the estranged sibling-like disciplines through rigorous engagement: "Bioethics is neither so frail that it cannot tolerate disagreement nor so strong that it cannot gain strength, agility, and energy from religion…religions help us to clarify what should be, based on larger values, stories, and visions of the good" (p. 29). Stempsey (2021) boldly declares "If bioethics does not confront the ultimate meaning of our boundary conditions, it is morally bankrupt" (p. 250).

Others are working toward bringing spirituality and bioethics back together with a focus on values. In contrast to these detractors named above, Gula (2000) observes that "Spirituality

[38] It is important to note here that in Chapter 2 I will address the relationship between spirituality and religion and my suggestion that spirituality is the larger bucket that encompasses religion. In addressing this conflict in bioethics I am including religion within the domain of spirituality and will provide more detail in the next chapter.

[39] I will expand on this suggestion of a "field of disputed territory" (Stempsey, 2021, p. 244) at points across this dissertation. And while referenced towards religion, I extend the spirit of this statement to the domain of spirituality in light of my suggestion that I will name in Chapter 2 that spirituality is the larger category that encompasses the domain of religion. I will also extend Stempsey's suggestion of this dispute in bioethics to the larger culture of medicine that is rooted in similar thinking focused on rational thought.

has to do with our relationship to what we ultimately value and with our commitment to live in a way consistent with what our ultimate love demands" (p. 17). McPherson (2015) also links spirituality with ethics and notes the importance of one's orientation to the good. McPherson suggests spirituality provides orientation to one's life with an "especially strong kind of strong evaluation" (p. 337) and that "we see ourselves as moving towards or away from what we understand to be the good, which connects up with a vision of spiritual/ethical fullness" (p. 337). This aligns with the call by Gula (2000) that "Spirituality and ethics cannot remain two separate spheres" (p. 19), and McPherson (2015) who suggests "The spiritual life in the fullest sense connects up then with the ethical life" (p. 336). Making it more concrete to bioethical decision-making, Gula (2000) suggests "the moral decision to refuse treatment or to undergo treatment cannot be separated from one's spirituality, from one's deepest longing for what makes life ultimately meaningful" (p. 19). But the dynamics of this territory dispute remain and cannot be left unaddressed. My concern is that the unfortunate onlookers who may be on the losing end of this dispute are the patients who may not be given the fullest opportunity to connect their bioethical and spiritual lives in decisions that involve their ultimate values.

1.4 A Summary of the Problem

1.4.1 Addressing a Two-Fold Problem

Having outlined above some of the contextual factors that contribute to the difficulty of integrating spirituality into ACP, I will now provide a summary of the problem that my research seeks to address. Beginning with a concise description of the problem, I will then unpack the layered problem, touching on the bioethical leanings in ACP, followed by philosophical and theological layers of spirituality's exclusion in ACP, and finally, the social and systemic layers that intersect with notions of discourse and ideology that are central to my approach. I will then

link the problem I am addressing to my chosen methodology of MCDA. A rationale for this methodology will follow in the next section.

I begin now with the problem at hand. It is out of the dense contextual landscape I have described above that the complex two-fold problem I am addressing in this present study emerges. First, that the "black box" of spirituality in ACP has been inadequately explored in the Ontario context. And secondly, considering the complexity of the domain of spirituality, as well as the social undercurrents of conflict regarding spirituality's exclusion in the field of bioethics that are outlined in the literature,[40] a comprehensive examination of spirituality's inclusion in ACP must address both the complexity of spirituality itself—including the embeddedness of spirituality within themes of death and values; the multidimensional nature of spirituality; and the diversity of understandings of spirituality in contemporary society—as well as the implicit values, assumptions, and ideologies embodied in bioethical discourses that shape the inclusion or exclusion of spirituality in ACP.

Unpacking this two-fold problematic further, I highlight the work of Ammerman (2013) in this problem description who aptly describes spirituality as an "unexamined black box" (p. 260)—a reference that evocatively portrays the problem of spirituality being both complex and mysterious, while also implying that a lack of adequate exploration has occurred. Extending this metaphor to ACP is helpful in illuminating the complex and layered problem I wish to address in my research—first, that the domain of spirituality is conspicuously absent and missing in ACP research as noted by Lutz et al. (2018), and also that it is both a mystery needing examination and one that must move beyond the American perspective[41] in bioethics. Hence, I have chosen to

[40] I note here again the work of Stempsey (2021) who refers to these conflicts as a "field of disputed territory" (p. 244). I explore other voices in the literature highlighting this conflict between spirituality and medicine in Chapter 2.
[41] See Fox and Swazey (2010) and their concern around an American expression of bioethics that has been extended globally. My research will focus on a Canadian perspective—and more specifically, the Province of Ontario.

locate my research in the Ontario context within Canada where no focused and critical exploration of the relationships between ACP and spirituality has occurred previously.[42]

Secondly, considering the diverse spiritual landscape that I have described above, along with the complexity embedded in the domain of spirituality—I am undertaking a comprehensive examination of spirituality in ACP resources on the ACPO website to invite a fuller exploration of spirituality, values, and death to help further value exploration and prioritization. This second part of my problematic addresses both the complexity of spirituality and the social undercurrents of struggle involving bioethics and spirituality. Considering the high stakes involved in helping guide individuals in making value decisions intersecting with themes of serious illness and death in bioethics, we simply cannot ethically turn a blind eye to a kind of territory dispute between spirituality and medicine and the possible impact of implicit assumptions, values, and ideologies within bioethics. Respected voices in the Western medical community are strongly suggesting spirituality has been excluded from bioethics. If this is true in our ACP resources that fall within the work of bioethics, a patient-centred shift must occur that fully invites the spiritual diversity of our patients into health care once more. If respect for personal autonomy is truly the foundation of health care decision-making, then minimizing the spiritual in our resources is not only unjust, but is also unethical, in my opinion. The values within our reflective tools in ACP should not privilege the perspectives of ethicist, philosopher, clinician, or health care system, but rather, the client's best interest where the focus should be on the "good of the patient" as Pellegrino and Thomasma (1988, p. 73) remind us, with a primary rootedness in one's ultimate beliefs and values. If future decisions are related to *their* life, *their* values and *their* ultimate meaning, then there is an obligation to invite the fullness of diverse spiritual expressions in the discernment of

[42] See my literature review for a summary of ACP research specific spirituality set in the Ontario context.

values and beliefs in ACP processes. For the good of the patient, the "black box" of spirituality needs examining with a fullness that the complex social dynamics require.

And here the problematic deepens with a host of potential questions that arise in ACP resources, starting with—how is the complexity of spirituality and its various understandings represented in ACP? What do Ontario ACP resources say—implicitly or explicitly—about spirituality and its relationship with death and values? What evidence exists regarding the undercurrents of struggle that exclude spirituality from bioethics? A concrete and multilevel exploration is needed that moves beyond more surface-oriented unidimensional questions focused on *whether or not* spirituality is included, towards the fuller questions of *how*[43] content-producers think about spirituality in ACP resources that involves the complex social context.

Borrowing from the field of psychology, and the growing importance of a clinician's self-awareness regarding personal values that may impact the psychotherapy offered, the field of bioethics must begin to turn the mirror towards itself and identify what social and systemic values might be embedded in their approaches that could impact authentic patient engagement regarding spirituality. I am suggesting that turning a blind eye to this territory dispute between spirituality and bioethics may in fact reveal blind spots where self-reflexivity is needed for the field-at-large. To borrow from psychology's approach to therapy, there is no "blank screen" in terms of values when a therapist is with a client (Yalom, 2009b, p. 75). And bioethics is no different. Without the systemic self-awareness of what values, assumptions, and ideologies are being suggested by government-approved ACP resources, there is a risk of being unaware that—not unlike psychotherapy—there might be an unintentional imposing of views on a patient that may not be in their best interest and may even be a form of a kind of microaggression (Sandage

[43] I owe my extension of this question to the work of Brody and MacDonald (2013) who ask the question: "how should bioethics think about religion?" (p. 133). I am asking—how we should think about spirituality in ACP?

& Strawn, 2022). There is an active social dimension animating our resources whether it is acknowledged or not. Values can emerge unknowingly, and this may be a blind spot for bioethics that needs to be explored.

1.4.2 Unearthing the Subtle Leanings of Bioethics

But what might a concrete examination of the "black box" of spirituality in ACP resources look like? I am suggesting an exploration that involves not only the obvious explicit spiritual or religious references that may be on the surface of ACP resources, but also critically examining the subtle nuances and value leanings reflected in discourses that intersect with spirituality, values, and death. This means exploring what is foregrounded, suggested, or inferred in language, image, and design, as well as an interrogation of the silences that may reveal what may be left unaddressed or backgrounded.[44] Could it be that ACP materials are saying more about the bioethical relationship between spirituality, values, and death than at first glance? Beneath words and images may be subtle suggestions of what is theoretically privileged and affirmed. Bioethical examples of these threads in Western health care include Sulmasy's (2006) observation that medicine is guilty of reductionism and the tendency to reduce the patient to a specimen, thus minimizing holistic care that includes the spiritual domain.[45] Marta (1997) utilizes words like disembodied, rationalistic, and disconnected to describe medicine's approach to bioethics. This assessment may contribute to an isolation or compartmentalization of one's spiritual views—separating them from values, death, and bioethical decision-making. Russo (2021) describes some of the dynamics in medicine with words like "mechanistic" (p. 443) and "paternalistic" (p. 444); paradigms that may suggest a doctor-knows-best approach. Fox and

[44] For more information about how silence may be interpreted in medicine, please refer to the work of Katz, who provides an excellent treatment of silence in his book, *The Silent World of Doctor and Patient* (1984).
[45] Reductionism is foundational to the biomedical model put forth by Engels that was prominent in the 1970s that actively sought an empirical approach rather than holistic aspects (Lutz et al. 2018).

Swazey (2010) suggest a closedness to particularism in the field of bioethics with what they have referred to as a "resolutely secular orientation" (p. 279) that may not leave room for diverse belief systems. Another layer connected to ideology is the limiting of Indigenous voices through "cultural imperialism" (Stewart et al., 2017, p. xvi) that may curtail acceptance of certain cultural beliefs.[46] Finally, commenting on the intersection between secularity and religion in medicine, Berger (2015) describes the secular leanings of the Western hospital as "a temple of modernity" that operates "with a strictly secular discourse" (p. 411). These are strong words—but what might be the impact of these kinds of discourses on individual choice in ACP resources? Seeing these references to reductionism, paternalism, rationalism, modernism, and secularism found in medicine, one begins to glimpse the potential for harm in the theoretical underpinnings of power that may hamper one's bioethical choices in health care. There is a potential territory dispute informing approaches to spirituality that cannot be ignored in research.

1.4.3 Examining Philosophical and Theological Layers of Spirituality's Exclusion

Exploring bioethical leanings in ACP resources that intersect with spirituality, death, and values is only a first step. Another layer of analysis makes theoretical connections to implicit philosophical assumptions and values that have significant theological consequences. Dupré (2008) writes of the impact of modernism on religion, suggesting the objectivist language of modernity can only describe "a one-dimensional universe" (p.115), producing an impoverished perspective without ontological grounding. This dovetails with Taylor's (2007) suggestion of a "dominance of instrumental rationality in our world" (p. 542) and an immanent frame[47] rooted in

[46] While an extremely important theme to bioethics in Ontario and the broader context of Canada in light of the Truth and Reconciliation Commission of Canada (2015) this particular theme is out of scope for the present thesis, but one that needs additional attention in future study.

[47] Again, the immanent frame is a helpful concept by Taylor (2007) that outlines a background picture of the present age. I will return to this later in this chapter when looking at philosophical perspectives of the researcher.

the natural order in what he says can "slough off the transcendent" (p. 543). And with this I arrive at the theoretical concept of epistemology. Taylor suggests that the modernist picture has produced "the package of epistemic and moral views" (p. 562) that has become dominant in the immanent frame characterized by "exclusive humanism" and "disengaged reason" (p. 569). Within this new frame, Taylor suggests "The convert to the new ethics has learned to mistrust some of his own deepest instincts, and in particular those which draw him to religious belief" (p. 563). Connecting this to ACP processes, and one's individual spiritual approach to value prioritization, the question emerges—do ACP resources include this default "package of epistemic and moral views" as Taylor suggests? Do ACP resources truncate the fullest exploration of individual values and one's strongest evaluations? Do they slough off the transcendent or other spiritual beliefs? Or do they open individuals up to their own unique spirituality and values regardless of epistemological leaning?[48] And so I ask—how do ACP resources embrace the broad range of epistemologies and their varying stances towards spirituality and values related to decisions involving death? This kind of inclusion led Brody and Macdonald (2013) to suggest an enhanced version of bioethics that includes a more "comprehensive and more nuanced understanding" of people[49] (p. 133), along with the movement past a single doctrine of the "linear, Euro-centric, and teleological narrative of modernity vanquishing religion" (p. 137). Spirituality cannot be addressed within bioethics without examining the philosophical underpinnings that have theological implications for an open or closed frame in regard to spiritual inclusion for people making choices in ACP.

[48] Byskov (2021) notes the work of Fricker (2007) who refers to epistemological injustice where certain approaches are silenced within the public setting and others are privileged. See Goodchild (2021) who brings an Indigenous perspective to the social sciences, suggesting the need for "an invitation to sit in circle with us, in the sacred space of non-interference between epistemologies" (p. 99). While out of the scope of this thesis, it is worth future study.
[49] Brody and Macdonald (2013) here are speaking of a better understanding of a specifically Islamic tradition, but I extend this to ask whether a fuller understanding can be extended to all spiritual traditions.

1.4.4 Examining Social and Political Layers of Spirituality's Exclusion in ACP

Connected to the bioethical, theological, and philosophical layers of this complex problem, I arrive at the social dimension of ACP that is interwoven with the concepts of death, spirituality, and values. While the philosophical and theological dimensions inform some of the conceptual underpinnings in ACP, it is the social and political[50] dimension of bioethics that animate these theoretical concepts and motivate their action. While I have touched on the edges of the social domain in previous paragraphs, this examination of spirituality in ACP needs to be extended to explicitly address the social dynamics that may be looming. Inevitably, power and influence enter the conversation in regard to what ideologies are knowingly or unknowingly underpinning ACP resources and how they might impact spiritual integration in value reflection and prioritization. I am asking—what is socially embedded within the words that lend to an openness or closedness to spirituality? Or using Dupré's (2004) phrase, what might be the "prevailing ideologies" (p. 312) that impact spiritual inclusion in value reflection? The notion of discourse, defined by Fairclough (2001) as "language as a form of social practice" (p. 16), or by Kress and van Leeuwen (2001) as "socially constructed knowledges (of some aspect) of reality" (p. 4), can be extended to ACP resources with the assumption that "linguistic phenomena are social in the sense that whenever people speak or listen or write or read, they do so in ways which are determined socially and have social effects" (Fairclough 2001, p. 19). Hence, the question regarding spirituality in the social and political domains becomes—what is informing spirituality's situatedness in these resources? Considering ACP resources are more than simply

[50]Much like the terms of ideology, discourse, and power, the word "political" is also charged with many meanings that I explore further in Chapter 3's methodology. But I will suggest my views align with Gee (2014) who suggests all language is political in that it involves giving "perspectives on the distribution of social goods" (p. 87). But I will not be referring to any formal political party or doctrine which is another layer outside the scope of this thesis.

words and pictures on a webpage, I am interrogating what power and ideology might be implicit in these discourses that may consciously or unconsciously guide one's future medical decisions.

While medicine would fashion itself as claiming "indifference or neutrality concerning the spiritual dimensions of illness" as Balboni and Balboni (2019, p. 205) suggest, these same authors would conclude "meanings of spirituality and religion are tethered to perspectives and to underlying motives of power and social control" (p. 199) that outline a deeper power structure. Fox and Swazey (2010) take this notion of power even further, criticizing bioethics by suggesting a "hegemonic thrust" (p. 279) of an American expression of bioethics that is not only individualistic, but polarizing of universalism and particularism. I am asking whether there is evidence of a theoretical disconnect between bioethics and spirituality that systematically limits the integration of spirituality in ACP resources. Goodchild (2021) references epistemological injustice in the privileging of one way of knowing—rationality—rather than an openness to diverse perspectives.[51] In these brief references to the deeper assumptions in bioethics, one can see the complex and multilayered social problematic that emerges philosophically and its impacts theologically as I critically explore the "black box" of spirituality in ACP in the Ontario setting. And so, I ask—what are the power relations that may be implicit in ACP resources that influence social actions? What theoretical perspectives might ACP be tethered to? And what is the impact on spiritual inclusion in ACP?

1.4.5 Addressing this Problematic Through MCDA

And so, I arrive at my chosen methodology that aligns with this two-fold problematic: that spirituality is inadequately examined in ACP in Ontario; and that considering the complexity

[51] Extending this ideology further into indigenous contexts in Canada, Stewart et al. (2017) suggests "hegemonic ideologies of surrounding settler societies" are needing to be reconstituted (p. vii). While an important theme in the Canadian context, additional elaboration is out of scope of this thesis.

of spirituality and the social undercurrents of conflict regarding spirituality's exclusion in bioethics, an examination must involve a methodology that explores both the complexity of spirituality, and the social undercurrents involved. The approach I have chosen to address this problem is centered around critical discourse that I will allude to only briefly here.[52] Critical Discourse Analysis (CDA), referred to more recently as Critical Discourse Studies (CDS),[53] is the broader theoretical paradigm I have chosen to analyze ACP resources because of its ability to socially analyze the nuanced language and complex underpinnings of complex problems. Wodak and Meyer (2016) describe CDA/CDS as a problem-oriented and interdisciplinary approach with a goal of "*analysing, understanding and explaining social phenomena that are necessarily complex*" (p. 2, italics theirs), and a paradigm "interested in analyzing hidden, opaque, and visible structures of dominance, discrimination, power and control as manifested in language" (p. 12). Further, CDA/CDS seeks to "reveal ideologies, showing how and where they might be buried in texts" (Machin & Mayr, 2023, p. 38). Considering the complex notion of spirituality, and the social undercurrents of conflict present in bioethics, this approach holds tremendous potential to help reveal what may be buried in ACP regarding spirituality.

In order to adequately examine spirituality in ACP with a sufficient depth to address the complexities and also the social undercurrents that may impact spiritual inclusion in an Ontario context, I am examining primary client-facing ACPO resources located on a centralized Ontario website (Hospice Palliative Care Ontario [HPCO], n.d.-a) that includes many resources including

[52]A background to critical discourse includes elaboration on notions of discourse, ideology, power, criticism, and language. In Chapter 3 I will go into greater detail on these terms and my methodology informed by the paradigm of critical discourse analysis/critical discourse studies (CDA/CDS).

[53] The rationale provided for utilizing CDS is that the workings of CDA do not involve a single method, but rather, a collection of methods and applications not captured in CDA that implies a single approach (van Dijk, 2013, cited in Wodak and Meyer in (2016). Hence, I will use CDA/CDS to capture the larger paradigm of critical discourse in this thesis while respecting the larger history, but utilize MCDA to refer to my specific methodological approach articulated by Machin and Mayr, (2023). A fuller explanation will occur in Chapter 3.

a resource guide, videos, ACP workbook, character stories, and frequently asked questions. Examining a website provides a concrete starting place to analyze the situatedness of spirituality in the context of death and value reflection, providing opportunity to analyze multiple expressions on a single site geared for Ontarians completing an ACP plan. Fairclough (1992) suggests a critical discourse approach has potential to be "both theoretically adequate and practically usable" (p. 1) which extends well to my focus on ACP. I believe this balance of what is theoretical and concrete that is embodied in CDA/CDS makes it a suitable interdisciplinary approach to the problem I wish to address. As will be described more fully in Chapter 3's focus on methodology, I am taking a methodological approach utilizing Multimodal Critical Discourse Analysis (MCDA) that is inspired by Machin and Mayr (2023) who take into consideration what is being revealed in both text and also other modes of communication.

In summary, before any recommendations can be made about spirituality in ACP, a thorough, concrete, and multilevel exploration needs to be undertaken to examine the current state of the "black box" of spirituality within ACP—including both the complexity of the domain of spirituality and also the underlying discourses and ideologies that may be present that may influence the openness or closedness in regard to spiritually integrated value reflection. I offer a fuller description of the methodology in Chapter 3 but now address a rationale for my approach.

1.5 Rationale

In this section I will explore my rationale for taking the MCDA approach in examining the ACPO website, including the concrete nature of this approach, the richness of exploring multiple modes of communication on a website, and the centrality of a single website that encapsulates authoritative bioethical perspectives for focused examination. I also explore my rationale for utilizing an interdisciplinary approach, as well as my theoretical methodology

rooted in MCDA rather than a phenomenological one. I close this section with reflection regarding my choice to examine ACP within Ontario and my rationale for a normative approach—a theme I explore later in the chapter focusing on the perspective of the researcher.

I begin by providing a rationale for my choice to critically examine the ACPO website through MCDA to address my research problem. As the central client-facing resource and channel of communication for ACP in Ontario, the ACPO website provides a unique, concrete, and unfiltered glimpse into what content is immediately available for those wishing to interact with ACP processes. Containing resources that are open to the public without relational interaction, the resources speak for themselves, presenting a unique opportunity to analyze the same bioethical content available to all Ontarians without interpersonal dynamics or the interpretive aspects that human communication of ACP might bring including the gestures, facial expressions, or body language of a clinician. This lends a level of control to the research, allowing analysis of resources to stand on their own merit within the established boundaries of a single website providing an excellent opportunity to examine the resources in and of themselves as a catalogue of available documents. Analyzing resources on the ACPO website provides an authentic opportunity to explore a concrete representation of where spirituality is publicly situated in Ontario at the present time.

In addition to the concreteness of exploring a website for its situatedness of spirituality, another benefit of examining the ACPO website is the uniquely multimodal nature of the website that enables reflection regarding multiple modes of communication and different nuances present in each. Media representation on the website includes resources like videos, client stories, reflection resources, glossary, and a frequently asked questions page—all contributing unique perspectives regarding spirituality's situatedness. With images, graphics, and design being

intertwined with textual description, there is a richness to the multiple modes in MCDA that provide an opportunity for interpretation and analysis from different vantage points that will provide a clearer picture. A diverse examination of discourse, values, and ideologies from the vantage point of multiple perspectives lends to broader perspectives and greater validity.

In addition to concreteness and multimodality, a centralized website provides a kind of focused repository for authoritative perspectives on ACP that have been produced by bioethicists and other health care content-producers who are invested in ACP. Considering that these resources have been—presumably—vetted by experts under some kind of bioethical jurisdiction or oversight, there is an authority presented here that can be more explicitly examined. The website makes for an excellent sample of current thinking—a kind of litmus test of how authorities, be it researchers, educators, or bioethicists, locate spirituality in ACP in Ontario. Taking a critical lens to the website itself enables a glimpse into the authority revealed in Ontario's approach to ACP and what it may suggest about social positioning regarding spirituality, values, and death.

This leads to a final reason for engaging in this approach. In addition to the opportunity for concreteness, multimodality, and the opportunity to observe authoritative perspectives on ACP, another reason for choosing an MCDA methodological approach to analyzing the ACPO website is in its layered ability to critically examine the complexity of spirituality and the undercurrents of conflict within bioethics that exclude spirituality. MCDA provides opportunity to critically explore multiple layers that include philosophical, theological, and social aspects of the field of bioethics revealed in ACP resources. MCDA provides perspective from different angles, aligning with what Kress and van Leeuwen (2021) suggest that "meanings are 'realized' differently in each mode" (p. xiv) and that they also are "in constant interaction with one or more

of the other modes" (p. xiv). Hence, MCDA provides a fuller lens of potential understanding. Considering the complex social underpinnings that I have referenced throughout this chapter, an approach is needed that can explore the discursive and ideological threads of these tensions between spirituality and medicine with a critical and theoretical lens to address the complexities of this struggle. From questions like Frank's (2019) wondering of whether medicine needs ultimate values at all, to Murphy's boldly irreligious stance (2012), to Sommerville's (2000) insistence on a science and spirit approach—my chosen methodology allows for the philosophical, theological, and social layers of this conversation to be critically examined.

With this multilayered theoretical approach, I believe that it may provide a foundation for future studies that can extend the conversation regarding spiritual inclusion further to methods like surveys or focus groups. A methodological approach like the one I am utilizing can provide a strong theoretical grounding for future phenomenological research that can serve to extend, and possibly test, the theoretical findings of this thesis with lived experience. And while I considered a phenomenological approach to address the problem at hand, it was clear that a theoretical and critical foundation for this topic was essential to engage with first because of the social complexity of the topic and the theoretical underpinnings that needed addressing. Additionally, a mixed-method approach was also considered—an approach that engaged the topic of spiritual integration in ACP first theoretically through a MCDA methodology, and secondly through a follow-up phenomenological approach—but it was deemed out of the scope for a single dissertation and better saved for a post-dissertation study. I anticipate a post-dissertation study that can extend the findings of this thesis phenomenologically.

As for my choice of geography in my study, I chose the Canadian context of Ontario because much of the research regarding bioethics and spirituality takes place in the American

context. Fox and Swazey (2010) boldly suggest that the American model of bioethics has been "exported to other countries and of what we have called the 'cultural myopia' that American bioethicists have frequently displayed in failing to recognize some of the American cultural patterns that are embedded in their thought" (p. 279). Heeding this acknowledgment, it is important to address the issue of spirituality within ACP from a specifically Canadian (Ontario) lens—a lens that has not adequately been addressed. The other importance in choosing a Canadian context is in response to Stempsey's (2021) suggestion of insufficient attention paid to multiculturalism in ethics.[54] With Ontario's rich demographics regarding diversity, this thesis seeks to contribute to a body of research that embraces the present diversity and ethically takes into the account the importance of diversity, inclusion, and belonging in ACP.

As for focusing specifically on the Ontario context within Canada, my choice is inspired by Ontario's proactive approach to decision-making regarding the SDM. Mindful of the provincial jurisdiction of health care in Canada, Ontario's legislation is clearer and more comprehensive than other provinces. In outlining how the SDM is to make decisions based on a loved one's best interests, *The Health Care Consent Act of Ontario, 1996* outlines with clarity the role of the SDM with a unique focus on: "values and beliefs that the person knows the incapable person held when capable" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A., s. 21(2)). This clarity is unique to Ontario, inspiring an imperative for ACP processes in Ontario, while solidifying expectations for the SDM to understand what values and beliefs are important to the patient before they became incapable. This focus on values, in particular, is especially congruent with the dimension of spirituality, opening a door to explore the fullness of this

[54] Considering the uniquely Canadian context, and a commitment to multiculturalism and addressing harms as noted by the Truth and Reconciliation Commission of Canada (2015), I observe the need to affirm bioethical structures that more fully address the spiritual needs of Indigenous peoples—respecting epistemologies that function outside the empirical frame of Western medicine. I observe positive examples of this very sensitivity in Chapter 4 and 5.

phenomenon in client-centered care. In addition to the robust systems in place in Ontario that offer client-centred spiritual expression through values, considering the researcher's own situatedness within the province of Ontario for work, an Ontario study may also present integrative potential and future study opportunities.

In terms of choosing an interdisciplinary approach to this study, considering the social complexity of the problem outlined above and its overlap with several disciplines adjoining the field of medicine—especially bioethics and theology—I decided that an interdisciplinary approach integrating MCDA is the most comprehensive option. Repko and Szostak (2021) suggest interdisciplinary studies can be divided into instrumental approaches that are problem driven and are led by societal demands, and critical approaches that seek transformation in the academy by interrogating dominant structures. Because of the mix of theoretical analysis and concrete patient-facing engagement, my research suggests a bridge between these two approaches where I am seeking instrumental and critical change in ACP processes that could potentially help patients facing future health care decisions. Drawing on the potential of this critical methodology as noted by earlier by Fairclough (1992) as "both theoretically adequate and practically usable" (p. 1), I am acknowledging complex discursive and ideological aspects in this thesis that impact change that is underneath the surface. And committed to an "epistemological pluralism" (Repko & Szostak, 2021, p. 11), an interdisciplinary approach presents a unique lens to deal with the conflicting perspectives that contribute to a complicated landscape for change. A single discipline or perspective would simply not be able to tackle this problem effectively. The complexity of this "black box" of spirituality within the dense ideological landscape of medicine requires an interdisciplinary approach that can examine multiple dimensions present in ACP.

Additionally, the personal and normative leaning in my approach purposefully aligns my critical approach to discourse, as van Dijk (1993) suggests the importance of being "unabashedly normative" (p. 253) in the research, and that "critical discourse analysts (should) take an explicit sociopolitical stance: they spell out their point of view, perspective, principles and aims" (p. 253). Hence, the positionality of the researcher is essential, as Wodak and Meyer (2016) suggest, that researchers "attempt to make their own positionings and interests explicit while retaining their respective scientific methodologies and remaining self-reflective of their own research process" (p. 4). In this normative spirit I carry out my thesis and will outline my own perspective in the section below to ensure a clarity of assumptions and theoretical values I bring to my work.

Finally, in the spirit of exploring discourse and ideology, it is important to note my choice to see spirituality in ACP as potentially an ideological problem. In observing ideology, Fairclough (2001) describes the dimension as the "relatively neglected ideological dimension" (p. 2). While the nuances of this term are debated, there is a clear presence of ideology in bioethics that I will unpack. As an example, Fox and Swazey (2008) summarize Callahan's (2003) suggestion of an ideology of liberal individualism "that has come to prevail in bioethics" (p. 168). This suggestion of ideology in bioethics is an important distinction to make because it acknowledges bioethics is not a value-neutral enterprise but one with a value system that underpins its work—aligning with what Gee (2014) suggests in their assessment that everything is political in that it influences decisions around social goods, as values "enter in" (p. 73) to conversations and discourses referencing historical debates. It is these underlying and embedded themes that need unearthing in bioethical materials to help examine the power within resources that may open or close opportunities for inclusion of spirituality in ACP value reflection. Ideology, within the context of other critical terms I will explore including power and discourse,

will provide a unique lens to observe the struggle between spirituality and bioethics in ACP that may also influence an openness or closedness in value reflection.

1.6 Perspective of the Researcher

1.6.1 Positionality

As noted in the paragraph above, a central characteristic of CDA/CDS is the perspective of the researcher. Aligning with this transparency and openness, I offer my own normative perspective and articulate in detail below the assumptions that influence my approach to examining spirituality in ACP. As a white male of Western European descent, I am privileged to be living in a rural Ontario setting with a wife and three children. I acknowledge that my own decade-long experiences in providing institutional spiritual care and chaplaincy support in end-of-life situations frame my normative perspective in wanting to provide opportunities for conversations to be deeper and respectful of multiple spiritual expressions. I have provided support for countless individuals facing serious illness and death in various health care contexts across southern Ontario. At the time of writing this thesis, I am also the manager and professional practice leader of a spiritual care department in a Catholic health care system in southern Ontario, holding credentials as a Certified Spiritual Care Supervisor/Educator through the Canadian Association for Spiritual Care and as a Registered Psychotherapist with the College of Registered Psychotherapists of Ontario. Outside of my employment, I serve a local congregation in my spare time in a volunteer capacity as an Anglican Priest in a small urban parish. Raised in a Mennonite Brethren family where both my father and grandfather were ordained ministers, my upbringing is deeply rooted in Christian spirituality with a heightened sense of value given to spiritual and religious practices and service to the community. And while I identify as Christian religiously, my spirituality has diversified over the decades to integrate

other lived spiritual practices like eco-spirituality, songwriting, art, and narrative expression. While identifying as Christian, and working in Catholic health care, my own philosophy, and how I choose to lead the spiritual care department I oversee, is in a client-centred frame, helping individuals discover their own unique spiritual perspective and personal spiritual orientation. I strive towards a practice that invites inclusion and diversity, seeking to be aware of the impact of colonialism and the power dynamics implicit in institutional health care.[55]

1.6.2 Theological Perspective

I also bring a strong theological lens to my bioethical work. Drawing on the suggestion provided earlier, that interdisciplinary research requires multidimensional perspectives to address the problematic "contested space" between disciplines (Repko & Szostak, 2021), my interdisciplinary work is focused on analyzing the contested space regarding spirituality within ACP, an examination that spans my two home disciplines—bioethics and theology. But it is important to note that the transformative role I see for theology in ACP is not through suggesting *a* theology for ACP, but instead, an openness to utilizing a method in theology[56] that underpins my research, that I hope can be extended from the partial usage in denominational and multifaith contexts, and into the full diversity of spiritual beliefs present in society. I will do this by connecting the detective work implicit in my theological approach, to the detective work needed in MCDA.[57] I believe theology is still relevant in bringing a unique perspective to illuminate the imagination around spirituality that is needed in health care. As stated earlier, in death, one's

[55] See Cadge and Rambo's (2022) collection *Chaplaincy and Spiritual Care in the Twenty-first Century* and *Postcolonial Images of Spiritual Care* edited by Lartey and Moon (2020) for perspectives that undergird this postcolonial aspiration I have.
[56] As noted earlier, I draw on Lonergan's (1972/2017) approach to a method in theology that seeks a transcultural viewpoint, articulated by Gregson (1985) as being beyond religion, towards a "spirituality" that is accessible to all.
[57] Interestingly, both the theologian Lonergan (Lonergan, 1978, p. x, as cited in Gregson, 1988, p. 16) and the MCDA work by Machin and Mayr (2023, p. 6) both use the image of "detective" to outline their methods. I too utilize this metaphor and will act as detective, examining ACP and drawing on both.

existential questions emerge—including philosophy, and its historic co-traveler of theology. The theology I am suggesting is rooted in the spirit of theologians like Tillich who have linked philosophy with a generous approach to theology. Reflecting on Tillich's writing in the 1950s, Cox (2014) suggests that Tillich's approach is extremely relevant for contemporary society with their prior suggestions that theological notions like "God" were "distorted" and "evacuated of meaning" (p. xxiv) which inspired Tillich's use of the word "depth" instead of "God" to cultivate this larger theological space. While this concept seemed audacious at the time, fast-forward some 70 years to the present transcultural context with hybridized spiritualities and diverse theological and existential understandings, and one can see Tillich's work was perhaps ahead of his time as a "boundary-crosser" (Cox, 2014, p. xxii) and extremely relevant today. I stand with Tillich in suggesting that theology is not only still a useful lens for those of traditional religious persuasions, but a transformational lens that can help open the ethical imagination as Sommerville (2006) would say.

In the context of death that is present in ACP, my theological perspective also invites "the much more besides" as Gregson (1988, p. 16) notes, summarizing Lonergan's perspective that aligns with that of Tillich. With death in the room as clients face sober future choices, I believe theology's sense of imagination can help inspire clarity around ultimate values—something so central to ACP. But my theological imagination is rooted not only Tillich. In considering the centrality of value reflection and prioritization to ACP, my work is also rooted in Lonergan's (1972/2017) transcendental method. Lonergan's work focused on human desires moving through levels of consciousness: through experiencing, to understanding, to judging, to deciding—all in what Lonergan describes as "the unfolding of a single thrust, the eros of the human spirit" (Lonergan, 1972, p. xix, as cited in Gregson, 1988, p. 16) or what is named by Conn (1988) as a

"radical dynamism of the human spirit" (p. 36). The process moves through each layer with what Gregson (1988) describes as a "search for any and everything that might be intelligible or true or good and our capacity to recognize when we have found it" (p. 25). The process moves deeper into their scale of value preferences which is a prioritization based on levels from vital, to social, cultural, personal and finally religious value in ascending order. Drawing on Gregson (1985), I translate the final, and highest category from religious to that of spirituality to be inclusive of all beliefs—a transcultural and ultimate place that inspires the fullest reflection.

1.6.3 Relational Perspective

I will also name my own relational and community-oriented leanings that inform my perspective that can move into the ethics of care.[58] Liégeois (2021) talks about an approach that considers "all dimensions of the being human" (p. 21) and an "openness and commitment to people and the world other than ourselves" (p. 21). They talk of a sense of responsibility humans have to each other and a reciprocity within a relational paradigm—that also moves into embracing tensions that are present in relationships and value discussions. This links to Taylor's (1989) work that suggests a "fundamental orientation" that "defines where you answer from" (p. 29). And having walked alongside many clients on the path to death, I sympathize with those facing the cross pressures[59] of culture alone when making significant decisions. I stand with Taylor (1989) in grieving the loss of "the given historical community" (p. 37) that provides "spiritual bearings" (p. 37). Having walked alongside many facing death and uncertainty, I bring

[58] Beauchamp and Childress (2019) position ethics of care within the family of virtue ethics with an emphasis on "intimate personal relationships" (p. 35) while Purtilo and Doherty (2011) suggest it assumes a whole person approach that looks at trustworthiness in relationships as central to care. While ethics of care implicitly informs my perspective, this thesis is not focused on ethics of care and is outside of the scope of this study. I share with the reader only to outline what assumptions and values I bring to this study.

[59] I will also make a nod to Taylor in the next paragraph, but for now "cross pressure" (p. 598) is a concept Taylor (2007) uses to describe a culture "suspended between the extreme positions" (p. 598) of conflicting beliefs including immanence and transcendence, or belief, or unbelief.

this sense of communal sensibility to my approach with a wish to help situate people's experiences within their story in ACP reflection. I echo the words of MacIntyre (1981/2007) who suggested people can only answer the question "What am I to do?" if they can answer a previous question "Of what story or stories do I find myself a part?" (p. 216). With ACP asking value questions of ultimate meaning, I believe in the significance of linking one's self to a larger story may help with clarifying and prioritizing values.

1.6.4 A Philosophical Perspective Rooted in Both Transcendence and Immanence

Another key theoretical perspective I bring to my research aligns with the theologically inspired philosophical work of Taylor (2007) that I have mentioned at different parts in this dissertation. Taylor makes an important distinction in the modern age between the immanent[60] and transcendent[61]. Taylor widely uses the term the "immanent frame" (p. 542) in modernity that is rooted in rational and disciplined thinking rather than openness to the transcendent. Taylor suggests there is a default setting in society that privileges immanence rather than transcendence. And while secular society may default to this closed immanent frame, individuals are marked by tension, confusion, and puzzlement in the face of cross pressure between immanence and transcendence. This approach not only provides a theoretical model to inform the struggles I have described regarding the lack of inclusion of spirituality in bioethics, it also provides a model for spiritual diversity. While some would suggest a focus on immanence in medicine is problematic because of its disproportionate attention to the physical (Balboni & Balboni, 2019) I extend Taylor's (2007) model to suggest the need for an openness to both the immanent and the

[60] Immanence is defined in different ways. Philosophically, Taylor (2007) suggests it as a Western invention where nature is "systematically understood and explained on its own terms" (p. 15). From a medical perspective, Balboni and Balboni (2019) define it as "a fundamental centering on bodily health, cure, and physical comfort as chief affection or ultimate concern" (p. 221).

[61] Transcendence is described by Taylor (2007) with words like supernatural or "something ontically higher" (p. 544) and from a medical perspective, Balboni and Balboni (2019) use words like soul and the sacred. I address perspectives on transcendence in spirituality in Chapter 2 in the section focusing on defining spirituality.

transcendent in bioethics. I believe in an openness of perspective that must embrace all beliefs—whether rooted in immanence or transcendence as this is the core of following one's own values. I am committed to a health care system that has intentional openness to all expressions[62] of spiritual belief—beyond just the potentially closed default setting of immanence, enabling individuals in ACP to make sound value choices.

1.6.5 A Belief in Both Science and Spirit

Broadening my own philosophical positioning within the health care field, I do not believe in spirituality only, or science only, but count myself as standing with Sommerville (2000) in suggesting "it is only through an undivided science-spirit approach that it will be possible to tell a collective story—to create a societal-cultural paradigm—of sufficient depth, breadth and width to capture our collective mind, heart and imagination. It will be the greatest challenge of the twenty-first century to realize the potential of this view" (p. 21). For the good of the patient, an openness to both science and the spiritual must emerge from this territory dispute and "confront the ultimate meaning in our boundary conditions" (Stempsey, 2021, p. 250). Academically, I believe that for a domain like spirituality to be inclusive of all beliefs and traditions manifest in a diverse province like Ontario, an epistemology must extend beyond just secular approaches.[63] I suggest a theoretical stance inspired by Aristotle's view of the good, as extended to medicine by Pellegrino and Thomasma (1988), who privilege the ultimate good of the patient, suggesting that "the ultimate good is the reference standard for all decisions, including clinical decisions" (p. 77)—a notion not unlike Lonergan's (1972/2017) hierarchy of

[62] Further to the diversity of understandings of belief that interest with ideology, I appreciate Taylor's (2007) assessment of the present age calling for a "new, more nuanced map of the ideological terrain" (p. 636).
[63] As noted previously, Fox and Swazey (2010) describe a "resolutely secular orientation" (p. 279) in bioethics while other secular descriptions include reductionistic (Sulmasy, 2006); modernistic (Berger, 2015); and rationalistic (Marta, 1997) that are dominant in health care.

value[64] that portrays a depth of holistic decision-making that has a scientific journey and a spiritual destination. A richer decision-making process in ACP is needed, integrating opportunity for a fullness of spirituality that links both science and spirit.

1.6.6 Underpinning of Critical Realism

In terms of a theoretical background, a key lens for my dissertation is critical realism that aligns with perspectives of both Lonergan (Liddy, 1993) and CDA/CDS (Fairclough, 2003). Hiebert (2008) suggests some approach critical realism as "a humble, more nuanced form of realism" (p. 259). In this "It is 'realist because it affirms that there are entities existing independently of our perceptions or theories…It is 'critical' because it recognizes that our understanding of those realities is always subjectively interpreted by humans in their social, cultural and historical contexts" (p. 259). Critical realism affirms the importance of ontology. Drawing inspiration from Bhaskar (2008), Ash (2022) suggests "a depth realist position and so differs from both idealism—by holding that the world is real—and positivism—by holding that there is depth to reality" (pp. 1 - 2). Critical realism also aligns with the work of Lonergan that underpins the scale of values (Liddy, 1993) that outlines Lonergan's concept of intellectual conversion as directed toward critical realism, and that one cannot confuse the "immediate world with the far larger world" (p. xvii). Liddy notes Lonergan's thinking that "It is this larger world mediated by meaning that we refer to when we speak of the real world" (Liddy, 1993, p. xvii). Epistemologically, this aligns with Lonergan's transcendental method in moving beyond just observing the world to the suggestion they make that "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27). A fullness happens through subjectivity and this kind of intellectual conversion—thinking that underpins my thesis.

[64] I will touch further on Lonergan's (1972/2017) scale of values in Chapter 2 when addressing value hierarchies and prioritization; returning to it again in Chapter 5 in recommending the enrichment of value discernment in ACP.

1.6.7 Critical Perspective to Research

Finally, adding to the underpinning of critical realism is my methodological approach using MCDA within "Critical Discourse Studies" and is inspired by the word "critical" that demands some exploration around my beliefs around this term and how I utilize it. While some in the field utilize a capital-C in connecting "critical" to the larger Critical Theory movement and the Frankfurt School[65], researchers like Gee (2014) bring a broader approach to being critical suggesting the need to move beyond description to criticism as all modes of language are political as they "inherently involve social goods and the distribution of social goods" (p. 10) and the need is to "illuminate problems and controversies in the world" (p. 10). For Gee (2014) "all discourse analysis needs to be critical" (p. 9) because of this political aspect of language. Machin and Mayr (2023) suggest critical means a denaturalization of "the language used in order to reveal the kinds of ideas, absences and taken-for-granted assumptions in texts" (p. 9) that reveals buried interests of the powerful. I orient to the small-c critical, unearthing hidden ideologies and discourse in ACP. Additionally, in critically analyzing potential ideologies in ACP resources including individualism, instrumentalism, reductionism, physicalism, and rationalism, I take a normative approach in suggesting an existential and transcultural spiritually integrated approach.

1.7 Relevance of the Subject

The academic relevance of this subject involves both the importance of MCDA, and also an exploration from an Ontario perspective that will provide a solid contribution to knowledge that can be extended to other parts of Canada. MCDA has not been used to critically study ACP resources in Ontario focusing on spirituality. Considering the socially complicated discourses and ideologies surrounding death, spirituality, and values in a diverse province like Ontario, a

[65] I note here that I will be elaborating on Critical Theory and its connection to CDA/CDS in Chapter 3 when focusing on the critical perspective underpinning this paradigm.

discourse analysis will serve to deepen theoretical understandings of discourse and ideology that have potential to narrow or hinder spiritual expression for some.

Academically, I am also extending the theoretical dimension and enabling a concrete and critical textual and visual analysis of existing resources that will open up discussion surrounding ACP. This research advances the conversation in medicine with significant opportunity for spin-off qualitative research like phenomenological or ethnographic approaches. And secondly, I am advancing ACP and spirituality from an Ontario lens that will contribute to a broader assessment of the Canadian context. Lutz et al. (2018) suggest a gap exists in conversation regarding spirituality and ACP and my dissertation is a significant step in engaging the ACP conversation surrounding spiritual discourses—and from an Ontario lens with potential for future extensions to other parts of Canada.

In terms of social relevance, my study takes a significant step in deepening respect for diverse expressions of spirituality within Ontario. Considering the spiritual landscape in society is tremendously diverse, our resources have simply not kept up with the dynamic changes manifest in Canadian spiritual demographics nor other multicultural changes as mentioned in the contextual factors provided earlier in this chapter. My study helps focus on the current state of ACP with a goal to expand opportunities for diverse spiritual expressions in order to help engage the fullness of decision-making.

Beyond the spiritually diverse landscape in Canada, another primary social contribution to my research is the harnessing of the potential of spirituality to help patients prioritize values in decision-making processes at end-of-life. An initial glimpse of ACP resources in Ontario reveals a perspective of spirituality largely as a compartmentalized menu item to provide comfort, end-of-life ritual, or general reflection. And while these expressions are important, they represent

only a fraction of spirituality's potential. I observe a deficit in ACP resources and an inability to draw on the fullness of spirituality to prioritize values. My research illuminates present discourses of spirituality in Ontario ACP resources in order to make key integrative spiritual suggestions. To answer the earlier question from Kübler-Ross (2003), I want to advance a more human health care that embraces death as part of being fully human and provide opportunity to enrich ACP choices and inspire the fullest reflection of values.

Aligning with this, my research also seeks to invite a reconnection of the domains of death and spirituality. As noted earlier, there is a call by some in ethics to be on the front line of death, as Zoloth & Charon (2002) note: "bioethics is the profession committed to facing death directly, calling out its name, and finally, unlike medicine, finding meaning in the lost places in the clinical world where death has established its dominion" (p. 29). While this bold expression invites a fuller treatment of humanity, I observe bioethics doesn't always wade deep enough into the waters of death, stopping short of a deeper aspect of meaning—spirituality. Sulmasy (2006) suggests death looms in illness which makes it a spiritual event: "Illness grasps persons by the soul as well as the by the body and disturbs both" (p. 17). Death, values, and spirituality cannot be disentangled and need to be dealt with together. This dissertation holds tremendous potential to examine existing ACP resources for spirituality as an initial step to advance this connection for the good of the diversity of each patient.

Finally, this thesis seeks to make a significant contribution to the examination of the social undercurrents of struggle between bioethics and spirituality that are implicit in medicine. The conflict regarding spirituality and medicine is well documented and needs a concrete examination. In taking a critical discourse lens to this topic, I not only engage in a layered conversation regarding hidden and buried discourses, values, assumptions, and ideologies

implicit in ACP in Ontario, but I do so in a concrete way in analyzing a website with centralized resources. This approach socially engages these deeper layers intersecting with the complex notion of spirituality while also concretely addressing the immediate and available resources in the present moment. This approach will help further the conversation in health care regarding spirituality's inclusion and provide additional analysis that can be extended in future.

1.8 Research Objectives and Questions

Mindful of the background provided, the contextual factors that frame the problem, and the rationale and perspective I bring to my study, I now outline my research objectives and the questions I am seeking to answer in this thesis. In my research I seek to achieve the following objectives: 1) explore how spirituality is currently situated in ACP resources found on the ACPO; 2) probe what discourses related to spirituality, death, and values might be both present or absent in ACP resources on the this website; 3) explore what bioethical values, assumptions, and ideologies might be embedded within these discourses related to spirituality; and 4) explore what might be the potential implications of these discourses, values, assumptions, and ideologies in regards to an openness or closedness to spirituality in value reflection and prioritization. Seeking these objectives, my overarching research questions is: how is spirituality situated in ACP resources found on the ACPO website? The sub-questions my research seeks to answer include: 1) what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website?; 2) what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death and values?; and 3) what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization?

1.9 Conclusion

To conclude this chapter, I offer a summary of the ground covered in Chapter 1. I began the chapter by painting a background picture of the landscape of bioethics and theology that frames my research topic. I linked the concepts of informed consent and ACP and made the connection between medicine and theology through the work of Sulmasy (2006) and their question of what is stirring beneath medicine. Linking the notion that serious illness inspires death, and that death inspires significant existential questions, I outlined the emergence of spirituality as the multidimensional concept that brings together ultimate values and transcendent themes in medicine making it an obligation in medicine and deserving of integrative prominence in ACP for the good of the patient's decision-making. After outlining six significant contextual factors that impact spirituality's integration in medicine, I articulated the two-fold research problem that I wish to solve in my thesis—that ACP has not been adequately addressed in Ontario; and that the examination of the complex "black box" of spirituality must go deeper to explore the multidimensional aspects of spirituality and interwoven aspects of death and values; and it also must address the social tensions and undercurrents of conflict within bioethics that have excluded spirituality. I concluded that we simply cannot address the spiritual dimension without also confronting the potential social and ideological underpinnings that inform openness or closeness to spirituality in ACP. After introducing the methodology I will utilize involving the methodological approach of MCDA, I outlined my own rationale for approaching my research in this way, my own perspective that influences this study, and the relevance of the current study. I closed the chapter by outlining my research objectives and questions. I turn next to the literature review in Chapter 2 where I outline important conversations and debates regarding spirituality, death, values, and important concepts within the field of bioethics.

Chapter 2
Literature Review

2.1 Introduction to Chapter 2

As noted at the end of the previous chapter, I will now provide a literature review addressing the key debates related to my critical examination of what I am referencing as the "black box" of spirituality in Ontario ACP resources, as well as the interwoven relationship of spirituality with the concepts of death and values. But before outlining the specific contents of this chapter, I will briefly review the broader outline of my thesis that inspires the approach I have taken to this literature review. Rooted in a transformational approach to research, I am seeking to improve ACP resources by increasing opportunities for personal autonomy by helping individuals align future medical decisions with their deepest sense of values. Specifically, I am committed to deepening spiritual inclusion within ACP resources to harness the fullest potential of spirituality in value reflection to help integrate one's strongest values with end-of-life decision-making. Yet, despite the view that spirituality is an imperative in medicine (Sulmasy, 2006); research suggests the culture of health care has been less than welcoming to spirituality (Balboni & Balboni, 2019; Sommerville, 2000). I will argue that with patient-centred care at stake, and with the ultimate theme of death in the room, this territory dispute cannot continue to be left unaddressed. If autonomy is truly rooted in the good of the patient and the suggestion that ultimate values are paramount to decision-making (Pellegrino & Thomasma, 1988), approaches must be critical of dominant structures that may inhibit the addressing of spiritual themes in decision-making processes. In exploring the relevant interdisciplinary debates relating to the domains of spirituality, death, values, and the bioethical notion of ACP in this literature review, I will conclude that the treatment of spirituality within ACP has been thin and lacking depth

(Colenda & Blazer, 2022) and conspicuously absent in most research (Lutz et al., 2018) which focuses disproportionately on the legal and biological factors while tending to avoid holistic aspects (Watson & Thomas, 2018). These conclusions regarding a lack of attention to spirituality in ACP research will inspire my own methodology outlined in the next chapter that seeks to critically examine how spirituality might be situated within ACP resources in the context of Ontario, paying specific attention to the potential territorial conflicts reflected in discourse and in ideological leanings—biases that may impact patient-centered care.

Before outlining the contents of this chapter, I also wish to acknowledge the lengthier nature of this literature review and offer a rationale. Considering both the complex and mysterious nature of the "black box" of spirituality that I have been articulating, as well as the key interwoven concepts of values and death that function within the larger bioethical mechanism of ACP, a thorough analysis of these themes and implicit debates in the literature necessitated a lengthier review. Any dissertation lauding the importance of depth and respect for the complexity of spirituality and its intersecting themes must itself treat the domain with the fullest possible interdisciplinary attention. And this is what I have sought to do by seeking interdisciplinary breadth and depth in exploring the history, debates, and gaps existing in research within the context of ACP. Additionally, considering the complex development of the field of bioethics that includes philosophical, legal, and human aspects, a fuller treatment of these themes necessitated greater detail to fully contextualize ACP. Further, central to the paradigm of CDA/CDS that underpins MCDA is the importance of context in research that includes what Wodak (2016) describes as the "activation and consultation of preceding theoretical knowledge" (p. 34). It is this focus on knowledge and context in the methodology I utilized that further necessitated the thoroughness and deeper level of engagement in this

literature review. Having established this background, I now outline the contents of the review focusing on spirituality, death, values, and bioethical foundations to ACP.

I begin this chapter by providing a background to the complex domain of spirituality, focusing on the dialogue and struggle in defining it—including the challenging differentiation between spirituality and religion. I will then explore the treatment of spirituality within the context of health care, outlining the history, gaps, and tensions within the culture of medicine, while also highlighting those in support of clinical integration—including Sommerville (2000) and their science and spirit approach, and advocacy from physicians like Sulmasy (2006); Pellegrino and Thomasma (1988); and Puchalski (2014). After exploring the domain of spirituality, I move to the interwoven concept of death and focus on the work of Sulmasy (2006) who suggests a trajectory in patient reflection that begins with one's awareness of serious illness, followed by thoughts of death that trigger existential reflection. And finally, this existential reflection inspires thoughts of one's spirituality and ultimate themes like meaning, connection, and transcendence. After outlining key health care debates on death and dying, I explore discourses of death in the contemporary age (Northcott & Wilson, 2022) and contextualize varied cultural expressions of death along with the interplay with spirituality in ACP dialogue. I close this section on death by exploring challenges related to the intersection of death and spirituality including themes of suffering, meaning, and the afterlife. The conversation will then move to debates regarding the notion of values. After providing an interdisciplinary survey that contrasts understandings of values in the broader literature, I explore the specific relationship between values and spirituality alluded to by Frankl (1946/2019), Gula (2000), and McPherson (2015) before drawing on philosophical approaches including Taylor (1989) that touches on the ontological aspects of value and also what Stanworth (2006) suggests as "our furthest

interpretive horizon" (p. 28). I will then address contrasting approaches to values in various cultures that intertwine with spirituality before closing this section by exploring how different value hierarchies have helped discern values and prioritization. After outlining several hierarchical approaches, I highlight a specific theological approach by Lonergan (1972/2017) that includes an explicit direction of value discernment towards transcultural spiritual integration. In the final—and largest—section of the literature review I will focus on relevant bioethical foundations of ACP. Here, I provide a theoretical outline of key debates regarding notions of autonomy and respect for persons before tracking the emergence of informed consent as the central principle in bioethics and its eventual relevance to ACP. I then summarize debates around capacity and substitute decision-making, before, finally, examining the rocky evolution of ACP and its relationship with spirituality in decision-making. I will conclude this section by arguing that there is a significant gap in the literature regarding the relationship between ACP and spirituality, an omission that will inspire the methodological approach I take in seeking to critically examine how spirituality is situated with ACP resources within Ontario. I begin the literature review with the first section exploring the domain of spirituality.

2.2 Spirituality

2.2.1 Background to Spirituality

At the heart of this thesis is the examination of what I am referring to as the complex "black box" of spirituality that I am seeking to examine in ACP resources in Ontario. But before setting out to examine spirituality within the health care context, a broader exploration of the origins of the word "spirituality" is necessary.[66] I begin this section by providing a background to

[66] I acknowledge, alongside Oman (2013), that while the term spirituality has been used in Western civilizations, globally and historically, other "human cultures have recognized a world of powerful but invisible forces…Concepts of a multilayered universe, generally containing an upperworld above and an underworld below" (p. 25).

early understandings of its usage. Rooted in early Christianity, the term "spirituality" stems from the Latin noun "spiritualitas" while "spiritual" originates from the adjective "spiritualis"—both emerging from the Greek noun "pneuma" meaning "spirit" that appears in the New Testament (Sheldrake, 2013, p. 2). The use of "spirit" can be poetically translated as "breath of life" which is a respiratory-focused metaphor well-known in Hebrew and Greek traditions (Jastrzębski, 2023). As for meaning, Sheldrake (2013) suggests early use of "spiritual" did not denote the opposite of the physical, but rather, a contrast to the notion of "flesh" that King (2008) observes as not meaning one's human body, but rather, "everything in human beings that opposes the influence of the Spirit of God" (p. 7). This moral sense of spiritual life remained consistent into the 12th century (Sheldrake, 2013) where usage of the word shifted with "newly recovered Greek philosophy" (Sheldrake, 2019, p. 1) to a polarized understanding that separated the spiritual from the physical. Spirituality eventually became associated with one's spiritual life in 17th century France (Sheldrake, 2019) and was influenced by the interiorized thinking of Ignatius of Loyola. Use of the French word "spiritualité" also emerged at this time that meant, "the interior life of the individual soul" (Carrette & King, 2004, p. 37). This word would be passed into English traditions and came to denote the interior "spiritual life" across Christian denominations in the 18th and 19th century focusing on piety, devotion, and perfection (Sheldrake, 2019). While the term fell out of fashion in Christian contexts for decades, it returned in the 20th century (Oman, 2013) and usage heightened after The Second Vatican Council in the 1960s that moved spirituality from the ascetical and mystical, to a more ecumenical and interfaith understanding[67] (Sheldrake, 2013). It is here that one can begin to see a shift away from an understanding of spirituality being a divine presence within, towards an anthropological aspect of human potential

[67] Of note, before The Second Vatican Council, the term spirituality was a term used almost entirely in the Roman Catholic tradition but broadened to other denominations and faiths at this time (Schneiders, 1989).

(Carrette & King, 2004). Spirituality increased in popularity with social changes of the time, taking on more universal meanings to include Eastern influences like meditation (Jastrzębski, 2023). This breadth of diversity in spiritual expression continues to be a defining characteristic of spirituality in the present age. With this historical and theological background in place, I turn to debates regarding definitions.

2.2.2 Defining Spirituality

With the domain of spirituality being central to my examination of ACP in Ontario, the question emerges—how might one define it? Extending the diversity of meanings into academic settings, a conundrum emerges about this "black box" and how best to offer a definition. As noted above, with spirituality definitions described as being "vague and wooly" (Carrette & King, 2004, p. 30), or characterized by "considerable fuzziness" (Streib & Hood Jr. Jr., 2016, p. 5) or being "unavoidably ambiguous" (Schneiders, 1989, p. 678)—a lack of consensus is noted in the field (Pargament, 2007; Oman, 2013). But why? Miller and Thoresen (1999) suggest the problem is that spirituality "is not adequately defined by any single continuum or by dichotomous classification" (p. 6). As a result, not only should spirituality be more accurately described as "spiritualities" (King, 2008, p. 14), rather than the singular, but there exists a multidimensionality to the term (Steinhauser et al., 2017; Pargament et al., 2013) inspiring diverse understandings. Oman (2013) outlines a variety of these dimensions, as observed by Zinnbauer and Pargament (2005), including "biology, sensation, affect, cognition, behavior, identity, meaning, morality, relationships, roles, creativity, personality, self-awareness, and salience" (p. 33). Other theoretical challenges with defining spirituality include the layered perspectives of stakeholder disciplines like psychology, theology, medicine, sociology, and the humanities (Oman, 2013), as well as the immersive quality of spirituality that Pargament (2007)

notes as being "fully embedded in the fabric of life" (p. 21). Responding to this complexity, Oman (2013) notes the twofold challenge: first, single dimensional definitions "risk producing highly truncated views of complex and dynamic phenomenon" (p. 33), and second, multidimensional approaches can lead to other risks that "may undermine its capacity to detect broad patterns" (p. 29). Considering the challenges of holding too narrow or too broad a scope, I return to the debate regarding how one might define spirituality. I will draw on Oman (2013) who discourages single definitions crossing all contexts, preferring a continuum approach with looser boundaries that group definitions by "*prototype*" or "*family resemblance* concepts" (p. 24, italics theirs)[68] where approaches "may be definable by *clusters* of features" (p. 25, italics theirs). Drawing on this view, I describe some of the clusters of qualities observed in the literature and then offer the position I will take in this dissertation.

Ontological and Functional Aspects of Spirituality Definitions. Drawing on Oman's (2013) approach in observing clusters of features in spirituality definitions, I begin by looking at ontological versus functional families of definitions as organized by Jastrzębski (2023). But first, a lineage of this polarized view of categorizing spirituality needs some highlighting. I first outline Oman's (2013) suggestion of two poles of spirituality that range from the substantive to the functional—with substantive understandings rooted in "a belief in an ultimate controller of destiny" (p. 35); and in contrast, the functional approach focusing on the purposes spirituality serves. In a similar way, Schneiders (1989) employs a theological and anthropological lens to spirituality definitions and summarizes views as either using a "definition from above" with a divine focus or "definition from below" (p. 682) that is focused on human lived experience. And here I arrive at the work of Jastrzębski (2023) who extends this work with a typology rooted in

[68] I note here that Oman (2013) credits the concepts of "prototype" and "family resemblance" to Eleanor Rosch and their work in 1973 and 1975.

two main categories: the ontological, and the functional. The ontological is based on metaphysical and substantial foundations that demonstrate a larger reality defined by one's relationship to the divine as observed in parts of Sulmasy's (2006) definition: "the characteristics and qualities of one's relationship with the transcendent. It includes attitudes, habits, and practices in relation to the idea of the transcendent" (p. 14). The functional view, by contrast, focuses on the human aspect of spirituality informed by social sciences where the divine is not required, as observed in a definition by Helminiak (2008) that is quoted by Jastrzębski (2023) as "the thoughtful engagement of a human person within the process of full growth in humanity" (Helminiak, 2008, p. 162, as cited in Jastrzębski, 2023, p. 11).[69] Jastrzębski's (2023) nuanced typology goes further in distinguishing the ontological category as theistic or non-theistic in characterizations, allowing room for both transcendent or immanent approaches[70] which overlaps with the next cluster of spirituality definitions.

Transcendent and Immanent Qualities in Spirituality. Another approach in defining spirituality involves the clusters of transcendence and immanence as noted in the paragraph above. Pargament (2007) sees the transcendent as simply "something that goes beyond our everyday lives and beyond our usual understanding" (p. 39)—an approach to transcendence that is open to theistic or non-theistic expressions. Streib and Hood Jr. (2016) articulate different

[69] The challenge of functional definitions focusing on human fulfillment like this are well documented by Koenig (2008) who suggests the "worrisome" (p. 351) inclusion of mental health and psychological dimensions in spirituality research. Koenig argues these psychological notions like connectedness, well-being, and purpose contaminate data, assuring that those who are deemed "spiritual" based on these measures will also have good mental health, and those who are mentally unhealthy will not be "spiritual". While the broad view of human spirituality represented in a functional approach truly inspires this "multidimensional space" (Miller & Thoresen, 1999, p. 6) where diverse audiences can belong, the downside is a decrease in definitional precision for research purposes, inspiring researchers like Koenig (2008) to suggest research focus on religious aspects like prayer, ritual, and activities that are more easily defined and controlled.

[70] Jastrzębski's (2023) typology also broadens the functional category through the nuances of "hard" and "soft" categories. A "hard" functional spirituality suggests an intentional human striving observed in definitions with movement toward an ontological destination, while the "soft" category involves the seeking of one's full potential with human terms like well-being and satisfaction as well as aspects like attitude or feeling that animates life without a necessary ontological destination.

nuances of this with ontological transcendence being vertically oriented toward the divine, and horizontal transcendence as being connected to the secular. Some non-theistic expressions of transcendence can also include one's meaning in life and connection to humanity (Frankl, 1946/2019), nature-oriented perspectives like eco-spirituality (van Schalkwyk, 2011), or other humanistic perspectives including Ferry's (2002) "transcendental humanism" (p. 7). A "spirituality of immanence" has been described by Balboni and Balboni (2019, p. 221) as focusing spirituality more reductively on one's physical body—an approach they view as being threatening to transcendent expressions in medicine. But tensions with immanence and transcendence also extend to humanistic approaches including the thinking of Comte-Sponville (2006) who argues for a spirituality defined by an "inexhaustible, indefinite immanence" (p. 145), in contrast to the perspective of Ferry (2002) who sees transcendent spirituality found in humanism rooted in love and humanitarianism. Others, including Frank (2019), suggest transcendence and immanence can harmoniously "exist in intimate reciprocity, and each is comprehensible only in relation to the other" (p. 6). Distinguishing transcendent or immanent beliefs can be a critical aspect of spirituality and how one orients themself in future decisions.

Spirituality as a Human Search. Another cluster of spirituality definitions relates to what Oman (2013) suggests as being search processes. One can see this in Frankl's (1946/1984) spiritually oriented "search for meaning" or Pargament's (2007) "search for the sacred" (p. 32). Pargament here also speaks of deep "spiritual strivings" (p. 246), while Taylor (1989), from a philosophical lens, draws on the thinking of MacIntyre (1981/2007) to suggest a kind of "quest" that people are on in contemporary society to define themselves and "the spiritual source they can connect their lives with" (p. 17). Interwoven with this language of questing and searching is Schneiders' (2003) anthropological suggestion that this search is an "activity of the human

spirit" (p. 167). This aligns with the work of Lonergan, as noted by Gregson (1988), who draws on Lonergan's image of a detective investigating the "much more besides" (p. 16). Whether using words of searching, questing, striving, or seeking, this human pursuit is prevalent in many understandings of spirituality. But the question becomes—what is the destination of this search?

One's Search Has a Destination. The destination of one's search is connected to the previous cluster that sees spirituality as a quest or pursuit. But what is the direction of this search? Pargament (2007) suggests spirituality as being a "search for the sacred" (p. 32) and they articulate the search focusing on a two-fold notion of one's sacred core that includes one's "ideas of God, higher powers, divinity, and transcendent reality" (p. 32), and secondly, another ring of sacred aspects of life that may include nature, music, marriage, or children. In contrast, Balboni and Balboni (2019) suggest a direction of spirituality towards "the object of one's chief love" (p. 120), while McPherson (2015) suggests a directedness "*towards what is seen as being of great value*" (p. 336, italics theirs). But perhaps most widely cited in definitions is the movement towards ultimacy[71] with examples from Zsolnai and Flanagan (2019) who suggest a destination of connection with "all living beings" (p. 3) and the suggestion of bringing "them back in touch with God or 'Ultimate Reality'" (p. 3); or the work by Schneiders (2003) who notes the striving "toward the ultimate value one perceives" (p. 166). An international conference (2012) definition noted by Steinhauser et al. (2017) from the field of palliative care notes ultimacy as well, "where persons seek ultimate meaning, purpose, and transcendence" (p. 430). Hence, one can see the

[71] Philosophically and theologically, this word "ultimate" is connected to the work Paul Tillich along with the concept of "ultimate concern" (Tillich, 1957, p. 1). It is a term Tillich used to describe one's spiritual concerns, whether aesthetic, cognitive, political or social, that hold a sense of urgency and demand for life beyond one's self. Tillich thought that in every day acts one can "stretch out towards the fullness of human and existential concern that points us towards faith in the ultimate" (van Deurzen, 2009, p. 102). Key to Tillich's impact to spirituality definitions is both the subjective movement of ultimate concern as noted as a quest, search, project, or concern—and secondly, the direction of this movement towards this destination they name as the ultimate.

varied articulation of destinations of this transcendent search to being articulated toward ends that include the sacred, love, great value, God, or ultimacy in its many forms. I will connect this with ACP in later sections as I explore how one might seek to connect high stakes decisions involving death with one's highest and ultimate value or greatest love.

Meaning in Spirituality. Another cluster of spirituality definitions involves the notion of meaning as a key element of definitions, as articulated by McCarrol et al (2006) in their survey of 27 systematic reviews of spirituality in health care definitions. But it was Frankl's book *Man's Search for Meaning* (1946/1984) that has provided a contemporary bridge between spirituality and meaning. Reflecting on experiences in a Nazi concentration camp, Frankl boldly wrote: "The consciousness of one's inner value is anchored in higher, more spiritual things, and cannot be shaken by camp life" (p. 83). Frankl suggested love as being "the ultimate and the highest goal" (p. 57), extending past the physical aspects of loved ones toward one's "deepest meaning in his spiritual being, his inner self" (p. 58). Frankl viewed the spiritual as the meaningful starting place, and the dimension that connects us with the "innate desire to give as much meaning to one's life" while animating "as many values as possible" (Frankl, 1946/2019, p. xviii). It is this larger sense of meaning that helps orient people to a bigger spiritual story they find themselves within. Stanworth (2006) quotes Tillich's suggestion that the spiritual is the "meaning that gives meaning to all other meanings" (Tillich, 1962, p. 7, as quoted in Stanworth, 2006, p. 28) and "concerned with how our lives fit into the grand scheme of things" (McPherson, 2015, p. 337). This kind of contextualization comes into play in ACP when discerning one's ultimate meaning in making future health care decisions and how choices fit with a larger story.

Relationship and Connectedness in Spirituality. The notion of relationship and connection is another cluster noted in many spirituality definitions including the palliative

consensus definition focusing on one's "relationship to self, family, others, community, society, nature, and the significant or sacred" (Puchalski, Vitillo, et al., 2014, p. 646). Sulmasy (2006) too suggests the notion of relationship in their definition and directs it towards the transcendent: "the attitudes, habits, and practices in relation to the idea of the transcendent" (p. 14). Reinert and Koenig (2013) focus specifically on connection, suggesting "Spirituality is distinguished from other things—humanism, values, morals and mental health—by its connection to the transcendent" (Reinert & Koenig, 2012, p. 46, as cited in Reinert & Koenig, 2013, p. 2630). Inspired by the European Spirituality in Society and the Professions Institute (2017), Zsolnai and Flanagan (2019) also suggest connection in their spirituality definition with a broader bond "to all living beings" (p. 3) and in a way that "brings them in touch with God or 'Ultimate Reality'" (p. 3). It is this sense of ultimate connection and relationship that provides a sense of rootedness to a larger reality that can impact ACP decisions.

Life Orientation and Integration. A final cluster of definitions of spirituality is related to orientation and integration. It is what Schneiders (2003) suggests as being "the experience of conscious involvement in the project of life-integration" (p. 166). Put another way, McPherson (2015) suggests spirituality is about orientating one's life holistically by saying: "Spirituality is not just practical; it is a practical *life-orientation*. In other words, spirituality involves a way of seeing and directing one's life as a whole" (p. 337, italics theirs). In a similar notion, as noted above, Stanworth (2006) suggests, "The spiritual is our furthest interpretive horizon" (p. 28). It is this kind of orienting and integrative quality of spirituality that will prove to be an important element later on in the dialogue around decision-making in ACP—especially regarding how one integrates life decisions into a bigger spiritual picture. This aspect of spirituality involving action guidance based on one's deepest orienting values will be explored in sections to come.

Choosing a Spirituality Definition. While individuals articulate and experience their spirituality with many aspects as noted above, the question emerges in the diverse medical setting—how does one go about choosing a functional definition that respects diversity? Steensland et al. (2022) note this challenge in saying: "it is misguided to search for an overarching definition of spirituality that would work transhistorically, transnationally, and transculturally" (p. 9). Functionally, Oman (2013) suggests the importance of context and that successful definitions "support positive communication with the broadest range of audiences" (p. 29) while Jastrzębski (2023) suggests "deliberately matching the kind of definition with the purpose for which it will be used" (p. 16). Addressing unique needs like birth or death, King (2008) suggests meeting the "concrete spiritual needs of others in very specific circumstances" (p. 84). Hence, as I assess the context of my research with ACP in Ontario as being grounded in decision-making in end-of-life contexts within the health care domain. As a result, I choose to ground my thesis in two definitions. The first is from the field of palliative care that provides the closest medical context:

> Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices (Puchalski, Vitillo, et al., 2014, p. 646).

The second definition of spirituality I utilize in my thesis is the integrative definition from Schneiders (2003) that provides opportunity to help orient individuals towards integral decision-making that is central to ACP: "the experience of conscious involvement in the project of life-integration" (p. 166). Together, the two definitions highlight aspects that are central to decisions

at the end-of-life including seeking ultimate meaning, purpose, and transcendence; experiencing relationship to what one views as sacred; and life integration that grounds decisions in the fullest possible way. There is a seeking of wholeness here that aligns with the definition of healing that means to "make whole" as suggested by Sulmasy (2006, p. 16). With the diversity of spirituality addressed in clusters above, and my own approach established, I acknowledge an overlapping aspect that has been left unaddressed thus far—that of religion. I address this relationship next.

2.2.3 Differentiating Spirituality and Religion

Considering the historical importance of religion to death, values, and end-of-life decisions, an aspect that has been conspicuously absent from my discussion thus far is the very relationship between spirituality and religion—a relationship so important it is deserving of its own section.[72] Steensland (2022) suggests this discussion as being so widespread that it is "a virtual cottage industry" (p. 5). Drawing on the work of Platvoet (1999), Oman (2013) traces definitions of religion from ancient understandings as "state-supervised acts of public worship" (p. 26) to meanings of "public ritual" (p. 26) broadly until the 1500s. And finally, the shift to meanings that have remained largely constant since 1750 that sees religion as "a particular system of faith and worship and/or…the human reverential recognition of a higher or unseen power" (p. 26). While psychology has continued to examine individual and systemic nuances of beliefs, traditions, rituals, and practices that often overlap with spirituality,[73] there has also

[72]Religion has been a central factor culturally, socially, and politically across history. I have certainly not delayed addressing religion thus far because of a lack of importance, but rather, my intention has been to first lay a groundwork for my understanding of spirituality. But I recognize by leading with a fulsome exploration of spirituality I am also demonstrating my leaning towards seeing spirituality as the larger category that encompasses religion. I will address this assumption more fully in the paragraphs below.

[73] Acknowledging the work of Leuba (1901), who noted 48 unique definitions of religion at the turn of the century, Oman (2013) suggests that while the discussion has not abated in psychology in regard to the many nuances of religion, there has been some resolution. But Oman is clear to not close the door on the ongoing debate, suggesting that a more restricted understanding is "increasingly common but far from universal" (p. 26).

emerged a more confined meaning referring to "organized and institutional components of faith traditions" (p. 26). Koenig (2008) suggests common understandings of religion have held a "relatively stable definition over the years" (p. 349) as evidenced in common descriptions like "an organized social institution" (Miller & Thoresen, 1999, p. 6) and "institutional contexts that facilitate spirituality" (Pargament et al., 2013, p. 13). While there are ongoing debates regarding the nuances of religion and its similarities to spirituality, including Streib and Hood Jr. (2016), I concur with Koenig (2008) that general agreement exists in seeing religion taking a more institutional and externally observable form through social customs and practices. But the question remains—how does religion relate with spirituality? This question is important because many individuals express their spirituality through religion, and this may become extremely important when making future decisions in ACP processes. But how are the notions of spirituality and religion understood in our culture? I begin this exploration by observing some of the tensions of their relationship that tend towards dichotomization.

The Dichotomy of Spirituality and Religion. As noted above, it is here I arrive at a dichotomy arising in discussions around religion and spirituality. On one hand there is a celebrated shift towards individuality in spirituality since the 1960s and 1970s, while on the other hand is what Schneiders (2003) articulates as the negative perceptions regarding religion in culture including challenges of institutional hypocrisy, corruption, and clericalism that contribute to individuals leaving "the religion of their past for the spirituality of their present" (p. 163). Pargament (2013) adds that a dangerous polarization can emerge where religion is seen as "bad" and spirituality is seen as "good" (p. 13)—divisions potentially rooted in a tendency to see religion being institutional and spirituality being individualized. Schneiders (2003) echoes a similar dynamic suggesting the two are characterized as "organized religion" (p. 172) and

"personal spirituality" (p. 172). But in the social domain this dichotomy breaks down. While psychology has tended to focus on the individual, there is growing attention on a socially situated spirituality (Steensland et al., 2022) that moves beyond "a discourse of Western individualism" (p. 4) towards what they name as the emergence of "Second-Wave" (p. 7) spirituality centering on "*collective processes*—such as socialization, group gatherings, common affordances, shared narrative" (p. 8, italics theirs). Steensland also suggests, "Though spirituality is associated with individualism, it is not predominantly individuated and idiosyncratic; it is socially influenced, enabled, and patterned." (p. 4). From this perspective, the socially influenced part of spirituality and the implicit or explicit prevalence of religion in culture are blended together and difficult to extract. Pargament (2013) suggests an absurdity in the notion that one can simply extricate one's self from their upbringing: "The perception that they have removed themselves from the influence of a larger religious context is as illusory as the belief that young adults who have moved out of their family homes are no longer affected by their families" (p. 13). Hence, as Pargament et al. (2013) conclude: "For better or worse, religion is in the air we breathe" (p. 13). But how can spirituality and religion exist together? This is an important question because autonomous decision-making in a diverse society requires medical culture to embrace the diverse spiritual language of each individual whether that be religiously oriented, or spiritually oriented. Without appreciation for these nuances patients may be forced into unhelpful binary categories in ACP that do not reflect complex belief systems that may include both spirituality and religion. Acknowledging the overlapping nuances of spirituality and religion, I ask the question—how might this conversation proceed? How do they fit together?

Navigating the Overlap Between Religion and Spirituality. In terms of navigating the relationship between religion and spirituality, Ammerman (2013) suggests resisting the "zero-

sum" (p. 259) task of choosing either phenomenon but embracing this overlap. Other researchers share this view, noting an "intrinsic link" (Balboni & Balboni, 2019, p. 126), or an "inevitable overlap" (Peteet & Balboni, 2013, p. 280), and a "mutual influence and interdependence" (King, 2008, p. 15) of these terms. But the practical question becomes—how can these concepts live together conceptually? Jastrzębski (2023) summarizes differing approaches to their relatedness, noting some models that see them as overlapping concepts with a shared middle while other models see them as two separate entities with no overlap. And still other perspectives see religion as being situated within the broader domain of spirituality. Schneiders (2003) offers a more poetic take, suggesting three relational descriptions of their relationship: 1) As separate entities and "*strangers* at the banquet of transcendence who never actually meet or converse"; 2) as "*rivals*, *if not enemies*, vying for the allegiance of serious seekers"; and 3) as "two dimensions of a single enterprise" (p. 164, italics theirs). Schneiders settles on holding an honoured place at the table for religion, yet at the same time notes that religion as not being an "optimal context for spirituality" (p. 176). This dovetails with Pargament et al. (2013) who suggest not dissociating the two concepts of religion and spirituality, but rather, to recognize the primary goal of religious institutions is actually to facilitate spirituality and that "spirituality represents the function most central to institutional religious life" (p. 15). Others still acknowledge the interwoven relationship with little chance of clear delineations, choosing to simply combine religion and spirituality in their writing as "R/S" for a single religious/spiritual category.[74] Having outlined the various perspectives on the relationship between spirituality and religion, I will now suggest the approach I will take in this dissertation.

[74] One rationale provided for using R/S was, "not to conflate the two concepts as identical but instead to indicate that it is not our current aim to solve this debate" (Balboni & Peteet, 2017, p. 5), while Oman (2013) gives no rationale for the use of R/S other than their complexity of their relationship.

Choosing an Approach for this Study. Considering all these approaches noted above regarding the bonded relationship between religion and spirituality, the question arises: what path will I take in my research? While I see merit in separating them, and even in acknowledging the symbols of "R/S" in research to note the challenge in separating them, when I consider the current popularity of spirituality, as well as the sometimes divisive political and social legacy of religion for some in society, I see the term "spirituality" as the most inclusive container that best holds a diversity of beliefs while minimizing detrimental aspects of religion's influence for some.[75] I appreciate Balboni and Peteet's (2017) summary of Cadge's (2012) suggestion that utilizing spirituality instead of religion serves to "positively communicate with strangers without causing offence or assuming too much" (p. 5). Because of the diversity of belief in society, I concur with Balboni and Peteet (2017) who suggest, "As Western societies grow increasingly pluralistic, there is a growing consensus that within the patient-clinician relationship, employing the language of spirituality is preferable to the language of religion" (p. 5). Hence, I will use "spirituality" as the larger umbrella that encompasses religion. Unless referring specifically to religious groups or activities, or within the context of quotes, I will use "spirituality" as the larger category including religion. With the domain of spirituality established, I move to the next section regarding spirituality—spirituality in the health care context.

2.2.4 Spirituality in the Health Care Context

Background to Spirituality and Health Care. Having established an understanding of the debates in the literature regarding spirituality and its relationship with religion, I will now explore the domain of spirituality within the context of health care. While an examination of

[75] Lartey and Moon (2020) suggest the importance of decolonizing spiritual care by using spiritual care over the more Judeo-Christian term pastoral care. I extend a similar perspective in privileging spirituality to minimize potential harm in the patient-centered environment for those who have had a negative experience with religion.

spirituality within ACP will be the final destination of this section, at this stage I must explore the preliminary context for debates surrounding spirituality within health care more broadly as well as the culture of medicine that may influence spiritual inclusion in bioethics. But first the initial link between spirituality and health must be established.

As noted in Chapter 1, Sulmasy (2006) makes a case for the obligation of addressing spiritual needs of patients in health care with the assumption that not only is "Illness a spiritual event" (p. 17), but that the etymology of the word healing is to "make whole" (p. 16). More specifically, offering healing means to, "understand not only what disease and injury do to patients' bodies but also what disease and injury do to them as embodied spiritual persons grappling with transcendent questions" (p. 16). It is this kind of understanding of healing that is my starting place—a view that has been integrated historically in many cultures. Miller and Thoresen (1999) suggest: "Long before there were science-based health care professions, people were served by culturally defined healers" (p. 3). And not unlike the contemporary authority vested in physicians, ancient approaches included a central role of leadership in healing. Gerkin's (1997) Judeo-Christian perspective notes "Our earliest pastoral ancestors are to be found among the leaders of the ancient people of Israel" (p. 23). And continuing further, Gerkin suggests these voices provided "moral guidance to the community" (p. 24) and that this role would grow in the West as Christianity began to grow. Gerkin (1997) also observes the pastoral influence of the shepherding image of Jesus (p. 27) in being influential in care giving while Ferngren (2012) notes the impact of Jesus' words "I was sick and you visited me" (English Standard Version, 2001, Matthew 25:36, as quoted by Ferngren, 2012, p. 8) to inspire holistic care. The book of James in Christian scripture would further suggest a healing relationship with words that invited elders to visit the sick and offer prayer and anointing (New Revised Standard

Version, 2012). Through the Middle Ages, Gerkin (1997) notes the development of a dichotomous evolution in the West with the pastor being "physician of the spirit" and the physician as "physician of the body" (p. 40). Ferngren (2012) suggests formal hospitals emerging in the late 4th century "grew out of the long tradition of the care of the sick in Christian churches" (p. 6) and healing movements expanded globally in centuries to follow with these same assumptions.[76] All told, spiritual healing was historically integrated in care.

But transformational change began to emerge with enlightenment thinking. While in previous centuries both spiritual and science-based approaches were "practiced side-by-side" (Pellegrino, 2012, p. v) in both Eastern and Western cultures, the emergence of the dominant "medical-technological model" (Miller & Thoresen, 1999, p. 3) ushered in a new approach to healing based on the assumptions of disease, diagnosis, and treatment. Ferngren (2012) suggests that secularization in the late 19th and early 20th centuries impacted spiritual leaders, noting "The professionalization of medicine eliminated from medical practice those without formal training in medicine" (p. 7). This philosophy would impact clergy involvement. In reflecting on this era of medicine, Puchalski & Blatt et al. (2014) note the specific impact of the Flexner Report in 1910 that grounded medical education in science but note "A regrettable consequence of this scientific grounding was that it altered the alignment between spirituality and health, resulting in the downplaying of the humanistic and spiritual elements of patient care" (p. 10). Hence, by the middle of the 20th century, Ferngren (2012) suggests "medicine no longer had formal ties to religious values" (p. 7) pushing the spiritual domain to the outskirts of medicine. Current debates of spirituality's inclusion are grounded in these changes.

[76] Further, Ferngren (2012) observes: "The large number of faith-based hospitals that were founded in North America indicates how seriously religious traditions took their call to medical philanthropy" (p. 6).

But where did spirituality go in health care? With Western culture rooted in Judeo-Christian foundations,[77] Bard (2016) notes that clergy became involved in debates over medicine in the US including a Presbyterian minister, Anton Boisen, who initiated training for pastors in the 1920s integrating psychology, psychiatry, and religion (p. 17). This program would become what is known as Clinical Pastoral Education and a College of Chaplains was founded in 1946 along with the launch of a journal a year later (p. 18). The profession of chaplaincy grew—including the expansion of Clinical Pastoral Education to Canada in 1952[78] and the establishment of its own association in 1974 (p. 20). And while chaplaincy emerged as a professional attempt to bring spiritual and theological perspectives to medicine, the new technologies[79] emerging in the 1960s that included dialysis and transplants (Faden et al., 1986), along with rights-based social and political changes at the time, inspired a complex era of societal change. This era was described by Engelhardt, Jr. (2003) as a time where "The authority of physicians, the clergy, the family, and traditional authority figures was displaced by the authority of autonomous, rights-bearing individuals" (p. xviii). The initial secularization of medicine in the early 1900s was now magnified by the additional dismissal of traditional religious authority in decision-making. Technology that inspired new ethical challenges pushed religion to the side in favour of secular approaches to ethics, and a newly minted profession of bioethics[80] would emerge that rooted itself in rational philosophical thought. In a span of decades, a discipline of bioethics emerged as "a body of moral practitioners recognized as appropriately providing moral guidance for the now major institution of health care" (Engelhardt, 2003, p. xvi). This group would become dedicated

[77] It is important to note here once again the work of Bibby (2017) who suggests in 1871 Canada, 42% of Canadians were Roman Catholic and 56% were Protestant—meaning forms of Christianity made up 98% of the population.
[78] Out of interest, Clinical Pastoral Education in Canada began in Ontario at Chedoke Hospital and also the Hamilton Psychiatric Hospital in 1952 (Bard, 2016).
[79] I will be expanding further on these technologies in the section ahead focusing on bioethical foundations of ACP.
[80] Additional background information to the emergence of bioethics will be explored in a section ahead.

to four bioethical principles put forth by Georgetown-based academics Beauchamp and Childress (Engelhardt, 2003) who published their first edition of *Principles of Bioethics* in 1979 (Beauchamp & Childress, 2019) claiming moral authority previously provided by spiritual traditions. While chaplains would provide care to some patients,[81] the new moral authority of bioethics would drive decisions and medical culture.

Despite the widespread secularization of medicine in the 20th century, there have been unique movements which have inspired a more human and a spiritually integrative lens to medicine. One is the advent of the palliative care movement[82] initiated by Dame Cicely Saunders and the founding of St Christopher's Hospice in London in 1967. Acknowledging the notion of total pain and a holistic approach with a view to humanity that included the physical and the spiritual (Ellis & Lloyd-Williams, 2012), the approach would include the "biopsychosocial-spiritual model" (Puchalski, 2014, p. 105) and a focus on spiritual distress. Kübler-Ross (1969/2003) also emerged around this time, criticizing a culture of "depersonalized science" (p. 25) while also advocating for holistic care for those facing death. Palliative care furthered this spiritual integration with the work of Puchalski (2014) who suggested the key contributions of spiritual care at end-of-life including "quality of life, coping, and end-of-life decision-making" (p. 105). Koenig (2015) too has outlined the significant benefits of spirituality in a summary noting efficacy across medical domains. And while Oman (2013) and Sulmasy (2006) observe signs of interest in spirituality in health care, a 2022 special report[83] by Balboni et al. (2022) tells

[81] The presence of chaplains at hospitals is widely noted as being underserviced and underfunded inspiring advocacy including a white paper in 2001 (Vande Creek & Burton, 2001) advocating for increased ratios. But the lack of spiritual care presence in hospitals continues to be a significant theme in spiritual care circles.
[82] From a Canadian perspective, Lazenby et al. (2014b) recount the founding of a palliative care unit in Montreal after the Canadian physician, Balfour Mount, visited Dame Cicely Saunders in London.
[83] A multidisciplinary Delphi panel contributed to a major 2022 report (Balboni et al., 2022) focusing on *Spirituality in Serious Illness and Health* including eight evidence synthesis statements: "(1) spirituality is important for most patients; (2) spiritual needs are common; (3) spiritual care is frequently desired by patients; (4) spiritual needs are infrequently addressed in medical care; (4) spirituality can play a role in medical decision-making; (6) spiritual care

a different tale: “Despite increasing data linking spirituality with improved health outcomes…such issues remain largely outside standard considerations regarding health” (p. 185). While Balboni et al. (2022) highlighted a lack of clinically focused spiritual caring, similar themes exist in bioethics where my thesis is rooted. Gula (2000) suggests that while some focus has occurred in advances to spirituality in medicine, palliative care, and other fields, “the relation of spirituality and ethics in health care has not yet received much attention. While considerable effort has gone into developing and refining modes of ethical thinking, little effort has been directed toward making the connections between spirituality and ethics” (p. 17). Having provided an overview of some of the challenges of spirituality’s historic relationship with medicine, I move now to debates regarding the exclusion of spirituality and medicine, as well as possible links to philosophical dynamics within medical culture.

The Culture of Medicine and the Exclusion of Spirituality. With a brief history of spirituality’s relationship with medicine provided in the previous section, some suggest that there is something deeper within the medical culture that may be excluding spirituality. Pargament (2007) for example observes a silence of the topic of spirituality in therapy rooms, described as an “elephant in the therapy room” (p. 14), while in bioethical circles, Sommerville (2000) names an intolerance to mystery and a focus on meaning in life explained “only in terms of scientific constructs” (p. 17). Pellegrino and D’Arcy (2011) outline an unwelcome stance in medicine toward religion in the last twenty years suggesting “the dominant spirit of modern bioethics has been philosophical, analytical, secular, and procedural” (p. 27). Using evocative language,

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is infrequent in medical care; (7) unaddressed spiritual needs are associated with poorer patient quality in life; and (8) provision of spiritual care is associated with better patient end-of-life outcomes” (p. 188). Three implications of the study included: “Routinely incorporate spiritual care into the medical care of patients with serious illness” (p. 194) and also, “Include spiritual care education in the training of all members of the interdisciplinary medical team caring for seriously ill patients” (p. 194). There is a clear call for increased attention to spirituality in health.

Berger (2015) describes the hospital as “a temple of modernity” (p. 411) where the philosophy that reigns is “a single overwhelmingly secular discourse” (p. 411). This is a feeling echoed by Pellegrino and D’Arcy (2011) who suggest “ethics and religious commitment have been systematically excluded from the secular discourse” (p.27). Despite the suggestion by Beauchamp and Childress (2019) that there be acceptance of one’s values and choices in patient care, medical culture seems reticent to include the spiritual in this conversation. But why? Kuczewski (2007) outlines a kind of culture in medicine where spiritual dialogue is “foreign to the clinical environment” (p. 4) and that “the language of spirituality is not the coin of the medical realm” (p. 4). One can glimpse this philosophy in Murphy’s (2012) bold articulation of aspiring to an “irreligious bioethics” (p. 3) that avoids “any rapprochement with religion that interferes with the ability to do its normative work” (p. 3). In this one can glimpse a culture of medicine that resists the inclusion of spirituality. And with this there is an epistemological piece that also needs critical examination.

With spirituality having been described by McCarrol et al. (2006) as being known practically, phenomenologically, linguistically, and subjectively, a challenge arises in bioethics where the field appears to privilege other ways of knowing including the positivistic, rational, cognitive, and empirical. This is an epistemological challenge that seems centred on different ways of knowing and the pitting of science against spirit as Sommerville suggests (2000). But the greatest impact may be to the individual client who is needing to make decisions based on their own way of knowing. There is a polarization that emerges that is articulated by Sommerville (2000) as being a dichotomy with poles of pure science on one side and being “intolerant of the belief that there is a mystery in human existence” (p. 18), and spirit on the other side with accusations of being “expressly anti-scientific” (p. 18). Stempsey (2021)

describes this gridlock of religious inclusion in bioethics as “a field of disputed territory” (p. 244) while Kuczewski (2007) articulates a “chasm between provider and patient/family in stark terms” (p. 5) regarding spirituality. They suggest this gap that needs to be addressed through patient-centred techniques, cultural competence, physician sensitivity, and the fostering of dialogue “by encouraging exploration of the patient’s beliefs and values” (p. 6). If medicine is about the “good of the patient” (p. 73) as Pellegrino and Thomasma (1988) proclaim, this dispute needs to be addressed in a way that is person-centred.

Glimpsing a Future with both Spirit and Science. Considering this unresolved debate, I am asking: what might be the best path forward? If Sulmasy (2006) is correct in suggesting that illness is a spiritual event that “grasps persons by the soul as well as by the body and disturbs both” (p. 17), there is an obligation to care for the spirit in medicine. In this same vein, Pellegrino and D’Arcy (2011) implore the medical community to embrace a holistic approach: “If the full dimensions of person are to be respected, then the spiritual dimensions cannot be ignored” (p. 17). But this resolution cannot come at the cost of each domain. Sulmasy (2006) is clear in describing a holistic need to bridge both: “People today are not ready to give up scientific progress and all that it has to offer, but they rightly sense the need for more. Their desire is spiritual. They want a form of medicine that can heal them in body and soul” (p. xii). Some offer suggestions on moving past the gridlock—including a focus on epistemology. Goodchild (2021), in speaking of Indigenous inclusion more broadly, suggests “an invitation to sit in a circle with us, in the sacred space of non-interference *between epistemologies*” (p. 99, italics theirs). This view of accepting diverse epistemologies aligns with Sommerville’s (2006) wish for “a new vision that can facilitate the marriage of science and our human philosophical-spiritual heritage” (p. 9) where “all of these ways of knowing must be held in dynamic balance”

(p. 29). It is what Sommerville (2000) describes elsewhere as a science-spirit approach that acknowledges that "life consists of more than its biological component" (p. 19) with a recognition of "the importance of using the full richness of our human ways" (Sommerville, 2006, p. 2). This approach embraces a sense of imagination and openness to different ways of knowing that Berger (2015) observes in non-Western medicine where there already exists "peaceful interaction between its secular discourse and religious beliefs and practices" (p. 411). Sulmasy (2006) describes this approach as "a form of medicine that does not abandon science but also does not eschew the mystical" (p. xiii). Sulmasy is asking the same question presented here: "attention to spiritual needs is a moral imperative. It is not simply a moral option…The only real question is how to put this obligation into practice?" (p. 169). And this task is what Sulmasy names as the "repersonalization" of medicine and the "rebirth of health care as a spiritual enterprise" (p. 20). This is the transformational work I seek to accomplish in this thesis through a critical examination of spirituality in ACP resources. With a foundation laid regarding spirituality and its relationship with medicine, I move to the overlapping concept of death.

2.3 Death

2.3.1 Background to Death

Interwoven with spiritual themes like meaning, transcendence, ultimacy, and suffering is the concept of death—a topic at the heart of ACP processes involving end-of-life. Later in this section I will address different discourses and understandings of death, but I start with debate around definitions regarding death and dying. At first glance it seems a simple question about the meaning of death and dying, but soon the dialogue splinters into many debates—from medical understandings to cultural notions of death, and finally to spiritual and existential aspects of death as humans. I begin this section by exploring debates around physical aspects of death in

health care, followed by reflection on the evolution of death in culture. I then explore discourses of death in the present age, before linking death to spirituality. I begin with death in health care.

2.3.2 Health Care Perspectives on Death and Dying

In this section I will focus on debates from a health care perspective regarding death that will underpin later conversations regarding ACP. I begin this exploration from a medical perspective where Northcott and Wilson (2022) differentiate notions of death and dying, suggesting "Death occurs following a process of dying that ranges in length from only a few minutes to many years" (p. 5). In terms of the practicalities of death in Canada, Northcott and Wilson (2022) quote numbers from Statistics Canada showing average life expectancy dipped to 81.3 years in Canada in 2022, from 82.3 years in 2019 with causes including 28% from cancer and 23% from circulatory diseases, followed by a number of categories below 5% including accidents, chronic lower respiratory diseases, influenza and pneumonia, diabetes/mellitus, Alzheimer's disease, suicide, and kidney disease (Statistics Canada, 2020c, Table 13-10-0394-01, as cited in Northcott and Wilson, 2022, p. 29). But determining the exact cause of death is often difficult with comorbidities and the lack of autopsies[84] that combine with the aging process and what is commonly referred to as senescence—the wearing out of the body (p. 41). But in terms of dying processes there is a longer trajectory as evidenced by Canadian Cancer Society (2020) statistics referenced by Northcott and Wilson (2022) that suggest the 5-year survival rate of cancer being just 25% in the 1940s versus 63% in contemporary society (Northcott & Wilson, 2022). Today, Northcott and Wilson observe the process of dying can take anywhere from days to years with factors including one's age, number of co-morbidities, support systems, and one's motivation (p. 30). Medical interventions can extend life for years, inspiring challenges in

[84] Northcott and Wilson (2022) suggest only 5% of deaths in Canada have an autopsy.

decision-making when “terminal illness trajectories are lengthy” (p. 36). The shift from acute to chronic illness has also been a major factor in shifts of disease progression to slower and incremental paces (Collier & Haliburton, 2021) with interventions that strangely “both work and do not work at the same time” (p. 342) resulting in a prolonged middle existence. Northcott and Wilson (2022) reference data from the Public Health Agency of Canada (2019) suggesting 44% of Canadians have at least one chronic illness including in an ordered list of “hypertension, osteoarthritis, mood and/or anxiety disorders, osteoporosis, diabetes, asthma, chronic obstructive lung disease, ischemic heart disease, cancer and dementia” (p. 38). The slow journey of these chronic diseases together with increased technology makes it difficult to note when patients are dying (Collier & Haliburton, 2021). But the active dying process is characterized by Northcott and Wilson (2022) as an “immediate and inevitable” (p. 36) progression stemming from “a major irreversible change in health” (p. 36). Finally, death is noted as “the culmination of all dying processes” and being “the end of cognitive (brain) and physical (heart and respiratory) functioning” (p. 36). Drawing on Wilson et al. al (2017), Northcott and Wilson (2022) suggest 40% of Canadian deaths are in hospital with patients on “oxygen, intravenous fluids, and other life-saving or life-prolonging technologies” (pp. 36 - 37). In the end, the chances are high that life-saving conversations will be a part of a patient’s care trajectory. And while the dying process continues to be extended through these measures, a core debate in bioethics centres on the moment of one’s death. I will address this debate next.

Defining Death. A key debate in medicine is when death has occurred. With the process of death extended with technology, the defining moment of death is indeed difficult, reduced to “a series of small events, each one amenable to further treatment, and not one, in itself, being seen as the moment where treatment should be halted” (Collier & Haliburton, 2021, p. 341).

Collier and Haliburton suggest that the traditional cardiopulmonary definition of death was "determined by the heart and lung function: a person was dead when breathing ceased and the heart stopped beating" (p. 342). This traditional definition of death served medicine until the late 1960s. It was the advent of the mechanical respirator or ventilator[85] that kept patients alive "indefinitely through artificially supporting heart and lung function" (p. 343) and the emergence of organ transplants that inspired changes to this definition.[86] A Harvard committee examined the existing definition and challenges to families, patients, and hospitals "keeping comatose patients indefinitely on ventilators" (p. 343), as well as dilemmas related to when one could harvest organs for transplant. A "whole-brain definition of death" emerged where one could be considered dead "when the functions of the entire brain have ceased" (p. 343)—this definition moved from an alternative definition to acceptance by the World Medical Association and the Canadian Medical Association in 1968 (Collier & Haliburton, 2021). Capron (1999) articulates this as the "bifurcated legal standard of determining death" (p. 118) where death divides the conversation into "two branches" of heart and brain (p. 118). But an important observation made by Capron was the emergence of "human determination, rather than a discovery" (p. 119), moving death beyond the physical body towards other aspects like "personhood" (p. 119). This shift inspired many questions involving the status of braindead patients and seemingly strange questions like "Is the person alive or dead?" (Collier & Haliburton, 2021, p. 344) and the potential for organ donation for "half-dead, half-alive people" (p. 345). While decades have passed, Collier and Haliburton (2021) suggest the challenge of ventilators has not been resolved

[85] Collier and Haliburton (2021) suggest there are technical differences between ventilator and respirator, but the two are often found in the literature and utilized interchangeably. I follow Collier and Haliburton (2021) to refer to ventilator as "the life sustaining mechanism used to aid or restore breathing" (p. 386).

[86] Collier and Haliburton (2021) quote the work of Lock (2002) in describing the significant change of definition when, "Almost overnight, the organs of the irreversibly comatose had become targets for procurement" (Lock, 2002, p. 65, as cited in Collier and Haliburton, 2021, p.343). This dynamic regarding definitions of death is deeply intertwined with the conversation around organ transplant but further exploration is out of scope of this dissertation.

with “an almost irreverent use of the not-quite-dead on the one hand, and an almost irrational respect for life, however vegetative it may be, on the other” (p. 346). And as Collier and Haliburton suggest: “The higher-brain criterion assumes that consciousness is the most relevant factor in determining whether or not a person is alive” (p. 343). With medical science debating these nuances of death, one can imagine the impact on families struggling to make decisions—including choices to withdraw or withhold supports.

Death and Withdrawal or Withholding Supports. While advances in life-saving technology extended life, they also complicated end-of-life decision-making. Collier and Haliburton (2021) note a significant challenge in contemporary medical decisions: “If the natural progression toward death from disease has been stopped by technology, someone has to make the decision about when to stop the technology” (p. 347). Hence, with nature no longer the master, there was suddenly human responsibility in being “morally responsible for the life or death of a person on life support” (p. 347). Arising from factors including “futile or pointless interventions” (Beauchamp & Childress, 2019, p. 171), or when “Burdens of treatment outweigh benefits” (p. 174) was the reality that decisions needed to be made weighing “quality of life judgments” (p. 175). Often these difficult decisions zeroed in on two words—withholding, or not starting treatment, and withdrawing, which meant stopping treatment altogether. Beauchamp and Childress reflect on the impact of these factors suggesting “decisions to stop treatments are more momentous, consequential, and morally fraught than decisions not to start them” (p. 162). Yet, despite the high stakes of death and the potential for heightened emotions in many decisions, they suggest “the distinction between withdrawing and withholding treatments is morally irrelevant and potentially dangerous” (p. 163) in that there exists in decisions the legitimate possibility of there being over or undertreatment to avoid challenging circumstances.

But perhaps a trickier conversation regarding withdrawal of support is that of artificial nutrition and hydration. Some argue that despite the presence of medical aspects like catheters to provide nourishment, that these interventions should not be seen as treatment like that of technology—including some who suggest withholding nutrition would be an act of starving an individual (Beauchamp & Childress, 2019). But the US Courts conflate the two under the same standard with the rationale being: "No morally relevant difference exists between the various life-sustaining technologies" (p. 166)—a position echoed by the Health Ethics Guide of the Catholic Health Alliance of Canada who suggest "Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort'" (Canadian Health Alliance of Canada, 2012). These debates extend to families making choices amidst a complex medical, spiritual, and cultural landscape—debates often charged with emotion.

One of the emotional themes arising in debates regarding withdrawal and withholding life is what some morally call the "distinction between killing and letting die" (Collier & Haliburton, 2021, p. 347). Collier and Haliburton (2021) reference the work of Rachels (2001), who sees passive euthanasia in withholding or withdrawing life being no different from active euthanasia—in that both are deliberate actions with the same intention in ending suffering. Collier and Haliburton (2021) summarize Callahan's (1992) response to this argument, noting "that the moral distinction between killing and letting die is fundamental and must be preserved" (p. 349) and that "death is caused by the underlying disease" (p. 349) and not the technology. And further, while an injection might kill a person who is well or unwell, any omission would not affect a healthy person. Other jurisdictions have legalized euthanasia and assisted suicide,

including Canada's Medical Assistance in Dying (MAID) legislation that came into effect in 2016 focusing on one's "grievous and irremediable medical condition" (Government of Canada, 2016, as cited in Northcott & Wilson, 2022, p. 64) that was initially only for reasonably foreseeable deaths but this clause was dropped in 2021.[87] The dynamic landscape continues to evolve including developments in the province of Québec in October of 2024 that include mechanisms for advance requests for MAID (Gouvernement du Québec, 2024).[88] These debates continue without clear resolution.

Death and Medical Culture. With a foundation laid regarding the significant debates surrounding scientific aspects of death, I now turn to more philosophical notions woven within a medical culture that has shaped societal understandings of death. Collier and Haliburton (2021) suggest "Advances in medical science have distanced us from the event of death, making it a rare occurrence in the life of most people" (p. 341) while Balboni and Balboni (2019) reference a "conspiracy of silence" (p. 95) involving all parties regarding death, including patients, family, and clinicians in avoidance of discussions around death. Finally, Sulmasy (2006) too suggests a denial of the inevitability of death in health care while acknowledging the harsh reality that needs to be accepted in medicine that "Every patient will die one day, and surgery, medicine, and nursing ultimately are powerless to stop it" (p. 6). But this acknowledgement is not an easy one in medical culture. Mortality is a thread noted by Gawande (2014) who reflects on their training to be a physician: "The shock to me therefore was seeing medicine *not* pull people through. I

[87] While Medical Assistance in Dying is a significant theme in Canadian medicine and central to the conversation around death and planning, further exploration is outside the scope of this dissertation as no provision exists for inclusion in Advance Care Planning at this point and any exploration would be speculative.
[88] It is important to note here that this mechanism is only for the province of Québec and not Ontario which is the focus of my dissertation. Additionally, it is important to note that this is not an advance directive but rather a request for patients to file an advance request if diagnosed with a certain disease that will lead to incapacity and for those who will desire MAID. There is no SDM involved in this process focused on the province of Québec.

knew theoretically that my patients could die, of course, but every actual instance seemed like a violation, as if the rules I thought we were playing by were broken" (p. 7, italics theirs). There is an aspect of death repression, as named by Balboni and Balboni (2019), who reference "Medicine's self-confidence in overcoming illness" (p. 99). Collier and Haliburton (2021) too observe a code in medicine with "the goal of conquering illness and, if not conquering, at least staving off death for as long as possible" (p. 341), as well as the tendency of seeing death as "a correctable biological deficiency" (p. 341). But more than this wish of conquering death, Collier and Haliburton note that "in reality we have often simply lengthened the process of death" and in more practical terms, "The moment of death has been wrenched from nature and given to the medical team" (p. 341). And here lies the tension when death is given to medicine, yet the medical team tends to avoid death. There is an absence of potentially key existential themes involving death like that of suffering and meaning—themes I will address in the section ahead on spirituality and death. But before moving to these themes of the domain of spirituality and death, I further explore some of the differing discourses of death.

2.3.3 Death Discourses in the Contemporary Age

One lens to look at the phenomenon of death and the implicit social aspects is to take a discursive approach. Machin and Mayr (2023) articulate discourse in the following way that I have found helpful: "The versions of events created in language… can overtly or covertly encourage us to place events and ideas into broader frameworks of interpretation…these broader frameworks are referred to as 'discourses'" (p. 26). I will expand on this definition of discourse later in Chapter 3 when I address the methodological approach I will take, but for now this simple description provides a lens to see the multiplicity of understandings of death in contemporary culture and the multiple frameworks of interpretation that vary from person to

person. I will explore various discourses regarding death in the paragraphs to follow that will help contextualize the conversation within ACP and spirituality. I begin by expanding on death denial and repression discourses prevalent in culture. And while this was addressed with in the medical culture above, here I will explore perspectives in the broader culture.

Death Denial and Repression Discourses in Culture. The first discourse I will explore includes death repression, death denial, and partial death denial—notions reflecting what Balboni and Balboni (2019) refer to as a generalized discomfort with death in the West and what Kübler-Ross (1969/2003) observed as "a denial of our mortality" (p. 29). Tracing this historically, Balboni and Balboni (2019) share from the work of Aries (1974) who suggested culture shifted radically in the 19th and 20th century from an attitude of death being tamed by religion, and a public and familial sense of resignation, acceptance, and trust, to something forbidden that resulted in the "total suppression of everything reminding us of death" (Aries, 1974, p. 100, as quoted in Balboni & Balboni, 2019, p. 95). Northcott and Wilson (2022) suggest that "By the twentieth century death had become dirty, ugly, shameful, hidden, and denied" (p. 114). But how might this impact one facing death? Extending this further, Balboni and Balboni (2019) summarize Hayslip's (2003) work in noting how the taboo of death surfaces for individuals, suggesting "death denial manifests itself in multiple intrapsychic and interpersonal forms" (p. 97) including one purposely avoiding death stimuli, hiding thoughts and feelings regarding death, the compartmentalization of death, a resistance to yielding to death, and self-deception around death's reality. This is reflected in Balboni and Balboni's (2019) notion mentioned in Chapter 1 of "The camouflaging of death" (p. 94). Linked closely to discourses of death denial are discourses of death terror that I move to next.

Death Terror Discourses. Extending death denial discourses further, I arrive at the centrality and intensity of fear. Northcott and Wilson (2022) summarize the work of Becker (1973) who argues that "awareness of one's ultimate demise creates an existential crisis centered on questions about the meaning of life" (p. 153) that precipitates "either a search for answers of their own creation, or more often, find answers in the form of socially constructed solutions" (pp. 153 – 154) taking the form of religion, love, or culturally notions of the good life. Northcott and Wilson (2022) note Becker's (1973) work in terror management theory (TMT) where individuals balance the predisposition to survive with a stark awareness of "the eventuality of death" (p. 153). It is suggested that this tension inspires one's functioning by "imbedding ourselves in a symbolically constituted reality according to which, the world is orderly, stable, and meaningful; and each of is a significant being who will survive in some way after physical death" (Greenberg et al., 2020, p. 5). This discourse inspires death transcendence—differentiated as a literal immortality through notions like heaven or the afterlife, or by symbolic immortality like that of one's achievements living on past death (p. 5). In sum, one's mortality becomes "a core motivational impetus" (Greenberg et al., 2020, p. 16) to develop and adhere to beliefs. Hence, one's fear is directed toward a belief system that helps one transcend death and the terror that it invokes. In contrast to this approach to death in culture, I move next to another present discourse around death—that of death acceptance.

Acceptance of Death Discourses. Rando (1984) suggests three general approaches to death including "*death-accepting, death-defying, or death-denying*" (p. 5, italics theirs)—and while death denying is perhaps the most widely noted in society, many cultures also embrace death in the former two categories of acceptance. Examples of this acceptance include cultural groups like the Fiji Islanders who see death as part of the circle of life to be accepted, as well as

Egyptian cultures who defy death with monumental constructions (p. 5). Lutz et al. (2018) reference thanatological perspectives suggesting "death as a journey into the unknown" (p. 668) where this journey denotes a positive perspective. Christian traditions meanwhile see death as revealing a heavenly reward with positive aspects as well. Further, Northcott and Wilson (2022) summarize the views of Zimmerman (2012) who suggests there is a movement towards death acceptance in some parts of health care including "contemporary discourse about what constitutes a good death and the correct way to die" (p. 155). Northcott and Wilson (2022) observe the sharp contrast between discourses of death acceptance and death denial in refrains like Dylan Thomas' (1971) "Rage, rage against the dying of the light" (p. 155) and the battles against death it suggests. Instead Northcott and Wilson (2022) note, "the prescriptive discourse now suggests that the dying embrace death, welcome it, make peace with it, and accept it" (p. 155). As shown in these examples, whether death denying or death accepting, much of our response is dependent on cultural factors. I move now to exploring other cultural discourses.

Cultural Discourses Around Death. As noted above, approaches to death will vary from culture to culture. Northcott and Wilson (2022) suggest one's culture "influences personal beliefs, subjective perceptions, and the meanings that individuals assign to dying and death" (p. 121). One example provided by Talamantes et al. (2000) outlines the view of death in Hispanic cultures captured by the artist, Diego Rivera, who "depicts death (as a skeleton) walking in the park on the arm of the artist" (p. 86) that indicates a level of comfort with death. In contrast, research on Chinese Americans observes a "cultural barrier against talking about death" (Yeo & Hikoyeda, 2000, p. 108) to preserve respect while avoiding bad luck. In terms of care for the body after death, cultures also have different practices with Muslim cultures ensuring the deceased are "handled with the highest possible degree of dignity" (Al-Shahri, 2014) and prayers

being said by those surrounding the dead body. By contrast, Hindu cultures place the dying loved one east facing and "a lamp is lit near the head and the relatives pray, read the scriptures and sing hymns (Akileswaran et al., 2014, p. 88). But more than just ethnic and religious perspectives on death, Northcott and Wilson (2022) suggest there are different cultural and social expectations around interacting with death based on "sex role socialization" (p. 150) where norms for "females legitimize emotional expression and nurturing responses" (p. 150) while the expression of emotion by males may be seen as "deviant and unacceptable" (p. 150). Northcott and Wilson (2022) here also reference the work of Wilson et al. (2018) in suggesting cultural impacts to the LGBTQ community who "may fear discrimination, stigmatization, harassment, and rejection" (p. 112) that may impact end-of-life care and increase potential for disenfranchised grief. Noting the diversity of cultural approaches to death, one can see the centrality of being culturally-sensitive in ACP to help safeguard beliefs regarding death—responses that are not just isolated individual preferences but intertwined socially. It is these social discourses of death I move to next.

Social Discourses of Death. A final discourse of death I will explore involves the social nature of our society that emerges with death. While Western culture has been characterized by increased individualism, death is undeniably a social phenomenon as well, as King (2008) articulates: "Death is a profoundly personal experience…But death is also a profoundly social experience that cuts deep lines into the lives of human groups and communities" (p. 99). Sulmasy (2006) suggests people who are dying connect to the social as well by asking relational questions like: "Is my value to be found only in my social contribution, now limited by my bodily condition? How does this affect my relationship with others? Upon whom can I depend? Can I achieve reconciliation with my loved ones before I die?" (pp. 166 - 167). Extending the importance of one's relationship even beyond death, Silverman and Klass (1996) put forth a

perspective of grief counseling that goes against the idea of grief that seeks to "sever the bonds with the deceased in order for the survivor to be free to make new attachments" (p. 22). Rather, their relational perspective focuses on continuing bonds with loved ones where "interdependence is sustained even in the absence of one of the parties" (p. 16)—a concept rooted in the work by Anderson (1974) who suggested, "Death ends a life, but it does not end a relationship" (Anderson, 1974, p. 77, as quoted in Silverman & Klass, 1996, p. 17). This perspective connects with the work of Ricoeur (1995) who notes our stories as humans are interconnected where, "My dying is a part of others' history; it is even that moment when we may say I simply fall over into others' history" (p. 310). And in this sense of social connectedness, one begins to see the interwoven story of life and death, and a sense that our story is not isolated but, as Ricoeur notes, "We are also a character in others' stories and histories" (p. 310). But more, our stories do not end at death, but "unlike a closed literary narrative, life is open at both ends" (p. 309). Considering the social nature of death, one can see the challenge arising with an individualistic focus in ACP, and even with notions of autonomy that will be explored later in this chapter.

Overlapping Discourses of Death. Finally, in addressing the various discourses surrounding death, including denial, acceptance, and various cultural and social discourses—I arrive at the reality that many perspectives tend to intertwine. Northcott and Wilson (2022) provide a few examples of overlapping discourses around death including an anecdote of a child pondering the death of a grandparent where one discourse involves their grandpa in heaven, and another discourse is their experience of grandpa being in the cemetery. The context of these discourses is shaped by culture and one's experiences regarding death. And if one considers the statistic referenced in Chapter 1 that suggests 34% of Canadian respondents had made a switch in spiritual or religious identity across their life and that 20% identify as being "Spiritual, but not

religious" (Ipsos, 2017, p. 7), one can begin to see the potential for overlapping spiritual, cultural and social discourses. Having explored a variety of discourses surrounding death in the paragraphs above, I now move the conversation to death and its relationship with spirituality—overlapping concepts that will serve as key notions in ACP reflection.

2.3.4 Death and Spirituality

While seemingly paradoxical, I begin this section on death and spirituality by starting with the notion of "life". Sulmasy (2006) suggests the context to all of illness, suffering and health care is the finite "richness, power, and mystery" (p. 6) of life and the reality that "Life holds within it the seeds of death" (p. 6). Sulmasy continues, "If there were no Life, there could be no illness" (p. 6), which sets life as a larger narrative to the concept of death. It is a similar notion to Tillich's similar perspective on life and death summarized by van Deurzen (2009): "He calls life the form and death the contents, the one containing the other…there would be no death if there had not first been life, but death is the very essence of life" (p. 100). Considering these larger perspectives, one begins to see spirituality in health care as containing all of life—including death. Hence, as noted in Chapter 1, with Sulmasy (2006) seeing illness as a spiritual event because it triggers thoughts of death that ultimately lead to one's existential concerns that inspire one's search for meaning—one can see that death is truly intertwined with spirituality. They are a chain of events functioning together where the realization of one's own mortality invokes the deepest reflection of spiritual meaning with questions like: what does death mean? Does my life have meaning? And—is there more to life after physical death? Considering the definition of spirituality suggested earlier in this chapter that includes a sense of ultimate meaning and life-integration, these existential questions become deeply spiritual questions of identity that I will explore in the sections below.

The Meaning of Death. As Collier and Haliburton (2021) suggest, "Life comes to an end at some point for each and everyone of us" (p. 339) inspiring many questions "about the meaning of death" (p. 339) that have been asked by philosophers across the ages. Ferry (2011) too situates death as a central phenomenon in both philosophy and religion including the ancient Stoics who lived in paralyzing fear of the irreversible, reducing "*all* philosophical questions to a single issue: the fear of death" (p. 7, italics theirs). Yalom (2009a) references the ancient story of Gilgamesh and the "wound of mortality" (p. 1) that has haunted humanity and disrupted life for many. And while philosophy has sought to treat this wound with reason and logic, Yalom concludes this anxiety around death "is the mother of all religions, which, in one way or another, attempts to temper the anguish of our finitude" (p. 5). It is the mystery of death that inspires a quest for one's sense of this larger meaning—a place of ultimacy in what Tillich (1957) suggests as an "all-embracing and all-transcending concern" (p. 8) that stretches out to an existential rest where "The human heart seeks the infinite because that is where the infinite wants to rest. In the infinite it sees its own fulfillment" (p. 13) And with this sort of reflection emerging at death, some have suggested an opportunity for awakening. I move to this theme next.

Meaning and Awakening. Death certainly inspires many human feelings regarding existence. Lutz et al. (2018) draws on Williams (2006) to summarize some of these responses encountered with death including "feelings of alienation, loss of self and autonomy, dissonance with reality, need to affect forgiveness and compassion for self and others, and self-actualization of beliefs" (p. 667). Clearly death serves as a moment of stark reflection regarding some of these bigger questions of life mentioned above and how one might choose to live their life. And perhaps there is an opportunity here. Yalom (2009a) suggests "Death awareness may serve as an awakening experience, a profoundly useful catalyst for major life changes" (p. 30). Churchill

(2015) suggests a similar notion of one's "innate human capacity for seeking and finding transcendent meaning at critical junctures in life" (p. 761), while Thomas (2018) suggests "Death focuses the mind on what is important in life—the end of life (time) points to the end of life (meaning)" (p. 14) and the invitation to "live in the context of our dying….[and]…reset the compass to ensure we live now in accordance with our values, goals and aspirations" (p. 14). This is what makes ACP so central. The high stakes of death in decisions invokes possible inspiration and motivation for life. And more than just benefit for the physical life, for many spiritual traditions this means consequences for an afterlife. I will address this theme next.

Death and the Afterlife. Along with existential reflection on one's present life, another theme that is likely to arise in reflection around death and spirituality is the afterlife. Collier and Haliburton (2021) suggest that philosophers have reflected on these notions of death over centuries including Socrates[89] describing death as a "journey to another place" (p. 339) while Plato speaks of the "immortality of the soul" as a kind of reincarnation (p. 340). But as Collier and Haliburton (2021) suggest, "If philosophers have asked questions about death and its meaning, it has often been religion that has supplied answers" (p. 340). And these spiritual answers in the West have been dominated by Christian influences and "a belief in an individual and immortal soul" (p. 340) in contrast to Eastern religions and a view of one "blending into a universal soul or consciousness" (p. 340). But in terms of particular beliefs around an afterlife, perspectives are varied. Catholic tradition suggests death is "the separation of the soul from the body" (Catechism of the Catholic Church, n. 997, as cited by DuBois, 2009, p. 166) and quite straightforwardly "death is an event, but the result of the event is a dead body" (p. 166). From a Muslim perspective, Al-Shahri (2014) note an afterlife of "heaven for eternal joy or to hell for

[89] This reference to Socrates in Collier and Haliburton (2021) is taken from Plato's Apology (p. 339).

either temporary eternal suffering based on their righteous or improper deeds in their worldly life" (p. 77).

In contrast, Northcott and Wilson (2022) draw on the work of Laugrand (2019) to outline the beliefs of the Inuit of Nunavut regarding the afterlife where "The body decays while the double-soul goes to the land of the dead and the name-soul lives on in newborn infants who are given the name of the deceased" (p .123). In traditional African contexts by contrast, Powell et al. (2014) draw on Kalu's work (2000) to describe one's journey to the spirit world, and the widespread belief in reincarnation where previous family members return in the next generation. While cultures hold different views, I return to the finding I shared in Chapter 1 from Bibby (2017) who notes only a slight change in three decades regarding those who belief in life after death[90] (from 65% in 1985 to 66% in 2015). This suggests an enduring belief regarding the afterlife in the broader public.[91] All told there is a wide diversity of belief, experience, and conviction regarding death and the mystery of the afterlife that needs to be considered.

Having explored approaches to spirituality and death in the first two sections of this literature review, I now turn to the other interwoven concept with spirituality and death—that of values. I begin by offering a background to values.

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[90] Those believing in life after death in Bibby's (2017) study note: "Yes, I definitely do" or "Yes, I think so (p. 172).

[91] It is difficult to address spirituality, death, and the afterlife without referencing the phenomenon of near-death experiences (NDEs). I briefly note here the work of Tassell-Matamua and Holden (2020) who reference the work of Moody in the 1970s who suggested NDEs as being "profound spiritual events that happen, uninvited, to some individuals at the point of death" (Moody, 1988, p. 11, as quoted by Tassell-Matamua & Holden, 2020, p. 51). Research has suggested qualities including a different relationship to time, a sense of transcendence, observing a bright light, interaction with deceased individuals and strongly positive emotions (Tassell-Matamua & Holden, 2020). Also, estimates suggest 4% - 35% of individuals in the populations have experienced NDEs, but some suggest they are underreported due to lack of disclosure because they "contravene societal norms" (p. 54) and that these can be easily pathologized (p. 55). I note this briefly for perspective, but any additional elaboration is outside the scope of this dissertation.

2.4 Values

2.4.1 Background to Values

After outlining the landscape of spirituality and death in the previous sections, I now turn to the other interwoven notion of values that is critical to ACP processes. A key starting place for this debate is the *Health Care Consent Act of Ontario, 1996* that outlines the process for an SDM to make a treatment choice for someone who is incapacitated, taking into account "the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable…[and]…any wishes expressed by the incapable person with respect to the treatment" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A., s. 21(2)).[92] This legislation reduces decisions to three personal factors—values, beliefs, and wishes. But why should values need special attention? Black's Law Dictionary (Black, 1979) suggests belief as being, "A conviction of the truth of a proposition, existing subjectively in the mind, and induced by argument, persuasion, or proof addressed to the judgment" and something based "at least on assumed facts" (p. 141). In contrast, "wish" is defined as one's "Eager desire; longing; expression of desire" (p. 1436). What is common to both these notions of belief and wishes is a quality of concreteness—beliefs are factually rooted in "the proposition to which it refers" (Cobb, 2012, p. 113) while wishes hold an explicit quality demanding unambiguous expression of longings. But values, by contrast, I will argue, hold a sense of abstractness and subjectivity. And here lies the challenge in what extends to the territory of what some call the fact/value dichotomy[93] where a legitimacy exists in rational fact, while value judgments are categorized as

[92] While I allude to it here, *The Health Care Consent Act,1996,* will be addressed further later in this literature review when I focus on Ontario approaches to substitute decision-making.

[93] The academic conversation around the fact/value dichotomy is expansive and beyond the scope of this interdisciplinary dissertation. A thorough treatment includes Putnam (2002) among others who suggests strong proponents of the view are based on "over-inflated dichotomies" (p. 1) resulting in consequences for the world. While a site of significant debate, further exploration will be beyond this thesis.

subjective, and as a result, more quickly dismissed. McGehee (1982) outlines a history of intellectual dialogue where objective rationality is privileged, and values are to be debunked as subjective "balloons to be popped by our intellectual darts" (p. 43). Richards et al. (1999) suggest the historic shift to a focus on naturalism and its assumption of no supernatural presence and the assumption that "all moral values are ephemeral and of human origin" (p. 134) and that "values (understood in ethical terms) were regarded as intellectually meaningless" (p. 135).[94] With my suggestion that health care adheres to this kind of positivistic, cognitive, and rational philosophical underpinning, I am suggesting that the concreteness of beliefs and wishes are privileged, while the more abstract notion of values—often linked closely with spirituality—is left ambiguously defined and underutilized because of its unwieldiness. While beliefs, wishes, and values are undoubtedly interwoven in many cases, and also potentially dismissed based on their spiritual content, the underexamined notion of "subjective" values is important to explore not only because of its centrality to Ontario legislation, but also because of the abstract qualities that hold significant overlap with spirituality.[95] Transformation in ACP requires a fuller treatment of ultimate values in decision-making for the good of the patient. In this section I will explore interdisciplinary approaches to values, values in end-of-life decision-making, the relationship between values and spirituality—and finally I will end this section by exploring scales of value preferences that help bridge moral decision-making and spirituality.

[94] While this reference is based in psychology, the spirit of this movement towards naturalism and the marginalization of values is applicable to the wider medical field. The suggestion from Richards et al. (1999), that therapists could be value free and "objective scientific technicians" (p. 135), is reminiscent of Sulmasy's (2006) argument of the reductionism being present in medicine.

[95] As Lonergan suggests with a kind of theological imagination, there is a relationship between the objective and subjective that needs to be explored. I will return to this in their scale of value preferences at the end of this section where Lonergan comments on subjectivity in light of the human spirit. Lonergan embraces this in saying, "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27).

2.4.2 Interdisciplinary Perspectives on Values

Where does one begin to explore values in the social sciences? While understandings of values often include the field of economics and concepts like cost-analysis and population ethics (Hirose & Olson, 2015), these domains are outside the scope of this dissertation focusing on treatment decisions in health care.[96] But how does one categorize values in relation to health care decision-making? One interdisciplinary perspective by Sagiv and Schwartz (2021) characterizes two perspectives in the social sciences—one focused on personal values and the other highlighting cultural values. Steinert (2023) on the other hand takes a more disciplinary approach in narrowing the focus in the social sciences to key domains of psychology, philosophy, anthropology, and sociology. Inspired by the applicability of this approach to bioethics, I will focus my exploration on three of these key disciplines. In the section ahead I will explore values in relation to psychology that tends to focus one's individual perspective on value, the perspective of philosophy that looks at "fundamental questions about values and valuing" (Steinert, 2023, p. 68), and also the discipline of anthropology that highlights "cultural processes" (Steinert, 2023, p. 52) regarding values. After exploring these approaches, I will extend the conversation to spirituality, decision-making, and finally, scales of value preferences. I begin with values and psychology.

Values and Psychology. In seeking a science of values, Sagiv and Schwartz (2021) summarize research in psychology with key findings around values including their importance as an aspect of self; their holding of inherent desirability towards what is good and worthy; their orientation towards what is desirable socially and shared; their ordered quality as a personal

[96] One could undoubtedly make an argument that values in ACP could include aspects of economics and the culture of medicine. But with a focus on individual client choices in ACP this exploration is outside the scope of this thesis.

hierarchy; their ability to be stably applied across time and in many diverse contexts; their ability to be brought easily to one's mind; and finally, their ability to help as standards for evaluation and to "serve as sense-making systems" (p. 520). In terms of a definition, Sagiv and Schwartz (2021) define personal values as a cognitive representation of "broad desirable goals that motivate people's actions and serve as guiding principles in their lives" (p. 518). Rokeach (1969) suggests values transcend situations as being a "yardstick guiding not only attitudes, but also actions, comparisons, evaluations, and justifications" (pp. 550 - 551). In terms of categorizing values, Schwartz was influenced by the work of Rokeach (1973) to develop a model in the early 1990s based on measuring values "as guiding principles in life" (Sagiv & Schwartz, 2021, p. 522) to help one cope with biological needs, interpersonal needs, and the survival needs of the group. Schwartz's (1992) model, as outlined by Sagiv and Schwartz (2021), was based on two main organizing principles of personal outcomes and social outcomes, followed by four higher-order values that included openness to change, self-enhancement, conservation and self-transcendence. And finally, a collection of ten basic values branched out from these four higher values including self-direction, stimulation, hedonism, achievement, power, security, conformity, tradition, benevolence, and universalism (p. 523). And while this work is foundational in theoretical approaches to psychology, in practice, values have tended to be diverse in contemporary psychological approaches like the prominent value-based modality, *Acceptance and Commitment Therapy* that focuses on four categories of values including relationships, work/education, personal growth and health, and leisure. These four values are then contextualized in other life values areas including family, marriage, friendships, employment, education, recreation, spirituality, community, environment and health (Harris, 2008). Or another example is the popular contemporary values-based approach by Brown (2018) who takes a social

work perspective to suggest discerning key values from a list of over 100 ranging from patriotism to job security. But the question remains—how might values emerge in ACP decisions involving death? How is spirituality integrated with values? And what about ultimate values?

Values and Philosophy. While psychology has attempted to scientifically measure personal values based on cognitional representations and diversity of personal choice, Steinert (2023) suggests philosophy reveals "underlying assumptions in our thinking" (p. 68) spanning metaethics, aesthetics, and metaphysics. In philosophy, a deep historical well of intellectual concepts[97] related to values emerges regarding normative approaches to value—including the evaluative concept of what is "good" and also the deontological concepts of what is "right" or what one "ought" to do (pp. 68 – 71). Commenting on these evaluative and deontological approaches Zimmerman (2015) suggests seeing them as "two families of concepts" (p. 13) that overlap and intertwine. For example, the "right" may be accounted for "in terms of the good" (p. 21) which can lend to a more consequentialist perspective; or the good can be accounted for "in terms of the right" (p. 21) which suggests a more deontological perspective (p. 12). Another dialogue surfacing in philosophy regarding values distinguishes "final value" where something holds value for its own sake, and that of "non-final value" (Steinert, 2023, pp. 68 - 71) where something is instrumental or contributes to a greater value. And connected to this same distinction is an ancient debate centred on the distinction of intrinsic and extrinsic values. Intrinsic value, in particular, has captured the imagination of philosophers historically with Feldman (2005) referencing Kant's intrinsic suggestion that an object without a use would "still sparkle like a jewel in its own right, as something that had its full worth in itself" (Kant, 1959, p.

[97] I acknowledge the breadth and depth of the philosophical conversation around values across history. A deeper dive into the theoretical foundations of values are outside the scope of this interdisciplinary dissertation.

10, as cited in Feldman, 2005, p. 46). Philosophers continue to explore nuances of value under the name "value theory" or "axiology" in what Hirose and Olson (2015) describe as covering a host of questions around what might be good or bad, as well as ranges of goodness and badness. Other debates surround value monism and pluralism that distinguishes a single cardinal value in contrast to the potential for many values to exist, as well as debates around subjective values where something is valuable because it has been deemed subjectively valuable by an individual, in contrast to objective approaches where values are present regardless of one's attitudes (Steinert, 2023). Philosophers have pondered these questions for centuries and the nuances continue to be debated. And while bioethics as a field seeks a more universal model based on philosophical notions like utilitarianism, the question remains—how might diverse Canadians grappling with decisions around death practically explore their particular values that integrate with spirituality?

Value and Anthropology. Having explored psychological and philosophical perspectives on values I now move to anthropological approaches to values. Considering the objective in anthropology is to "understand humans as cultural beings and to illuminate culture's influence" (Steinert, 2023, p. 52), one can see the importance of an anthropological lens to value conversations including "cultural processes responsible for value creation, re-creation, and transmission" (p. 52). Considering Brislin's (1993) understanding of culture articulated by Braun et. al. (2000) as "the worldview, values, norms and behavior guidelines shared by a group of individuals" (p. 2), one can see both the centrality of values and also the implicit connection with the concept of worldview that Hiebert (2007) defines as "what people in a community take as given realities, the maps they have of reality that they use for living." (p. 15). Of note, these maps of reality here, bare striking resemblance to understandings of values being "yardsticks"

and “guiding principles” in the realm of psychology noted above. And while no dominant system of value exists for anthropology, Steinhert (2023) suggests the work of Kluckhohn (1951) as being particularly influential in revealing underlying value orientations in cultures with a focus on clusters of humanity exploring what it means to be good or evil; one’s relationship with nature; the theme of time in the present, past, and future; the theme of motivation for activity; and finally social relationships. Steinert (2023) quotes the work of Gallagher (2001) in regards to this notion of value orientation as being how “a group is predisposed to understand, give meaning to, and solve these common problems as being an outward manifestation of its innermost values, its window on the world: its value orientation” (Gallagher, 2001, p. 2, cited in Steinert, 2023, p. 54). More than value orientations, Steinert (2023) references the work of Dumont (2013) who links values to meaning systems with hierarchies, but more—the notion that several orders can be present at the same time in a culture, depending on social aspects. With this interplay between values, culture, and orientation, the worlds of the individual and the social intertwine, inspiring reflection around spiritual underpinnings of individuals that orient decision-making. And questions arise here including: what are their maps of ultimate value orientation grounded in? This brings the conversation to values and spirituality.

2.4.3 Values and Spirituality

And so, I arrive at the interplay between values and spirituality—a critical link because one’s values drive ACP decisions, and one’s values are rooted in spirituality. While interdisciplinary aspects of values noted above include instrumental, extrinsic, and pleasurable aspects of values, I also observe end-state and ultimate value themes also arising in the discussion including one’s desirable goals, orientations, principles, yardsticks, intrinsic values, and one’s maps of meaning. In relation to spirituality now, I note here that this list of qualities

expressed in relation to ultimate values holds a striking resemblance to the list of characteristics of spirituality explored in the previous section including notions of meaning, transcendence, ultimacy, and what is sacred or greatly valued. So how might these domains come together? McGehee (1982) argues for a restoration of a human approach to values and explicitly names one's own principles as spiritual values while Frankl (1946/2019) links the spiritual dimension with both meaning and values, noting one's "innate desire to give as much meaning to one's life" (xviii) and at the same time "to actualize as many values as possible" (p. xviii). McPherson (2015) too explicitly defines spirituality with a connection to values as "a practical life-orientation *towards what is seen as being of great value*" (p. 336, italics theirs) while Edwards (2012) understands one's values as being the bedrock of spirituality: "Values (what we value) and evaluations (how we value) constitute the hard core of religion or spirituality. We need a general frame of reference that orders and makes sense out of the things we value spiritually and out of how we evaluate them" (p. 12). And extending the conversation to normative decision-making, McPherson (2015) continues, "the values towards which we orient our lives involve an especially strong kind of strong evaluation" (p. 337) that provides a holistic ethical orientation to decisions where "we see ourselves as *moving* towards or away from what we understand to be the good, which connects up with a vision of spiritual/ethical fullness" (p. 337, italics theirs). Additionally, Gula (2000) talks about one's "most cherished values" (p. 19) that give us a sense of purpose and orientation in decisions, suggesting, "Spirituality can never be separated from the moral life as some external aid that helps us to be good" (p. 18), but rather, there is a commitment that arises from our values being expressed that animates us. And so I arrive at the framing of one's decisions with one's deepest and fullest values that integrate with one's spiritual underpinning—not as a compartmentalized dimension, but the ground that is central to

decisions.[98] Considering ACP involves the high stakes of death and ultimacy, it requires the fullness of decision-making that includes an integrated approach to values that are grounded in the ultimate bedrock of one's life. It is here where decisions involving the highest stakes around death and the fullness of meaning can be made. But what is this deeper ground?

Values Grounded in Something Bigger. And so, I move the conversation regarding values to the deepest ground of values with the help of Taylor's moral ontological perspective. Taylor (1989) articulates a challenge to the reductive tendency in contemporary society to "treat all moral ontologies as irrelevant stories" (p. 9) or "pure fiction" (p. 8). Instead, Taylor suggests one's "background picture" (p. 8) is often left unexplored, a picture that can inspire "moral and spiritual intuitions" (p. 8). Taylor draws on MacIntyre to suggest a 'quest' that people are on to define themselves and a "spiritual source they can connect their lives with" (p. 17). And here, Taylor emphasizes the strong evaluation and a focus on ends and goods as a personal spiritual framework to carry out moral decisions rooted in one's commitments that, "provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose" (p. 27). In connecting to the greatest source of meaning, Taylor suggests humans aspire to a fullness that builds "some pattern of higher action, or some meaning; or it can be met with connecting one's life up with some greater reality or story" (p. 43) and "within a world shaped by our deepest moral responses" (p. 8). In a similar notion, Pargament and Exline (2022) speaks of a "spiritual orienting system" (p. 30) that helps guide our search for the sacred not unlike a compass or map. Gula (2000) reflects, "When we begin to touch what we ultimately love, what deeply motivates us, what gives us meaning and

[98] This theme arises later in this section with Lonergan's (1972/2017) scale of value preferences that propels one to the deepest level of one's spirituality, but also in the work of Pellegrino and Thomasma (1988) where one's greatest good is an ultimate good underpinning one's life. I explore deeper reasons for spirituality in ACP to close Chapter 2.

identity, then we are making the connection between spirituality and ethics. The spiritual connects with the ethical at the point of what counts most for us in living" (p. 18). This sense of identity and what we most cherish moves into the place of the "heart" as Nullens (2017) suggests in that "there is a unique type of reasoning of the heart, a kind of experience that leads us to the world of values" (p. 33). Hence, Nullens (2017) suggests, "Ethics is a highly intuitive exercise...It explores the orders and disorders of the heart" (p. 33). In response to this depth of values, ACP then must provide individuals with the fullness of opportunity to explore values intuitively on a "heart" level. Expanding on this further, Taylor (1989) suggests one finds this identity much like the physical world: "Orientation in moral space turns out again to be similar to orientation in physical space. We know where we are through a mixture of recognition of landmarks before us and a sense of how we have travelled to get here" (p. 48). And this orientation is noted by Nullens (2017) as an intuitive exercise: "Values are like ideas of orientation, not primarily known cognitively, but intuitively and emotionally" (p. 41). And here I arrive at the tension of epistemology once again and the frequent privileging of the rational and logical in ethics. Steinert (2023) quotes McIntyre (2007) to encourage this openness to different epistemologies: "Questions of ends are questions of values, and on values reason is silent; conflict between rival values cannot be rationally settled" (McIntyre, 2007, p. 26, as cited in Steinert, 2023, p. 26). And with ACP involving high stakes decisions regarding death, inclusion of ultimate values and one's spiritual bedrock may involve diverse ways of knowing.

Having laid a foundation regarding values and the aspiration toward the deepest sense of values to help one's orientation, I move next to the link from spirituality and values to end-of-life decision-making.

2.4.4 Spirituality and Values in End-of-life Decision-Making

Having explored spirituality and the potential to draw on the ontological bedrock of one's values for decisions, I move to the integrative question—what is at the heart of difficult decisions at end-of-life that are included in ACP processes? Gula (2000) comments on what they see as being behind advance directives, saying: "But what lies behind those directives as the unexpressed limit is the deeper sense of what we most value about life and the kind of life that we believe follows from what we most cherish. Thus, the moral decision to refuse treatment or to undergo treatment cannot be separated from one's spirituality, from one's deepest longing for what makes life ultimately meaningful" (p. 19). There is an integrated quality of our decisions and our deepest longing for ultimacy and meaning. But what might this look like for diverse individuals making health care decisions? In the space below I will outline a small sampling of cultural and spiritual expressions of value that may arise in patient care—but more specifically in end-of-life decision-making with the high stakes of death involved. After outlining these cultural and spiritual destinations for values, I will extend the conversation to value hierarchies and the work of Lonergan (1972/2017) that inserts a spiritual destination to value reflection.

Cultural Values. In terms of value reflection, a significant influence on one's health care decision-making is one's culture that can overlap with spirituality. Bruera and Delgado-Guay (2014) provide examples of Latin American values and suggest "spirituality and religiosity are commonly enmeshed with Latino cultural values and daily lives" (p. 65). Practically speaking, they name "enduring cultural values among Latinos in which their faith experiences are embedded" (p. 65) to include *Personalismo* which means a value related to one's "warmth, closeness, and empathy and one's relationship with others" (p. 65); *Familismo* which means "an enduring commitment and loyalty to immediate and extended family members" (p. 65) and also

Fatalismo which means "one's future is preordained" (p. 65) which can be a deterrent to some medical interventions. Additionally, Al-Shahri (2014) highlights values in Arabic culture that align with Muslim values of predestination and the belief that "suffering should be perceived as a mode of atonement" (p. 75) or additionally as a "a test of faith" (Akileswaran et al., 2014, p. 87). Another Muslim belief that may impact medical decisions is the conviction that "Human life is considered sacred, and acts that hasten or take a life are forbidden" (p. 86). The authors note that these values may result in declining "any potentially sedating medications with the intent of maintaining their wakefulness" (p. 87). In a similar vein, Buddhists in Southeast Asia seek to be alert to suffering in the dying process and "not oversedated or made unresponsive" (p. 89). Traditional African values, as noted by Powel et. al. (2014) includes the notion of "Ubuntu" which is a sort of "cultural collectivism" (p. 30) that undergirds social values with a focus on interconnectedness with those upholding "Ubuntu" in life being "considered to achieve, in death, a unity with those still living" (p. 30). Nutrition can also play a factor in values as noted by Yeo (2000) in Chinese Americans where dying on a full stomach went along with being with family in contributing to a peaceful death.[99] With 450 cultural and ethnic backgrounds in Canada (Statistics Canada, 2022b), as noted in Chapter 1, one begins to see the challenge in outlining key values at end-of-life and how they may impact decisions. It is this diversity that demands ACP resources invite spiritual inclusion.

Spiritual Values Expressed in Religion. Closely related to cultural values are spiritual values that are often expressed in religious terms. Suffering in the Christian tradition for instance holds many stances—including references in Christian Scripture to God's "retributive justice"

[99] Yeo et al. (2000) note one study by Norberg et al, (1994) in China where Chinese nurses tended to favor feeding those at the end-of-life or patients with dementia more than Western nurses.

(Rowell, 2000, p. 151) towards those who do not act uprightly, as well as suggestions of suffering as being an act of witness, a benefit to those in their community, or the thinking that "suffering is educative and a means of spiritual development through which humans may learn to rely on God and come closer to God" (p. 152). Finally, Rowell notes the example of suffering given by Jesus Christ where "Christ describes his suffering as necessary for human salvation" (p. 152). Other Christian values that emerge in conversations around health care include compassion, sanctity in life, and the dignity of life as a gift under one's stewardship where "our oversight does not extend to a right to take a life" (p. 157). Jewish values at end-of-life include the pervasive value of *pikuah nefesh* which means "saving life" (Kavesh, 2000, p. 185)[100] as well as debates around autonomy considering it is understood that it is God's role to determine the time of death. Additionally, Muslim traditions hold values of submission "to the will of God" which is what the word Islam means—and while treatment is strongly recommended for a curable disease, Muslim beliefs do suggest, "artificial prolongation of life is not desirable by ethics or common sense" (Hai & Husain, 2000, p. 207). These examples provide a small sampling of situations where spiritual beliefs intersect with the theme of death.

In summarizing how one's spiritual beliefs may impact specific choices, Balboni and Balboni (2019) built a model based on four theological beliefs that transcend religious expressions that impact decision-making for patients. Their model includes divine sovereignty, miracles, sacredness of life, and suffering as God's test. They suggest that in relying on divine sovereignty, where God has control of one's life, some will defer to God to help them cope and make decisions. They suggest that this can be seen as being "morally faithful" on one hand or

[100] Of note, Kavesh (2000) suggests that some Jews would even violate laws like driving on the Sabbath to fulfill this value.

may be seen by others as being “irresponsibly avoidant” (Balboni & Balboni, 2019, p. 41). Secondly, they suggest belief in miracles frames some conversations that are rooted in one’s belief that God could intervene with a miracle which can inspire more aggressive medical choices and decisions not to pursue avenues like hospice that may suggest a closedness to miracles. The sacredness of life is the third theological category that suggests the importance of pursuing every medical option to respect life and extend it as much as possible. And finally, the last category involves suffering that is seen as something virtuous as God could be testing someone. Spirituality is closely intertwined with values, often circling into the process of discerning ultimate values that inspire one’s final choices. But how might one discern one’s highest value? This next section will explore value hierarchies to determine one’s deepest values before I move the conversation in this literature review to the bioethical foundations of ACP.

2.4.5 Value Hierarchies and Scale of Value Preferences

Having explored interdisciplinary approaches to values and also the cultural and spiritual aspects of values and their influence in medical decisions, I now explore the prioritizing of values through hierarchies—eventually landing on the work of Lonergan (1972/2017) whose focus includes a clear spiritual orientation that aligns with ACP and the high stakes involved in end-of-life decisions. But the question that inspires the need for a value hierarchy includes –how does one prioritize one’s deepest value orientation in light of the high stakes in decisions involved in ACP? While psychological, philosophical, and anthropological approaches may help frame the conversation, there remains a question of a deeper sense of value discernment that integrates the spiritual and cultural. I am arguing in this thesis that the missing element is a deeply spiritual perspective that I have painted in the previous pages. But how can the diversity

of spiritual expression be integrated? I will briefly outline several value scales before turning to the theological work of Lonergan to outline a scale of value preferences integrating the spiritual.

Scale of Value Preference. The question arising in high stakes decision-making regarding death is—how does one choose their highest values? While it is acknowledged that every individual has some sort of scale of value preference (Byrne, 2009) different models have emerged that I will briefly outline before expanding on Lonergan's version. Edwards' (2012) hierarchy of values, inspired by Hartman's (1967) work, sees intrinsic values being most valuable, followed by extrinsic values, followed by systemic values. This model, while simple in categorization, tends to be more philosophical and lacks a functional progression and specificity. Byrne (2009) outlines other scales by theorists including von Hildebrand and Scheler. Their assessment includes criticism of Scheler's approach to ranking as being "convoluted" (p. 26) and lacking precision that makes it difficult to observe a single expression. While criticism of von Hildebrand's model includes the suggestion that it has too many complicated nuances without examples to make it practical to operationalize. Byrne (2009) advocates for the scale of value preference by Lonergan that includes a focus on the "structure of the human good" (p. 31) with reference to both social and cultural values, as well as placing religious values at the top of the scale which is not done by either Scheler or von Hildebrand. Considering my assumption that spiritual integration of values in ACP is essential, the centrality of spirituality in a model is essential. But more, Byrne (2008) elsewhere notes the centrality of emotion to Lonergan as an "existential felt scale of value preference" (p. 59) that includes the "felt horizons of value preference" (p. 59). This inclusion of emotions in Lonergan's approach includes the possibility of marshalling factors that are "governed ultimately by our feelings" (p. 59) that inspires an emotionally integrated approach making Lonergan's approach attractive. Also central to

Lonergan's approach is an anthropological focus on the human spirit that aligns my approach to spirituality in ACP. And so I will briefly explore Lonergan's scale of value preference.[101] The scale begins with vital values that include one's health and strength; social values that include one's community and a sense of social order; cultural values where individuals "find a meaning and value in their living and operating" (Lonergan, 1972/2017, p. 33), personal values that suggest one's ability to love and be loved; and finally, religious value that suggests the heart of living. And this final level of is pivotal in our discussion around ACP as high stakes decision around death involve the fullest and strongest evaluations involving ultimacy. But it is important to note here that the role of feelings for Lonergan is central with the suggestion that "feelings respond to values" (Lonergan, 1972/2017, p. 32). In this there is a deeper value process at stake in discernment that invokes feelings. Byrne (2016) suggests that a "horizon of feelings both elicits further new questions and establishes the criterion of the pertinence of the new questions of value" (p. 175). But this requires a level of discernment and openness to value exploration.

Spirituality in Lonergan's Scale. As one can see, the direction of Lonergan's (1972/2017) scale flows towards the destination of religion that can cause some questions transculturally for those without a religious perspective. In response, Byrne (2008) observes the work of Lonergan suggesting a customizable approach, sensitive to all humanity with their own

[101] While a larger treatment of Lonergan's work is out of scope. This scale is tucked into the fourth stage of Lonergan's (1972/2017) transcendental method. Lonergan's method includes the interiorized unfolding of four incremental levels of consciousness that move with a human "pulsing flow of life" (Gregson, 1988, p. 16) and what Conn (1988) describes as a "radical dynamism of our spirit" (p. 36) from the first stage of experiencing life with empirical sensing, to one's intellectual understanding that includes asking questions and engaging intellectually, to the engagement of rational judging that involves passing judgment on what may be true or false, and finally taking responsibility on deciding what action that will be taken based on individual values. Gregson (1988) suggests it is called the transcendental method "because they transcend all other methods and are operative in all other methods" (p. 25). And while some would argue this approach is purely subjective, Lonergan embraces this in saying, as noted above "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27).

"abiding commitments to their own scales of value manifesting a deep human aspiration for normativity in value priority" (p. 43). But it is Gregson (1985) that outlines the breadth of Lonergan's understanding of religion that extends beyond religion to the more inclusive expression of spirituality as being "a clear meeting point of many of the world's great religions" (p. xv). In naming it as spiritual, Gregson further outlines Lonergan's approach of a religious interiority as transcendent mystery that leads to expressions of both "grace" (p. 64) and also "love, as a shorthand for this transcendent state" (p. 67). This is a broadly inclusive notion to all spiritualities as a movement of the human spirit that Gregson outlines as a move "from the desire for truth to the desire for value" (p. 73) and that "The desire for value is deepened and made stable through love" (p.73).

It is here one can catch a glimpse of these notions of cherished love (Gula, 2000) or chief love (Balboni & Balboni, 2019) or great value (McPherson, 2015) that has come to be a destination of the search for the sacred in spirituality and decision-making as noted above. In contrast to the focus of cognitive representation in psychology, Lonergan moves to deeper levels of knowing that include emotions and spirituality. And for Lonergan, there is an emergence of understanding of moral self-transcendence where there is "a deep-set joy and solid peace" (p. 40) related to love and grace (Lonergan, 1972/2017). This scale can hold both the existential longings of humanity as well as the spiritual. It is this scale that holds potential to inform an ACP process that moves reflection into the deepest values of the patient, aligning with the good of the patient as noted by Pellegrino and Thomasma (1988) and holding the spiritual as the fullest value measure. With a foundation established with debates in the literature regarding the overlapping concepts of spirituality, death, and values, I move next to the context of bioethics where these notions play out in health care situations.

2.5 Bioethical Foundations of Advance Care Planning

2.5.1 Background to Bioethics and ACP

Having explored debates and perspectives around spirituality, death, and values in the previous sections, I arrive at the final section of this literature review—the bioethical foundations of ACP where these themes play out. Considering that ACP has its roots in bioethics, this section will trace the lineage of ACP beginning with a philosophical grounding for autonomy and respect for persons, followed by the evolution and debates regarding informed consent. I will then explore the emergence of substitute decision-making, the development of ACP, and finally, provide an exploration of the spiritual within ACP and dynamics surrounding this. I begin this section with the philosophical roots underpinning this bioethical conversation.

Foundational to bioethics in the West is the principle of respect for autonomy, noted as running "deep in morality as any principle" by Beauchamp and Childress (2019, p. 99). But what are its origins? Beauchamp and Childress note the word "autonomy" stems from the Greek word *autos* meaning "self" and *nomos* meaning "rule" or "governance" that combine together to mean "self-governance" or "self-rule" (p. 99). Theoretically, Jennings (2007) suggests the bioethical concept of autonomy is grounded in two philosophical paths—Kant's objective notion of autonomy centered on one's personal "obedience to the moral law or categorical imperative as it discerned by the self exercising reason" (Jennings, 2007, p. 83); and Mill's subjective focus on personal liberty characterized by "the exercise of judgment and choice by each individual person" (p. 83). While theoretical arguments and debates relating to both paths continue in bioethics,[102] Jennings (2007) notes "the subjective conception of autonomy, which stresses liberty over reason, holds sway" (p. 85). But Jennings (2007) observes it is Berlin (1969) who is

[102] This is a larger intellectual conversation that is outside the scope of this dissertation. I give this information to briefly frame the context of autonomy to examine ACP and will not be exploring them in greater detail.

credited for helping further Mill's approach in bioethics by introducing the notions of *negative liberty* that sought to carefully protect autonomy against external influence and *positive liberty,* which denoted the importance of mastery of self. It is out of this theoretical soil where the focus in Western bioethics emerges to both fiercely protect autonomy, while at the same time advocating for one taking charge.

Beyond its philosophical grounding, the notion of autonomy began to emerge in bioethics amidst many social, legal, and technological factors. Kalousova and De Vries (2014) suggest bioethics "began to germinate" (p. 329) in both America and Canada in the 1950s in response to vast possibility and technological advances that included the advent of open-heart surgery in the middle of the 50s, while Faden et al. (1986) highlight the emergence of both dialysis in 1962 and heart and kidney transplants by the late 1960s that helped usher in "a new era of moral reflection in medicine" (p. 91) and autonomous choice.

But more than just massive technological changes during this time, Engelhardt, Jr. (2003) suggests, as noted in Chapter 1, "The authority of physicians, the clergy, the family, and traditional authority figures was displaced by the authority of autonomous, rights-bearing individuals" (p. xviii).[103] Additionally, Pellegrino and Thomasma (1988) observe other social forces at work during this era including consumerism, civil rights, medical advances, and higher education—forces they note as being "powerful enough to erode the twenty-five-hundred-year-old tradition of medical status contained in beneficent authoritarianism" (p. 5). The importance of one's rights became paramount at this time and with it a movement toward the notions of respect for autonomy and respect for persons.

[103] It is important to note here that the social tremors in America and the development of bioethics would extend globally including to Canada where "theoretical perspectives on bioethics have closely paralleled U.S. thought" because of geographical closeness, overlapping academic involvements, and shared influence of landmark cases and principled focus (Kenny, 2003, p. 6). As a result, Canada's early history of bioethics parallels that of the US.

2.5.2 Respect for Autonomy and Respect for Persons

But how does the conversation arrive at the notion of respect for autonomy? Lysaught (2004) notes an "intellectual archeology" (p. 665) is helpful to trace the non-linear development of autonomy that includes the key notion of "respect for persons" (p. 668). Much debate emerged at this time including thinkers like Ramsey (1970) who drew on Kant to emphasize personhood from a theological perspective marked by a "robust account of respect" (p. 673). Lysaught describes the intellectual dialogue as "Kantian sensibilities competing with unabashedly utilitarian perspectives" (p. 674). But it was the Belmont Report in 1979 that represented a "pivot in the story" (p. 667) where the principle of respect for persons was further articulated with a focus on individuals being "treated as autonomous agents" (p. 668). Lysaught suggests that post-Belmont Report, the references to "respect" moved "in a radically different direction" (p. 668) towards the notion of "respect for autonomy" (p. 675) that dovetailed with the initial 1979 publication of *Principles of Biomedical Ethics* by Beauchamp and Childress (2019). While the Belmont Report utilized *respect for persons* as a foundational notion that led to informed consent, Beauchamp and Childress (2019) focused their bioethical approach on *respect for autonomy*, effectively marginalizing the notion of respect for persons (Lysaught, 2004). The two terms are now often conflated—much to the chagrin of some in the medical community including Pellegrino and Thomasma (1988) who suggest that the two are different, noting "Protecting autonomy is an important ethical principle because it provides a key way to respect persons" (p. 10). Despite differing views and much debate, mainstream notions of respect for autonomy have largely prevailed in medicine. But how might these theories be integrated?

Extending Autonomy into Medical Practice. Amidst immense change in medicine, questions emerged as to how this new thinking might be operationalized in medicine. To help

integrate these new concepts, the new discipline of bioethics "crystallized" (Kalousova & De Vries, 2014, p. 328) in North American in the 1960s with a goal of "exploring ethical questions in medicine and the life sciences" (p. 328). In the span of a few decades, a new group of experts in morality emerged, committed to "the Georgetown four principles of Beauchamp and Childress" (Engelhardt, 2003, p. xvi) that included respect for autonomy, nonmaleficence, beneficence and justice (Beauchamp & Childress, 2019).[104] But arguably the central principle in these four principles was respect for autonomy that would provide the grounding for bioethical decision-making, echoing the importance of both *negative* and *positiv*e liberty as noted above—articulating autonomy as more than just not interfering in one's affairs, but also, "building up or maintaining others' capacities for autonomous choice" (p. 104) in a way that did not ignore or demean one's "rights of autonomous action" (p. 104). But it is this notion of "choice" that is critical for Beauchamp and Childress as they intentionally place their focus not simply on the *autonomous person* and their appropriate "capacities of self-governance" (p. 100), but on a process of autonomy focused on *autonomous choice* and three key conditions: intentionality, understanding, and noncontrol (voluntariness). Simply put, intentionality meant that one must plan with the intent to act; understanding reflected an ability to adequately understand a situation; and voluntariness suggested one's freedom from external or internal controls (Beauchamp & Childress, 2019). And while the goal for one's *autonomous choice* was "intentional action that is fully understood and completely noncontrolled" (Faden et al., 1986, p. 238), the authors also observed a sense of adequacy characterized by substantial satisfaction where "The proper threshold is the general goal of *substantially* autonomous action" (p. 240, italics theirs). In this they acknowledged varying degrees of understanding and voluntariness in

[104] Long past the first publication in 1979, their landmark book, *Principles of Biomedical Ethics*, is now in its 8th edition (2019) and continues to serve as a key framework in bioethics.

seeking substantial autonomy and the limits that included communication, illness, and maturity level—as well as barriers that could include manipulation, persuasion, or coercion that could take the form of economic, physical, legal, or psychological pressures. The approach by Beauchamp and Childress (2019) has had a "remarkable influence" as noted by Lysaught (2004, p. 674), providing an underpinning to mainstream bioethics. Yet, despite the influence of this text, others in the field have offered significant challenges to their approach that I touch on next. This is important to my thesis not just because autonomy is rooted in the absence of coercion, but also because of the questions that arise regarding the privileging of autonomy over other values like community—themes that may arise in ACP. I explore some conflicting perspectives next.

Conflicting Perspectives on Autonomy. While the work of Beauchamp and Childress (2019) became the standard approach to autonomy in bioethics, not everyone celebrated "the triumph of autonomy" (p. 106) that swept over bioethics. Pellegrino and Thomasma (1988) note "The Perils of Autonomy" (p. 18) and argued that "The autonomy argument proceeds on the assumption that one principle should prevail in every medical situation" (p. 18) and suggest that "strict adherence to autonomy is not always the best way to respect patients as persons" (pp. 18 - 19). To their credit, Beauchamp and Childress (2019) are not oblivious to these criticisms, describing their detractors as seeing their work as being "a model of an independent, rational will inattentive to emotions, communal life, social context, interdependence, reciprocity, and the development of persons over time" (p. 104) as well as being "too narrowly focused on the self as independent, atomistic, and rationally controlling" (p. 104). Others in bioethics have been even stronger in their criticism of individual autonomy, including Candib (2002) who suggests that while bioethics has only recently ushered in a culture of individual autonomy, other cultural foundations rooted in community stretch back centuries and are deserving of more attention.

Feminist bioethics has also been critical of the assumption of individualism where one "can make whatever choices it feels like as long as they are not harmful to others; unencumbered by obligations or commitments to others" (Collier & Haliburton, 2021, pp. 117 - 118). Collier and Haliburton quote Friedman's (2003) suggestion that, "Many feminist philosophers have recently suggested that women find autonomy to be a notion inhospitable to women, one that represents a masculine-style preoccupation with self-sufficiency and self-realization at the expense of human connection" (Friedman, 2003, p. 35, as cited in Collier and Haliburton, 2012, p. 118). Further, Sherwin (2012) suggests the language of autonomy "is often used to hide the workings of privilege and to mask the barriers of oppression (p. 246) while Liégeois (2021) reflects on the human person without rational capacity. Collier and Haliburton (2021) conclude that humans "exist in a web of relationships and that these relationships provide the context within which any of our choices are made" (p. 118) while Colenda and Blazer (2022) note that "The centrality of personal autonomy and control at EOL…has not been found to be universally accepted as a cultural norm among different ethnics groups or faith traditions within the US or abroad" (p. 752). With so many perspectives in this unresolved debate regarding autonomy, a question emerges regarding the best road ahead.

Potential Paths Forward for Autonomy. With so many conflicting perspectives on autonomy, what options might help navigate these conflicting perspectives? How might bioethics navigate what Pellegrino and Thomasma (1988) suggest as "the almost autonomic assumption of some ethicists and patients that autonomy must always supervene" (p. 6). Jennings (2007) suggests a balanced approach, noting "If there is a danger inherent in bioethics today—and I am convinced that there is—it comes from an excessive emphasis on autonomy and too little appreciation of human interdependence and mutual responsibility" (p. 88). In addition to the

centrality of relationships in autonomy, Pellegrino and Thomasma (1988) also argue for a human approach suggesting an approach "based on the existential situation of the patient" (p. 7). In many ways this marks a kind of return to "respect for persons" (p. 23) that means honouring the diversity of patients and their own hierarchy of values and goods that "may not always place medical needs in the highest position (p. 23). Having examined autonomy in the sections above, I now extend the dialogue to informed consent which operationalizes the philosophy of autonomy into medical practice that will eventually lead to substituted decisions and the need for ACP.

2.5.3 Informed Consent

A Legal Introduction to Informed Consent. Emerging from the theoretical foundation of autonomy is the notion of informed consent, described by Purtilo and Doherty (2011) as "one of the cornerstones of the current U.S. and Canadian health care system" (p. 245) and by Tran (2023) as "probably the most controversial and debated of all the health law issues" (p. 2). Described as a dance between the medical and legal systems, Tran suggests informed consent is based on a simple relationship where clinicians look to respond to the individual needs one might have in health care while the discipline of law focuses on "the relationship among individuals as defined by the legal rights of individuals and their legal duties to respond to those rights" (p. 2). Influenced by a consumer movement in Canada, Tran compares this relationship in medicine to a vendor and buyer, or "the relationship between those providing services and those receiving services" (p. 3). And as I will demonstrate later this chapter, this relationship includes rights of patients to respond litigiously "when the results have not met the satisfaction of the patient" (p. 3). Each case builds a foundation of common law where the understanding of informed consent is established over time. I begin this section with a brief history of consent.

Historic Development of Informed Consent. The development of informed consent is far from linear.[105] While the roots of Western medicine go back to ancient Greece and the Hippocratic Oath, communication and permission-giving were left unaddressed with the primary focus being beneficence (Faden et al., 1986). This focus continued in the medieval period, with some added theological views before the enlightenment inspired some exchange of information between physician and patients. But it wasn't until the modern age where "medical etiquette" (p. 67) emerged in American and British medicine with expectations of "moral conduct" of physicians (p. 67 - 68). But it was the Schloendorff Case in 1914 that set the precedent for patients having the right to choose medical treatment with the oft-quoted finding that "Every human being of adult years and of sound mind has a right to determine what shall be done with his own body" (*Schloendorff v. The Society of New York Hospitals*, as cited in Pellegrino & Thomasma, 1988, p. 158) and that "interference with this right may constitute unauthorized bodily invasion—a battery—regardless of the skill with which the treatment was administered and even if it was ultimately beneficial" (Faden et al., 1986, p. 123). Reflecting on the early 1900s, Faden et al. observe a time where, "The law was beginning to weave its garment of requirements of consent —ultimately of informed consent" (p. 86). But more, another influential thread was the Nuremberg Code of 1947 which is "generally seen as the first authoritative statement of consent requirements in biomedical ethics" (Manson & O'Neill, 2007, p. 2) focusing on respecting autonomy in research. The trials "exposed the Nazis' horrific medical experiments" (Beauchamp & Childress, 2019, p. 118) inspiring focus on consent in both research and medicine.

[105] Faden (1986) outline a very complicated history of informed consent and suggest consent "can no more be reduced to a linear narration of social events and practices than can the history of major concepts in Western thought such as 'democracy,' 'autonomy,' or 'scientific law'" (p. 60).

Another key milestone in the history of consent was the coining of "informed consent" during the 1957 *Salgo Case* in California where a judge ruled the patient was not informed of risks of an intervention that resulted in permanent paralysis (Beauchamp & Childress, 2019).[106] The decision added the new provision "informed" to consent as well as an added "new duty to disclose the risks and alternatives of treatment…a logical extension of the already established duty to disclose the treatment's nature and consequences" (p. 126). Informed consent had arrived. It was a phrase embodying the right for patients to choose based on "All pertinent topics of consent—the nature, consequences, harms, benefits, risks, and alternatives of a proffered treatment" (p. 126).[107] Faden et al. (1986) observe that this short phrase was soon "lifted from this narrow legal base by a new medical ethics and placed in the center of a debate about decisional authority and the doctor-patient relationship" (p. 87). But what about Canada?

The Canadian Doctrine of Informed Consent. Considering the strong influence of America on Canadian bioethics (Racine, 2020), landmark cases south of the border had a strong influence on Canada as well. But Canadian law has also made an imprint on informed consent with two specific cases having "established the principles of what is often referred to as the Canadian doctrine of informed consent" (Fontigny, 1996, p. 17). As informed consent grew globally, new questions emerged about the standard threshold for disclosure—should it be what a "reasonable physician" notes as adequate, or should a patient's view hold greater importance? Two *Supreme Court of Canada* cases, both in 1980, helped forge the Canadian doctrine of

[106] While specific medical terminology is undoubtedly important to the medical aspects of the case, I will not be providing therapeutic details on this case and others as my focus is on the broader context of informed consent. Further medical understanding is out of scope of this dissertation.

[107] It is important to note that the judge, Justice Bray, also introduced "discretion" in this case for the physician which Katz (1977) critiques as wishing "at one and the same time to give decisional authority to patients and to maintain the authority of the physician" (p. 138). While I will not explore this further as it is out of the scope of this thesis, it is monumental because it gave power back to the physician after supposedly empowering patients.

informed consent—*Hopp v. Lepp,* focusing on the duty of disclosure, and *Reibl v. Hughes*, centering on the standard of disclosure (Fontigny, 1996).[108] In the *Hopp v. Lepp* case, a patient was left with permanent damage following an intervention the patient insisted was performed without consent. The judge declared "the patient had a right to decide what, if anything, should be done with his body" (Fontigny, 1996, p. 1) as well as the right to be informed of "the nature of the proposed operation, its gravity, any material risks and any special unusual risks" (Fontigny, 1996, p. 1). In *Reibl v. Hughes*, a patient left paralyzed after an intervention suggested if they would have known the odds of this disability they would have "opted for a shorter, normal life rather than a longer one as a cripple" (Reibl *v* Hughes, 1980; 114 DLR (3d), as quoted in Wheeler, 2017, p. 1119). The judge concluded material risks must be disclosed "Even if a risk is a mere possibility" (Fontigny, 1996, p. 2). A new precedent for quality in disclosure was set with the elimination of the professional disclosure standard and the emergence of the reasonable person standard—what a reasonable person in the same situation would have chosen. Despite calls for a subjective standard[109] to include the unique voice of the patient, Mazur (2013) suggests the reasonable person standard is still the position of the *Supreme Court of Canada*.

Building on these cases, provinces established legislation reflecting elements of common law including the province of Ontario's *Health Care Consent Act, 1996* that outlined specific elements of informed consent including: "The consent must relate to the treatment…The consent must be informed…The consent must be given voluntarily...The consent must not be obtained through misrepresentation or fraud" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A.,

[108] While out of the scope of this dissertation, these two cases also marked a change in common law. Before these cases a lack of consent in law in Canada was considered "assault and battery" while after these cases it became "negligence" (Tran, 2023, p. 5) because negligence would cover these situations where physical touch was not involved. For a detailed analysis see Tran's (2023) work.

[109] Fontigny (1996) as well as Beauchamp and Childress (2019) both advocate for a subjective patient standard to allow for greater particularity but the standard continues to be the reasonable patient standard.

s. 11 (1)). But more, it outlined what matters should be included in consent including "The nature of treatment…The expected benefits of the treatment…The material risks of the treatment…The material side effects of the treatment…Alternative courses of action…The likely consequences of not having the treatment" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 11 (4)). Further, one can see explicit language around the reasonable patient standard where matters discussed were to be what "a reasonable person in the same circumstance would require in order to make a decision about the treatment" as well as a clear opportunity to obtain "responses to his or her requests for additional information about those matters (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 11 (2)). And while legislation would provide structures, clinical operationalizing of this would include significant debates and leave significant hurdles—obstacles that would eventually be encountered in ACP as individuals began to reflect on future medical scenarios.

Integrating Standard Elements of Informed Consent in Clinical Practice. With the legal and legislative background established, I turn to the clinical dimension of informed consent. In this section I outline what Jennings (2007) refers to as the "standard" (p. 73) approach to informed consent rooted in the "seminal" work of Beauchamp and Childress (Jennings, 2007, p. 73). Beauchamp and Childress (2019) suggest two meanings of informed consent that exist in current practices: first, the autonomous authorization of procedures in medicine or participation in research, where one authorizes an intervention based on "substantial understanding and in absence of substantial control by others" (p. 120); and secondly, conforming to any social rules around consent by professionals both institutional or legal.[110]

[110] And while both are important, Beauchamp and Childress (2019) suggest substantial understanding is "the benchmark for the moral adequacy of institutional rules of consent" (p. 121).

Practically, Beauchamp and Childress (2019) provide seven elements of valid informed consent including *competence* that refers to one's psychological, legal, and cognitive capacity to be able give a valid consent; *voluntariness* referring to a decision that is free of influence, coercion, or manipulation; *disclosure* that suggests receiving adequate material facts and information required for sufficient decision-making in nontechnical language; *recommendation* that refers to the treatment the physician is suggesting; *understanding* that denotes comprehension and appreciation of risks and benefits; and finally, the elements of *decision* and *authorization*. While all are key, the topic of disclosure has spawned considerable conflict and is often deemed as "the sole major condition of informed consent" (p. 123) as noted in legal cases above.

Problems in Operationalizing Informed Consent. While development of the doctrine of informed consent has been refined over time, it has also included many challenges. Beauchamp (2011) notes several difficulties obtaining informed consent. First, while consent might make sense legally, clinical integration has been fraught with difficulty. To begin, early responses by physicians revealed condescension towards patients (Faden et al., 1986) with suggestions that "the demands of informed consent as impossible to fulfill and—at least in some cases—inconsistent with good patient care" (p. 91). Today, Grady (2015) notes an ongoing gap between theory and practice, suggesting doctors as not being trained in informed consent while experiencing increased demands on their time. In addition to physician perspectives, Tran (2023) highlights personal and psychological dynamics between patient and physicians impacting conversations carried out "in an atmosphere of fear, nervousness, and often denial" (p. 3).[111] But more than the dynamics of the physician-patient relationship, Stanton-Jean et al. (2014) name

[111] Katz (1990) too has been critical of the silent dynamics between physician and patient as "intimate, anxiety-producing, and fateful encounters with one another" (Katz, 1990, p. xiii).

several barriers to receiving adequate information including literacy and cognitive ability in navigating health care's bureaucracy, as well as cultural factors, noting "the decision-making process may vary from one country to another, or even within the same country from one group to another" (p. 742). And here I arrive at the influence of spirituality on consent.

Cultural and Spiritual Tensions in Informed Consent. Building on cultural aspects noted above, the dimensions of spirituality impact consent processes as well. Zhang (2021) highlights the sensitivity required to honour the "complexity of cultural, societal and religious differences" (p. 61) that may include fundamental differences to Western notions of autonomy. Examples of world religions functioning outside secular perspectives of consent include Buddhism that "questions the ontological/epistemological reality of the self" (Zhang, 2021, p. 64) and Confucianism that emphasizes family in decision-making with "shared family decision-making for the medical matters of the patient" (Fan, 2021, p. 73). Additionally, some Jewish traditions can be resistant to informed consent for reasons that "Jewish religious thinking does not consider the individual as sovereign over this own life, and even his body is not considered his property" (Heyd, 2021, p. 101). In sum, evidence suggests "many religious traditions challenge the Western idealization of the autonomous self" (Tham, 2021, p. 7) and lean into a "a more relational or communitarian understanding" of informed consent (p. 7). And with these notions of culture, spiritual belief, and community entering the conversation, I arrive at the next challenge—the potential for individuals to be incapacitated. I now move to the next key theme of substitute decision-making that is essential to ACP that flows from this question of capacity.

2.5.4 Substitute Decision-Making

While respect for autonomy and informed consent provide the foundation for medical decision-making, a significant challenge arises when individuals are incapable of making an

informed decision. Research presented by Geros-Willfond et al. (2016) reports a study by Raymont et al. (2004) where 47% of patients in the hospital context that were over the age of 65 were deemed incapable to make decisions. Torke et al. (2020) share findings of the number in ICU being even higher at 71%. This high likelihood of incapacity is an unfortunate barrier to the aspiration of personal autonomy regarding treatment decisions. And this is where the role of substituted decision-maker (SDM)[112] arises. I begin this section by outlining the meaning of capacity that precipitates SDM involvement, before exploring how the SDM is established. I will then outline approaches to making a medical decision for another within Ontario, explore spirituality within SDM processes and debates around navigating conflicts, and finally move to the topic of ACP. I begin this exploration of the SDM process with a look at capacity.

Capacity. Before an SDM is thrust into the role of decision-maker, the topic of incapacity or incompetence is the first step. Despite often being used interchangeably, Purtilo and Doherty (2011) differentiate the terms with capacity being a *medical* term that "implies that a patient has the ability to understand and weigh medical information to make health decisions" (p. 262), while competence is a *legal* term—noted by Beauchamp and Childress (2019) as meaning "the ability to perform a task" (p. 113). With competence as their focus, Beauchamp and Childress (2019) ask "whether these persons are capable—cognitively, psychologically, and legally—of adequate decision making" (p. 112) based on criteria that "they have the capacity to understand the material information, to make a judgment about this information in light of their values, to intend a certain outcome, and to communicate freely their wishes" (p. 114). In Ontario,

[112] As noted in Chapter 1, I am using SDM in alignment with the Health Care Consent Act of Ontario (1996). I note here that Godkin (2008, p. 6) suggests the language for substituted decision-maker varies according to region including terms like "healthcare proxy", "attorney for healthcare", or "agent". As noted above, the Ontario designation is substitute decision-maker (SDM) which is what I use in this dissertation.

the word incapacity[113] is used and expectations are outlined in the *Substitute Decisions Act, 1992*: "A person is incapable of personal care if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, nutrition, shelter, clothing, hygiene or safety, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision" (Substitute Decisions Act, 1992, c. 30, s. 45). Tran (2023) points out, key to this legislation in the Ontario context are the words "understand" which notes one's ability to understand relevant information needed to make an informed decision, and "appreciate" where one can process what this might mean in terms of future consequences.[114] And while one needs capacity to understand and appreciate, no obligation exists do both.

Establishing an SDM. With incapacity established for patients unable to make decisions, a process for choosing an SDM comes into play that varies provincially (Tran, 2023). In Ontario, the *Health Care Consent Act, 1996* defines the SDM as one authorized "to give or refuse consent to a treatment on behalf of a person who is incapable with respect to the treatment" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 9.) and chosen from a hierarchy of decision-makers including the incapable person's: 1) guardian; attorney for personal care; representative appointed by the Board; spouse or partner; child, parent or children's aid society; brother or sister; and finally other relative (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 20 (1)). If this hierarchy has been exhausted, or none of the representatives are available, a Public Guardian and Trustee is to make the decision (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 20 (5)). Additional requirements given for the SDM include them being capable, at

[113] I will take this opportunity to note that while "incompetence" and "incapacity" are used interchangeably, I am aware that Ontario legislation utilizes "incapacity" and I will follow suit as my analysis focuses on Ontario resources.

[114] *The Health Care Consent Act, 1996* also qualifies this further suggesting a shifting might occur where one might be "incapable with respect to some treatments and capable with respect to others" (1996, c. 2, Sched. A, s. 15 (1)) and also "incapable with respect to a treatment at one time and capable at another (1996, c. 2, Sched. A, s. 15 (2)).

least 16 years of age, not prohibited by the court, available to be engaged in this process, and finally, willing to assume responsibility for the giving or refusing consent (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 20 (20)).[115] This last provision is important as not everyone desires this significant responsibility. In terms of assigning a SDM, Ontario assigns one automatically based on the above hierarchy, but should an individual want to voluntarily name an SDM outside of this defined hierarchy, the *Substitute Decisions Act, 1992* suggests a Power of Attorney for Personal Care can be named with the following responsibility: "A person may give a written power of attorney for personal care, authorizing the person or persons named as attorneys to make, on the grantor's behalf, decisions concerning the grantor's personal care" (Substitute Decisions Act, 1992, c. 30, s. 46 (1)).[116]

Making Decisions for Another. With the SDM established, the next question in the process becomes—how might the SDM best honour the autonomy of the incapacitated individual? Bioethics has taken approaches to making decisions on behalf of another with options outlined by Beauchamp and Childress (2019) as being – the *substituted judgement standard*, the *pure autonomy standard*, and the *best interests standard*. The *substituted judgement standard* involves the SDM stepping into the shoes of the incompetent person. This approach is based on what a patient would want, requiring "deep familiarity with the patient that the particular judgment made reflects the patient's views and values" (p. 140).[117] The *pure autonomy standard* by contrast aims at a sense of "real autonomy" (p. 140) where decisions are

[115] I have tried to provide context here that will be applicable to the broader thesis relating to ACP. While there are other qualifiers in the legislation, they will not be elaborated on further as they are outside the scope of this study.
[116] This provision will prove to be a key piece in the ACP process for many, as outlined in the section below, in order to ensure one has a voice to make decisions as autonomous as possible.
[117] Considering the values of the patient need to be known, this approach would not be appropriate for those who have never been competent as "no basis exists for a judgment of their autonomous choice" (p. 140).

based on previously expressed "clear preferences" of individuals when competent (p. 140).[118] If the former approach asks what *would* the patient want, this approach asks what *did* the patient want. Finally, the *best interests standard* acknowledges personal preferences cannot always be determined forcing an SDM to make a decision based on "the highest probable net benefit among available options" (p. 141). Considering the challenge of anticipating the wide range of medical scenarios one might encounter if incompetent, the *best interests standard* is often utilized "requiring surrogates to assess the risks and probable benefits" (p. 141). In addition to these three mainstream approaches of decision-making, Torke et al. (2008) suggest another approach using the patient's life story in focusing on "each patient's dignity and individuality" rather than autonomy (p. 1514) while Sulmasy and Snyder (2010) suggest a *substituted interests model* focusing on authenticity. While the *substituted judgment standard* might ask the SDM, "What would your mother choose if she could tell us?" (p. 1946), and that the *best interests standard* might ask, "What do you think is best for your mother?" (p. 1946), the *substituted interests model* simply asks, "Tell us about your mother." (p. 1946) that inspires a sense of authenticity of the individual. While debates persist with little resolution in bioethics the context of Ontario provides clearer guidance in this regard. I turn now to these expectations in Ontario.

Ontario Expectations for SDM Decision-Making. While jurisdictions have taken different approaches to SDM decisions, as outlined above, practice in Ontario has been legislated by the *Health Care Consent Act, 1996.* The Act declares treatment decisions must align with two principles: "If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or

[118] It is worth noting that regardless of whether a formal advance directive exists the pure autonomy standard suggests the SDM "should act on the patient's prior autonomous judgments" in what is also be referred to as "precedent autonomy" (p. 140).

refuse consent in accordance with the wish", and secondly, "If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests" (Health Care Consent Act of Ontario, 1996, c. 2, Sched. A, s. 21 (1)). And rather than leave it open for the SDM to determine what "best interests" might mean, the legislation clarifies the meaning of "best interests" in two distinct parts:

> In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration, (a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable; (b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and (c) the following factors (Health Care Consent Act of Ontario, 1996).

It is here the Act also outlines a list of medical factors and outcomes that include the weighing of quality of life, benefits, and burdens of treatment, as well as other considerations. But in essence, Ontario has first tried to integrate the *pure autonomy standard* in respecting known wishes of the patient; and secondly, if there are no known wishes, they invite the use of a combination of the *best interests standard* with the *substituted decision standard*—a shift to the values and beliefs the patient held when capable, together with the weighing of the medical and quality of life factors. Despite this clarity legislatively, many challenges emerge for the SDM within the medical context that I outline next.

Challenges Facing the SDM. While Ontario legislation has tried to make the process clear and simple, there is no mistaking the difficulty for SDMs in making a potentially complex treatment decision on behalf of someone else. In a systematic review of the effects of decision-

making on the SDM by Wendler and Rid (2011), the results reveal a heavy burden including factors like being "Unsure of patient's preferences…Uncertain prognosis…Logistics of making decisions…Poor communication by clinicians…Insufficient time…Conflict with clinicians and family…Sense of sole responsibility…[and]…Uncertainty or guilt over decisions" (p. 344). Additionally, several tensions emerged in the SDM comments during this same study including one saying, "The thing I love most in my life I don't want to kill. That's the part that I agonized over a lot" (p. 343) while another expressed their doubts, asking: "Did I do the right thing?" (p. 343). This last comment links to a very challenging part for SDMs—the lack of knowing what a loved one would want. Sibbald and Chidwick (2010) reference studies suggesting as few as 20% of SDMs making a decision in critical care knew "exactly what they would have wanted" (p. 171.e2) while a study involving patients and surrogates by Shalowitz et al. (2006), referenced by Torke et al. (2008), reveals surrogates predicted a patient's wishes only 68% of the cases (p. 1515). Adding to this, Torke et al. reference a study by Garrett et al. (1994) summarizing dynamic shifts in one's wishes across life with more than half of those who said yes to one treatment, having changed their mind in just two years (p. 1514). One can begin to see the importance of ACP in helping a SDM understand one's values, beliefs, and wishes. And a theme that often arises in conflicts within these situations is the role of spirituality that I address next.

Impact of Spirituality on SDM Decisions. Adding to indecision and uncertainty, additional research notes the presence of religion being central to conflict in 25% of decisions involving life sustaining treatments (Bandini et al., 2017). Analyzing cases brought to the Consent and Capacity Board (CCB) in Ontario, Sibbald et al. (2010) suggest a central theme in eight of twelve cases that were analyzed involved God and religious values, with court references from SDM testimony noting, "No one should play God" or "Where there's life there's

hope" (p. 171.e4). But more than just patient-related themes, much is written on how SDM spiritual beliefs impact decisions, as noted in a second theme emerging in the study by Sibbald et al. (2010)—a tendency for the SDM to report *their* values rather than the patient (p. 171.e5). A similar finding arises in Torke et al. (2020) where the SDM's "belief in miracles was associated with lower surrogate preferences for DNR status and lower enrollment in hospice" (p. 6). Reflecting on this finding, the authors summarize research suggesting a focus on miracles or hope may indeed "lead a surrogate to focus on religious beliefs and minimize the importance of prognostic or other clinical information from the physician" (p. 6). But more, the SDM's choice to avoid hospice may be rooted in a sense of "giving up" which is "inherently in conflict with their hope for a miracle" (p. 6). One can begin to see the importance of spirituality to ACP dialogue to help mitigate some of these situations. But the question remains—how are these conflicts resolved?

Navigating SDM Conflicts in Ontario. As Chidwick et al. (2013) suggest, conflict can emerge between SDMs and health care providers that require some sort of resolution process. Outlining Ontario's process, Chidwick et al. suggest the physician begins by outlining possible treatments and the standard of care, then determines prior patient wishes or values, before bringing this plan to the SDM who must consent or refuse the plan.[119] And should the SDM refuse care and the physician believes it is against the best interests of the patient, the physician can bring the case to the CCB[120] who assess whether the SDM has followed legislation and "the legally interpreted best interests of the patient" (p. 23). After hearing both sides the "quasi-

[119] Chidwick et al. (2013) note this is very different than the UK where "physicians determine best interests and do not require a family's consent to act on this determination" (p. 23).
[120] Tran (2023) suggests that the CCB is a distinguishing factor for Ontario legislation and Collier and Haliburton (2021) outline the CCB as a group of three representatives—a physician, a lawyer and a layperson—who seek to determine patient best interests should there be a dispute over patient best interests.

judicial body with specialized jurisdiction" (Collier & Haliburton, 2021, p. 338) then "try to establish the patient's best interests" (p. 338) and "Particular attention is paid to religious beliefs where they are relevant" (p. 338). Sibbald (2018) is critical of the CCB, suggesting, "since 2010, 18 of 39 (46%) cases were dismissed in a manner that appeared as if the CCB's intention was to avoid difficult decisions" (p. 1161) and notes that "troubling decisions taken by the CCB" (p. 1162) indicate a trend where "the legal system seems to favour treatment at the end-of-life irrespective of outcome, medical evidence, or suffering" (p. 1162). In one case the CCB suggested, "Without specific direction from the patient, the daughter resorts to her religious beliefs and those of her mother insisting that life be prolonged, no matter what the suffering" (Consent and Capacity Board, File No. L0-10-3745, as cited in Sibbald, 2018, p. 1162). Chidwick et al. (2013) suggest "CCB decisions have broadened our notion of best interests to discuss suffering as a value" (p. 27). But Chidwick et al. also note the challenge for physicians. While respecting a patient's right to values like suffering, this also inspires ethical tensions that may "violate their own professional values and ethical codes if a patient's values are seen to outweigh the clinical prognosis" (p. 27). Chidwick et al. conclude, "Despite a common framework from which to address the patient's clinical condition and values, disagreement on what constitutes best interests for individual patients persist" (p. 22). And here I return to the challenge of paternalism versus autonomy and the notion by Pellegrino and Thomasma (1988) of multiple goods in patient care—where medical good may not always prevail. One can see in these scenarios the strong philosophical positions of medical culture and the dynamic clash that can exist with spiritual beliefs and conflicting situations that may be aided by stronger ACP processes that increase value articulation. Having outlined the evolution of the SDM role, and the debates and challenges implicit in deciding on behalf of another, I move to the final link of this

literature review—ACP and its potential to invite reflection on future decisions to ensure personal autonomy.

2.5.5 Advance Care Planning

Having traced the evolution of ACP in bioethics in the previous sections by exploring notions like the principle of respect for autonomy, the doctrine of informed consent, and the SDM role, I finally arrive at core of this dissertation—ACP. In this section I will outline the development of ACP starting with a brief history, followed by a differentiation of key terms and challenges. I will then articulate the shift from language of advance directives to ACP, before distinguishing the nuances of ACP, goals of care, and medical decision-making. After defining ACP, I explore ACP in Canada before examining spirituality in ACP that invites the larger focus of my dissertation. I will conclude that there is a notable gap in the integration of spirituality in ACP processes—a gap that will inspire my critical examination of Ontario resources and exploration into how spirituality is currently situated. I begin with some historical background.

Historical Perspectives. Every bioethical notion has a lineage and ACP is no different. Much like the landscape of autonomy and informed consent, legal cases have framed the development of ACP. McCune and Rogne (2014) suggest that the "legal approach to documenting desires regarding one's future medical care" (p. 18) began in 1969 when an Illinois lawyer, Luis Kutner, proposed a living will to help individuals make decisions if incapacitated and initiated this "legal-transactional approach" (p. 18) that informs the current paradigm. But it was two high profile legal cases that galvanized the need for the patient's voice when incapacitated—the Quinlan case in 1975, and the Cruzan case in 1983 (Brown, 2003). The 21-year-old Quinlan was resuscitated following a cardiac arrest but unfortunately stayed in a vegetative state; and while the courts approved the right of the parents to withdraw life supports,

Quinlan's feeding tube remained until their death in 1985 (Brown, 2003). The Cruzan case in 1983, in contrast, involved a 32-year-old car accident survivor left in a persistent vegetative state. After seven years of court challenges and parent advocation for the right to withdraw life support, the *U.S. Supreme Court* "authorized the removal of the feeding tube" (Brown, 2003, p. 5) in 1990 and Cruzan died shortly after. This decision confirmed one's constitutional right to decline treatment and set the course for "legalizing advance directives to clarify a person's wishes" (Brown, 2003, p. 5). Different states responded with legislation during this time followed by the *American Patient Self-Determination Act* in 1990 that mandated individuals have "the right to formulate advance directives" (p. 5) and to "document in the individual's medical record whether or not the individual has executed an advance directive" (p. 5). And not unlike the influence of US approaches to autonomy and informed consent, Canada addressed similar issues, including Ontario's *Substitute Decisions Act, 1992* outlining the power of attorneys for personal care and the *Health Care Consent Act, 1996*—both responding to needs for guiding the SDM in difficult decisions.

Differentiating Advance Directives, Living Wills and ACP. As legislation emerged, terms like advance directives, living wills, and ACP arose with nuanced meanings. I will distinguish these terms next beginning with advance directives, whose purpose, as outlined by Godkin (2008) was to enable patients to self-determine their choices if incapacitated and to decrease the burden on family members and health care professionals—providing potential peace of mind to patients, and for some, an increased sense of preparation for death. Godkin (2008) suggests advance directives fall into two domains—treatment/instructional directives that include

one's health care wishes outlined in a written document[121] should one be incapable; and secondly, proxy directives that designate a person or persons to make health care decisions if they are incapacitated. Others provide similar differentiation, including Davis (2007) who notes two categories of advance directives being either living wills; or health care powers of attorney—what some refer to as "durable power of attorney for health care" (p. 351). While Godkin (2008) distinguishes advance directives from the term living will, it is noted that the two are "sometimes used interchangeably"—especially in the US (p. 7).[122] Godkin suggests living wills in the Canadian setting have tended to focus on what the patient does *not* want including "treatment refusals in the context of terminal illness or immanent death" (p. 7)[123] while advance directives provide instruction about medical treatment—both not wanted and wanted. All told, Godkin suggests the concept of the living will has "fallen somewhat out of favour" for reasons "not entirely clear" (p. 8). Canada's provincial jurisdiction of advance directives has made for what Browne and Sullivan (2006) describe as "an unusually wide variety of legislative approaches to advance directives" (p. 256). In Ontario, where my research is focused, Myers et al. (2016) note advance directives "are not a legally recognized entity" (p. 1) with consent coming only from an individual or SDM. While great hope was placed in advance directives, real limitations soon emerged that I will briefly address next.

Tensions with Living Wills and Advance Directives. While it was anticipated that living wills and advance directives would help ensure individual autonomy, Rogne and McCune

[121] Godkin (2008) suggests that advance directives are "most often conceptualized as written documents" (p. 7) with specific needs for legality. In Ontario, as I will note below, there is no legal worth given to a written document, rather, the SDM makes the in-the-moment decision.
[122]Adding to this in the American setting was the advent of the Physician Orders for Life-Sustaining Treatment (POLST) that included "a doctor's order specifying treatment desires for those with life-threatening conditions" (McCune & Rogne, 2014, p. 15). But considering this has not taken shape in Canada it will not be explored further.
[123]A helpful example of one of these "not" statements given by Godkin for a living will includes, "I do not wish to be hooked up to a machine that would breathe for me" (p. 7).

(2014) suggest that "By the mid-1990s the rosy glow only half a decade old had begun to dim, and scholars and practitioners began to question whether this initiative had the results it had intended" (p. 3). Rogne and McCune (2014) reference Tonelli (1996) who lightheartedly suggested it was "time to pull the plug" (p. 3) on living wills as little evidence existed that patients were experiencing better experiences at end-of-life while the costs of promoting advance directives where unjustified. But the question remained, as Fagerlin (2000) notes: "How can anything so intuitively right be proved so infuriatingly wrong?" (p. 31). Fagerlin goes on to articulate a constellation of factors including individuals not reliably knowing what they want, unfamiliarity with illness and complicated end-of-life scenarios, and more pointedly—a lack of ability to trust doctors who "convey that information wretchedly" (p. 33). But a main tension noted by Fagerlin was: "The world abounds in dreadfully drafted forms because writing complex instructions for the future is crushingly difficult" (p. 34). Hence, while the form-based approach was a great aspiration, Fagerlin (2000) suggests, "The failure to devise workable forms is not a failure of effort or intelligence. It is a consequence of attempting the impossible" (p. 35). Rather, Fagerlin argues "powers of attorney have advantages over living wills…surrogates know more at the time of the decision than patients can know in advance" (p. 39). Ontario took this path in giving decision-making authority to the SDM and not legalizing a formal advance directive.

Transition from Advance Directive to ACP. Advance directives would soon evolve into what we know today as ACP. McCune and Rogne (2014) suggest the pursuit to "find the perfect form" (p. 23) began to take on a Goldilocks scenario of being "too specific or too vague" (p. 23) with the search for the perfect form. But the result was a "plethora of documents" (p. 23) inspiring a "sense of overwhelm and confusion" (p. 23). The spirit of ACP emerges in the conclusion by Rogne and McCune (2014) who observe that: "No forms or legal documents, no

matter how carefully crafted, can automatically guarantee us the death we want for ourselves and loved ones. But we can prepare ourselves by having the courage to convene conversations about dying, death and loss within our families and communities" (pp. 4 - 5). In this sentiment, one can see the movement to see advance directives not as an end in themselves but as "tools or vehicles to stimulate meaningful discussion" (p. 23). Thomas (2018) suggests ACP as a movement began to crystallize around the year 2000 with the thinking that advance directives should not overly focus on the medical aspects, but instead, preparing people emotionally for the future and "personal aspects of care" (p. 11). Factors contributing to this shift from advance directives to a process of ACP are named by McClune and Rogne (2014) as including the referencing of Butler's (2008) notion of the "longevity revolution" (p. 16) describing the growing cohort of those over 85; ongoing technological advances in medicine that have increased difficult decisions; the continuation of the rights based consumer environment around death; and finally the legal environment that "blurred the lines between rescue and long-term suffering before death" (pp. 16 - 17). McClune and Rogne (2014) note the shift from "product (the form) to process (the conversation)" (p. 23) and the suggestion that advance directives are only one part of the larger picture of end-of-life planning with ongoing conversations regarding values and beliefs happening over months and years and "in the contexts of their relationships" (p. 24). Rogne and McCune (2014) reference an insight by Levi and Green (2010) who note: "At the end of the day, an advance directive is just a piece of paper. But an effective program for advance care planning is an opportunity to help people grow, create meaning, and make their lives (and deaths) better" (Levi & Green, 2010, pp. 8 – 9, as cited in Rogne & McCune, 2014, p. 1). Clear benefits of ACP noted by McClune and Rogne (2014) included help in, "managing the emotional conflict engendered in decisions about care near the EOL" (p. 19), helping "ensure self-

determination and quality of life near the EOL" (p. 19), while inspiring "peace of mind, comfort, and certainty to patients, their loved ones, and clinicians" (p. 19).

Differentiating ACP and Goals of Care. Still, questions remained regarding how these notions fit together clinically. Borenko et al (2023) note some confusion regarding terminology including ACP versus Goals of Care Discussion. Starting with Goals of Care (GOC), Edmonds and Ajayi (2019) conclude "there remains no consensus approach to describe the process or components of GOC conversations" (p. 1546) and that although this phrase shows up clinically, they suggest this phrase "means little to patients or families" (p. 1546). Myers et al. (2016) add ACP to the mix in suggesting, "a lack of widespread agreement" (p. 29) regarding GOC discussions and ACP and "their critical elements, and desired outcomes" (p. 29). How then can these terms be distinguished here? Myers et al. suggest "ACP conversations focus on preparing for future healthcare decisions" in contrast to GOC Discussions that relate to "current healthcare decisions" (p. 1). But more—ACP is directed towards providing information for a SDM "to guide future decision making if the person becomes incapable." (p. 1). Barwich et al. (2018) draw on Sinuff et al. (2015) to describe ACP as being "an upstream communication process" (p. 210) while patients are able to make decisions while GOC conversations tend to be "illness-specific, patient centered conversations framed around illness, understanding and prognosis" (p. 210). My focus in this thesis is this "upstream" planning where reflection reveals one's values.

Defining ACP. Having outlined the lineage of ACP, I turn now to a definition of ACP. Observing a lack of formal definitions of ACP, experts in the field of ACP (Sudore et al. 2017) undertook a Delphi process to forge a definition. The group's work resulted in a unified one-sentence definition: "Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding

future medical care" (p. 826) while their goal statement was: "The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (p. 826). Some of the assumptions informing their definition included the importance of focusing on the process; limiting the definition to be a patient-centered definition for adults with capacity; intentionally including trusted individuals in the process; a focus on ACP "as a process on a continuum over time" (p. 827) rather than a "one-time event, such as completion of an advance directive" (p. 827); and openness to both chronic and serious illnesses. Thomas (2018) suggests this new definition "demonstrates the growing movement towards the less medicalised model" (p. 12) and moving towards a deeper "integrated, individually tailored model" (p. 12). I will move this conversation to the Canadian context in a section below but first explore some contemporary ACP resources.

A Sampling of Contemporary ACP Resources. Having outlined definitions of ACP, I turn now to some of the tools that have emerged to help in this process. While numerous resources have arisen in the previous decades, I take a moment now to outline a few of the popular ACP tools that have emerged to help broach difficult conversations with loved ones. One includes *Death Over Dinner* where an introductory video offers an open "straightforward conversation" around death with a series of thoughtful questions (Roundglass, 2024). Another resource named *The Conversation Project* invites conversations around death in a humourous way (Institute for Healthcare Improvement, n.d.). And finally, a UK website entitled *No Barriers Here* (Mary Stevens Hospice & Dudley Voices for Choice, n.d.) takes an arts-based approach to reflection for diverse communities with videos and resources for reflection. In Ontario, an organization under the banner, *Advance Care Planning Ontario* (ACPO) has been involved in a national *Speak Up* initiative and is centred around resources on the ACPO website (HPCO, n.d.-

a) that forms the heart of my dissertation. These organizations have evolved over the past decades and continue to change. The national *Speak Up* initiative, sponsored by the *Canadian Hospice Palliative Care Association*, emerged from a campaign in 2010 entitled "Advance Care Planning in Canada" with a goal to "raise awareness of ACP among Canadians" (Howard et al., 2021, p. 710). The authors describe the campaign as offering web-based and paper-based ACP reflection tools—that was first focused nationally, before differentiating based on provincial legal differences. The national program evolved further with *Advance Care Planning Canada* launching a new broadly Canadian focused resource in September of 2024 under the banner "My Advance Care Planning Guide" (Canadian Hospice Palliative Care Association & Advance Care Planning Canada, 2024) without reference to the original "Speak Out" perspective in the 68-page document housed on pan-Canadian website with links to provincial resources including a link to the ACPO website (HPCO, n.d.-a). But with my research uniquely focused on the province of Ontario, it is this HPCO-sponsored ACPO website that will be examined in this thesis in order to provide a focused Ontario perspective to spirituality and ACP.

Canadian Engagement in ACP. And so, I arrive at a Canadian expression of ACP that will ground my research. In terms of a specifically Canadian definition of ACP, the *Advance Care Planning in Canada: Pan-Canadian Framework* (Canadian Hospice Palliative Care Association, 2020) put forth the following definition of ACP: "A lifelong process of reflection and communication in which people express their wishes for their future health and/or personal care if they could not speak for themselves. It also involves choosing who you would like to make decisions about your care if you could not" (p. 39).[124] The 2024 guide that was put out by

[124] The second part of this definition in the framework suggests "It also involves choosing who you would like to make decisions about your care" (p. 39). This thesis focuses on the values reflection aspect of ACP but it is important to name both these parts of ACP.

Advance Care Planning Canada describes ACP more simply as "the process of thinking about what matters most to you in your life and what that means for your health and personal care" (Canadian Hospice Palliative Care Association et al., 2024, p. 5). As for knowledge of ACP in Canada, much study has been done regarding ACP engagement over the last ten years with some diverse findings. A 2015 study by Teixeira et al. (2015) suggests only 16% of Canadian respondents "were aware of the term" ACP, and 52% "acknowledged having discussions with their family or friends" (p. 42) compared to just 10% with clinicians.[125] In this same study 20% had a written document regarding ACP while 47% had named an SDM. A 2021 study (Canadian Hospice Palliative Care Association & Advance Care Planning Canada, 2021) suggested that while 93% believe it is important to talk to family about care wishes, 59% are doing so—and just 7% are talking to health care practitioners. Barriers to engagement (p. 5) included the following findings: "not relevant" (16%), "Can't afford lawyer" (16%), "Don't know how to prepare plan (14%), "Don't know where to go for information" (12%) and the topic being "Morbid or depressing" (10%). Finally, a recent study released in 2024 suggests only 17% of Canadians currently have an ACP plan with 20% having talked to their health care provider—with family or close friends still being the ones most likely to be engaged on this topic with 61% and 33% respectively (Canadian Hospice Palliative Care Association et al., 2024). Yet still, in this same study, 27% suggested they did not feel confident in their ability to communicate their values and wishes. Some of the barriers listed in this same study included 58% suggesting "I can't afford a lawyer or a professional to help me prepare in advance" (p. 18) and 47% acknowledged the difficulty "for people across different backgrounds to find services and supports" (p. 18).

[125] In addition, the study by Teixeira et al. (2015) revealed demographically that women talked more about ACP with family and friends versus men while increased level of education and higher income impacted one's likelihood of recognizing the term. Higher income also influenced the likelihood of discussing ACP with both family, friends, and health care practitioners (p. 44).

Especially poignant in this study was the finding that 37% of Canadians with a disability suggested their disability has had an "impact on their ability to engage in conversations about advance care planning" (p. 22). In sum, there is acceptance of the topic as being important, and people are comfortable with family—but plans are still only discussed with clinicians 20% of the time despite an increase of engagement over the years.

Pan-Canadian Responses to ACP. Addressing ACP in Canada has been challenging considering provinces and territories differ in SDM and ACP policies including "legal status and validity requirements of Advance Directives" (Canadian Hospice Palliative Care Association, 2020, p. 35). With *The Canada Health Act* giving federal bodies the responsibility to set national principles and provide funding, the way provinces and territories operationalize these plans varies region to region (Borenko et al., 2023). And while no national policies exist, a national ACP Framework was launched in 2012, and a follow-up published in 2020, called, *A Pan-Canadian Framework*, sponsored by the Ca*nadian Hospice Palliative Care Association*, to provide a larger umbrella of understanding and principles that serve as a guide with "a common lexicon of definitions and terms that still respected regional variations" (Canadian Hospice Palliative Care Association, 2020, p. 6). Key aspirations of the 2020 document that are relevant to my thesis include increased person-centered respect for diversity and normalizing and de-stigmatizing one's values and beliefs; engaging communities with "culturally appropriate and safe approaches that embrace communities' own ways of approaching health and wellness, care planning, death and dying, and decision-making" (p. 11); as well as systemic integration including "faith/spiritual communities" (p. 11). Another key aspect noted in the framework acknowledges the critical role of culture and respect for "how people view decision making, future planning, care at the end of their lives, and death" (p. 33). The new 68-page guide "My

Advance Care Planning Guide" et al., 2024) seems to build on this framework with additional focus on culture, references to faith and a focus on engaging those with disabilities. Overall, the aspirations of this report and evolving developments to increase person-centredness dovetails with my research in seeking to deepen the spiritual aspect of ACP for truly patient-centered care. Finally, having laid the groundwork for ACP more broadly, I turn to spirituality in ACP.

2.5.6 Spirituality in Advance Care Planning

After introducing the development of ACP more broadly above, and then outlining a uniquely Canadian perspective, my review of the literature now arrives at the intersection of spirituality and ACP—the crux of this dissertation. What is the role of spirituality in ACP? I begin by suggesting that while traditional approaches to palliative care often include spirituality to support domains like wellbeing and coping (Watson & Thomas, 2018), I echo Lunsford's (2014) suggestion regarding "the importance of the spiritual for health care decision making" (p. 93). With value-based decision-making being so central to ACP, there is opportunity for spirituality to play a key role in helping patients orient their decisions towards one's ultimate values. Chappell (2023) echoes the importance of spirituality in decision-making for those in critical care suggesting, "religious faith and spirituality profoundly influence their experience of sickness and death, their perception and meaning of suffering, and their decisions regarding their care" (p. e1). While palliative care models have often focused on comfort measures, coping, and rituals—that are all important patient-centered activities—the hidden role of spirituality in ACP is its ability to help deepen future decisions around ultimate values. But what are these opportunities for this kind of depth in discernment processes?

The Deeper Reasons for Spirituality in ACP. In the previous paragraph I noted the potential for spirituality to deepen decision-making processes, but the question arises—how

might this unfold in practical medical scenarios? Churchill (2015) observes different layers of medical decisions noting: “The major issues around dying and death for humans seem to be only incidentally about feeding tubes, respirators, ICU admissions, DNR orders, living wills, assisted suicide or any of the other medical and bioethical preoccupations” (p. 762). In reflecting more, Churchill suggests ACP resources can help SDMs become “in touch with the deep reasons for either choosing or forgoing the respirator, the feeding tube or the next experimental protocol” (p. 763). These deep reasons align with Gula’s (2000) suggestion that underneath the weighing of choices exists cherished values, and that “deciding whether to accept treatment or not is fundamentally a spiritual exercise yielding a practical judgment” (p. 19). Colenda and Blazer (2022) also note the spiritual aspect of values being integral in ACP with choices “not just measured by prolongation of life, but also by dignity; personal agency and values…and for many patients, reconciling personal R/S values with dying” (p. 748). Hence, decisions in ACP are not just physical decisions on biological matters but practical opportunities to make meaningful spiritual links to one’s ultimate values. Colenda and Blazer (2022) describe a range of choices ranging from the medical to personal, while highlighting the crux of ACP processes providing spiritual history that helps “to more fully understand how a patient’s religious beliefs and R/S values influence their EOL preferences” (p. 749). This is a similar motivation behind what Churchill (2015) suggests as “an argument for probing into the spiritual intentionality behind advance care documents… attentiveness to learn what deeper significance these documents have” (p. 763). What deeper values are behind these documents? While decisions require practical judgments, one’s “deep reasons” (p. 763)—or what is also reminiscent of strong evaluations (Taylor, 1989) or one’s ultimate concerns (Tillich, 1957)—underpin functional decisions of ACP. There is too much at stake with the presence of death in the conversation to

settle for surface-level value reflection. But while the idea of seeking deeper reasons for medical decisions seems alluring, ACP tools, as I will discuss, are largely silent in this regard, leading to an underutilization of spirituality in decision-making. But what factors in medicine might contribute to this lack of spiritual integration? I will address this theme next.

Clinician Reluctance to Address Spirituality in ACP Conversations. While spirituality holds incredible potential to frame ultimate values and deepen decision-making in ACP, it is an often-neglected topic. While Lunsford (2014) advocates for integrating the spiritual in medicine, they suggest it is often avoided in ACP conversations as many practitioners feel a lack of training, while others are fearful of spiritual conversations being misinterpreted as proselytizing with these topics assumed to be "the realm of clergy, pastors, and other spiritual leaders" (p. 92).[126] Colenda and Blazer (2022) have summarized studies regarding who on the clinical team might take spiritual histories to help deepen ACP, and concludes there is a, "reluctance by and inconsistency of physicians and nurses to conduct them" (p. 749) with reasons given that include a "lack of perceived time; training; perceived professional role conflicts; and preferences for chaplains to conduct such interviews" (p. 749). This aligns with similar findings regarding spiritual integration in palliative care settings where "evidence suggests that there is a great deal of confusion, ambiguity, uncertainty, and lack of confidence in addressing spiritual needs" (Ellis & Lloyd-Williams, 2012, p. 261). Some have suggested spiritual care conduct these conversations involving deep reasons (Churchill, 2015) and ultimate concerns (Tillich, 1957) in ACP, including a suggestion by Kwak et al. (2022) who looked at the possibility of chaplains addressing concerns with deep listening. But the experience of chaplains

[126] The irony in this apprehension in leaving this job to clergy and religious leaders is that medicine effectively banished these helpers from the hospital in the early 1900s as noted in the first section of this literature review. This reveals a gap and a sign that a reintegration of the spiritual in healthcare is needed.

in another study suggested chaplains were typically not included in this discussion (Kwak et al., 2021). If spiritual care professionals are not being called in to help with ACP, and clinicians are not addressing these issues consistently for reasons noted above, it would seem that individuals are left to engage in ACP resources independently, putting much pressure on ACP resources to invite spiritual reflection regarding decision-making in a welcoming and inclusive way. But on another level, I observe the arrival at this familiar tension mentioned throughout this thesis, where spirituality is often pushed to the margins and not being consistently addressed. Critical questions need to be asked regarding spirituality's role in ACP and what barriers might be contributing factors. Additional barriers include biases regarding some groups in society that may intersect with spirituality.

Bias Towards Some Groups in ACP. One barrier emerging in the research that may impact spiritual inclusion is bias towards certain groups over others. In researching underserved Black/African American and Hispanic communities, Van Scoy et al. (2022) note that while ACP efforts to increase engagement "have nearly doubled the percentage of white Americans who have engaged in ACP" (p. 3), rates for underserved communities have remained lower. Echoing this, Aslakson et al. (2015) engaged in a systematic review of ACP decision aids that included videos, websites, and paper-based aids, and found a lack of diversity in studies. They found that research was largely based in the US and that 62% focused on white participants. Colenda and Blazer (2022) also addresses this theme suggesting that minority populations are "known to exhibit higher levels of religious practices and R/S values" (p. 748) but are also exhibiting lower rates of ACP participation (p. 748). And here I return to some of the barriers intersecting with ACP resources, including language and culture. Pesut (2009) suggests: "Part of the challenge of including spirituality in health care decision making is that these values, beliefs and experiences

are often expressed in a language that seems foreign to nurses. Patients use narratives and metaphors that are commonly understood within their faith tradition, but may seem incomprehensible to outsiders" (pp. 418 – 419). While spirituality holds potential to aid in decision-making, research reveals some implicit barriers in terms of language and cultural engagement—but more, there is an overall lack of research geared to examining spirituality in ACP resources that I will address next.[127]

Inadequate Treatment of Spirituality in ACP Research and Resources. Despite the potential for spirituality to aid in a deeper ACP decision-making process that invite reflection regarding one's ultimate meaning and deepest values, the literature reveals a different story. Instead of spiritual integration, Watson and Thomas (2018) observe in ACP a disproportionate focus on legal aspects of dying, including capacity, autonomy, and biological aspects while ACP resources are "usually silent about what dying and death actually is for the individual person" (p. 59). This intersects with both the death denying discourses noted above and also the avoidance of spirituality that is well noted in this thesis. A review of ACP decision aids by Bridges et al. (2018) suggests the focus of resources is on legal aspects with little engagement on client values. Mitchell et al. (2017) explored ACP videos on YouTube across Canada, US and Australia, and found a focus largely on the completion of legal documentation involving medical care, and the focus on a directive itself, rather than the process of ACP—again there is no mention of spirituality and/or religion. In addition to this tendency to focus on legal aspects, other studies emphasized completion rates as a measure of efficacy. For example, Volandes et al. (2016) outline ACP rates increasing from 3% to 39% after a video ACP intervention by a clinician, or

[127] I note some attention to the spiritual, religious, and cultural aspects of ACP emerge in the Australian context with researchers Pereira-Salgado et al. (2017)—but their finding included resources that were informational and often geared to healthcare professionals and not client-focused decision-making tools.

Sudore, Boscardin, et al., (2017) compare the efficacy of an ACP website and an easy-to-read directive for veterans, concluding an increase of 35% in ACP documentation with the website.[128] Aslakson et al. (2015) undertook a systematic review of ACP decision aids and found studies included illness-specific tools around treatment choices and explicit focus on specific interventions like CPR—but they suggest that what appears to be missing is inclusion of the "substance" of ACP tools. There is generalized lack of depth emerging in the literature and a general aversion to spiritual and existential value reflection that I have been suggesting. Positive signs of change do emerge in the work of You et al. (2019) who focuses on values integration and some engagement in deeper values. They acknowledge many ACP tools focus on illness-specific medical decisions and respond by trying to validate a tool that was "disease- agnostic" (p. e777) to help increase value-based decision-making more broadly. And while I applaud their inclusion of spiritual and religious beliefs in their study, there was only limited examination of spirituality—with little integrative opportunity. But I do observe a positive step in the author's suggestion that future directions should focus on "whether the tool can increase the quality of decision making during serious illness" (p. e783). Another positive step is recent resources produced by the Canadian Hospice Palliative Care Association et al. (2024) that do include new questions regarding spirituality and past beliefs shaping decision-making. But there has been no critical analysis in research needed more broadly in the literature for a fuller assessment of the larger complexity and multidimensionality of spirituality in ACP decision-making and the interwovenness of conflict between bioethics and spirituality—especially from an Ontario

[128] Of note in this study is also that there were no clinician or system engagement to the clients but only client-facing resources. Sudore, Boscardin et al. (2017) cite the work of Ramsaroop et. al. (2007) to note "passive ACP education with written materials is less effective than ongoing education by a trained health care professional" (p. 1107) with a reason given being the inaccessible language. But as observed above, there continues to be a challenge with only 20% of Canadians sharing with their healthcare provider. There is a tension here that needs increased attention.

perspective. The critical examination of spirituality and ACP in Ontario has been inadequate. Considering the high stakes of decisions involving death, it is these aspects of *quality* and *substance* that are arguably most central to ACP should be about—but still are largely relegated to the fringes of ACP and without adequate examination in research.

Responding critically to spirituality's role in ACP, I am suggesting that more than just echoing Watson and Thomas (2018) observation that human responses to death and dying are absent in ACP resources, I am suggesting it is more than just death denying, but also largely spirituality-denying. There is a barrier implicit in medical culture that resists this aspect of patient-centered care. I am suggesting that despite widespread research about spirituality's impact across health care domains (Koenig, 2015; Balboni et al., 2022), as well as studies that suggest spirituality leads to less treatment regret in men with prostate cancer (Mollica et al., 2016) as well as links to less decisional conflict in palliative care for those with greater spiritual wellbeing in another study (Rego et al., 2020)—there is still a resistance to spirituality's explicit inclusion in ACP decision-making. I note Colenda and Blazer's (2022) observation that while research instruments have focused on spirituality and religion in coping, "few have been developed to directly investigate ACP and EOL care preferences" (p. 748) leading to the conclusion that faith and religious beliefs have "not been studied in depth" (p. 748). I add spirituality to this equation as a gap needing to be addressed. Considering the high stakes of death, and the potential for spirituality to inspire deeper value reflection regarding decisions, an integrative approach to spirituality is needed that begins with a comprehensive examination of spirituality in ACP resources—a focus that has been missing. I take inspiration from the words of Cobb et al (2012) who suggest, "If spirituality in healthcare is to move beyond the *ad hoc* arrangements and particular interests of individuals that it commonly relies upon then it must

become better integrated within health systems" (p. viii). I echo the suggestion by Lutz et al. (2018) that spirituality in ACP research has been conspicuously absent. My research seeks to address this gap with a thorough and concrete assessment of ACP processes in Ontario resources.

In sum, while coping, comfort, and general spiritual well-being may be well represented in end-of-life resources, what is missing is an examination of spirituality as a key construct in value-based decision-making in ACP. In reflecting on Balboni and Balboni's (2019) four main spiritual themes arising in end-of-life decisions, as mentioned above, Colenda and Blazer (2022) observe, "we may be missing important opportunities to explore how different components of 'faith in God' guide patients making tough decisions at EOL" (p. 754). I am suggesting that wading into deeper conversations about spirituality's inclusion or exclusion in ACP resources in Ontario is necessary—for the good of the patient and their deepest and fullest choices. More than avoidance, siloed, or compartmentalized approaches to spirituality, ACP presents an opportunity to engage in meaningful life integration. And this is not currently happening consistently. There is tremendous potential in ACP to help people live fuller lives. But do our ACP resources invite this fullness and depth? And if not, what underlying assumptions, principles, and ideologies may be implicit in medicine that may unknowingly inform engagement of individuals in ACP and limit autonomous choice. A concrete assessment using critical tools is needed to analyze what we currently have with regards to spirituality's integration in ACP resources in Ontario—an exploration that respects the complexity of the topic, and the need to dig beneath the surface of the words themselves, towards the philosophical, theological, and epistemological leanings. An approach is needed that extends into the ideological domains to more fully understand *how* spirituality is situated and its social impact. Transformation is possible and begins with a

thorough and critical examination of how the “black box” of spirituality is situated within ACP resources to see possible discourses and ideologies that may be barriers to patient-centered ACP.

2.6 Conclusion

I began this chapter by surveying the landscape of spirituality, drawing on its history and definitional debates before outlining different clusters of definitions (Oman, 2013) in the literature including ontological and functional aspects, transcendent and immanent qualities, the notion of spirituality as a human search, as well as the centrality of meaning, relationship, connectedness, and life orientation. I then outlined factors in choosing a definition before differentiating between spirituality and religion. I closed this section by exploring spirituality and health, including debates regarding a culture of medicine that has distanced itself from spirituality (Balboni & Balboni, 2019). After exploring spirituality, I examined the notion of death, beginning with debates on medical perspectives on death, followed by the evolution in medical culture due to technology, and then exploration of some of the death discourses in society (Northcott & Wilson, 2022). This led to discussion around spirituality and death that included Sulmasy’s (2006) suggestion of death inspiring existential reflection that leads to transcendent and spiritual themes. I then explored themes in death related to existential meaning, awakening experiences, and finally the importance of beliefs in an afterlife.

After exploring death, I introduced the topic of values, exploring interdisciplinary understandings before shifting the conversation towards the overlap between spirituality and values (McPherson, 2018); eventually exploring values and end-of life decisions involving culture and spirituality. I closed this section by examining different value hierarchies, zeroing in on the work of Lonergan (1972/2017) who provides an existential approach rooted in spirituality as a destination of value discernment. The final section of this chapter I addressed the bioethical

foundations of ACP. I began with the roots of respect for autonomy and informed consent from an historical and legal perspective. I then explored some of the challenges, before moving to themes of incapacity and debates regarding the SDM role in decision-making. This chapter finished by exploring the emergence of ACP in medicine and the landscape of ACP in Canada. I closed the chapter by exploring the relationship of spirituality and ACP, highlighting resources before outlining the inadequacy of research focusing on spirituality in ACP.

Having laid this foundation for my research by reviewing the relevant debates and challenges, I move now to Chapter 3 and an outline of my methodology chosen to seek transformation in ACP by examining the "black box" of spirituality in Ontario ACP resources.

Chapter 3

Methodology

3.1 Introduction to Chapter 3

At the conclusion of Chapter 2, I offered a summary of the ground I covered in the literature review including a background to spirituality, definitional debates, and its relatedness to religion, as well as the strained relationship between spirituality and health care. I also summarized the interwovenness of spirituality, values, and death in health care decision-making before reviewing the bioethical foundations of autonomy, informed consent, the role of the SDM, and finally the need for ACP in helping with decision-making. After outlining ACP my broadly, I summarized the landscape of ACP in Canada as well as the relationship between ACP and spirituality before arguing that the literature fails to adequately address the "black box" of spirituality—a gap I suggested needing attention that inspires my research questions. I now move the discussion from the literature review to a focus on methodology.

In this chapter I address the methodology I utilized in this thesis. Considering both my commitment to deepening spiritual inclusion in ACP resources to help enable one's fullest values to be present in high stakes medical decisions involving death, as well as my suggestion that dominant ideologies may be present in medical culture that may inhibit this expression, I am suggesting that a critical perspective grounded in the paradigm[129] of Critical Discourse Analysis/Critical Discourses Studies (CDA/CDS) provides a helpful lens to examine how spirituality in all its complexity is situated in ACP resources, while also exploring potential

[129] CDA/CDS is described by Catalano and Waugh (2020) as frameworks, approaches, models, or research strategies, while Wodak and Meyer (2016) use descriptions including a school, perspective, paradigm, or programme. Considering no overarching agreement of use, I note my choice to refer to CDA/CDS as a "paradigm" to encourage consistency, avoid confusion, and differentiate from the MCDA "approach" I will note ahead.

conflict through discursive and ideological lenses. And the Multimodal Critical Discourse Analysis (MCDA) approach[130] is an expression of the CDA/CDS paradigm that can adequately examine these complex and interwoven themes as I outline next in the chapter ahead.[131]

I begin this chapter by providing a theoretical outline of the broader paradigm of CDA/CDS that grounds the methodological approach of MCDA that frames my research. After outlining CDA/CDS, I will narrow my focus to the MCDA approach and how it emerged from Social Semiotics. I will then articulate some of the strengths and limitations of both CDA/CDS and MCDA before offering a theoretical rationale for why I chose this approach to answer my research questions. Acknowledging the theoretical importance of several key concepts that underpin the entire paradigm of CDA/CDS and the MCDA approach I used, I will follow this opening section by providing a brief overview of several core theoretical concepts. These key concepts include discourse, power, ideology, a critical perspective, and finally the centrality of the social domain. It is essential to outline these overarching theoretical concepts adequately before outlining the MCDA methodological approach I utilized because of their theoretical centrality, and also because of the nuanced and diverse understandings of these concepts by theorists in different contexts. By clearly articulating how these concepts are used within the MCDA approach, I increase clarity and ensure congruency of usage.

After laying this conceptual groundwork, I will outline the MCDA approach I utilized to answer my research questions, followed by an articulation of how I will build on the strengths of the MCDA approach while addressing potential limitations. I will then articulate the methods I

[130] I will explore the MCDA approach in greater detail later in this section but pause here to emphasize that Machin and Mayr (2023) refer to MCDA as "an approach" (p. 21). This aligns with Creswell and Creswell's (2018) outline of an approach to research involving "philosophical assumptions and distinct methods" (p. 4).
[131] Further to the chapter ahead, I note here that this chapter integrates excerpts from my formal *Research Proposal* approved by my research committee and elaborated here with increased context.

utilized including the MCDA tools of inquiry I used to carry out my examination of spirituality within ACP resources in Ontario, followed by the process I used for coding data and generating themes by extending Braun and Clarke's (2022) method of reflexive thematic analysis (reflexive TA) to MCDA by focusing on discerning discursive and ideological themes in the data. I close this chapter by outlining the validity of the approach I have taken, followed by a conclusion to the chapter and a brief introduction to Chapter 4. I begin by providing an understanding of CDA/CDS and MCDA.

3.2. A Broader Understanding of CDA/CDS and MCDA

3.2.1 CDA/CDS

The MCDA approach I utilized in exploring my research questions is grounded in the paradigm of CDA/CDS—a name and acronym that need some background. Critical Discourse Analysis (CDA) was used as the broad title of this paradigm for decades. Crystalized at a symposium in 1991, a group of scholars including Theo van Leeuwen, Teun van Dijk, Ruth Wodak, Gunther Kress, and Norman Fairclough recognized common critical themes of their work that would eventually evolve into CDA (Catalano & Waugh, 2020). More recently, Critical Discourse Studies (CDS) evolved to include the diversity of methods and approaches within CDA and "to denote the expansion of CDA into a larger transdisciplinary/cross-disciplinary research domain" (Catalano & Waugh, 2020, p. 2). Honouring both the historic notions of CDA, and the diversity reflected in the newer name of CDS, Catalano and Waugh (2020), suggest using the name Critical Discourse Analysis/Critical Discourse Studies (CDA/CDS) and this is

the approach I take in referencing this paradigm in this thesis.[132] Having established this title, I continue with a description of the paradigm.

Considering the diversity of CDA/CDS, as alluded to above, there are common elements that unite the paradigm. Wodak and Meyer (2016) suggest CDA/CDS as aligning with several key principles including being problem-oriented, interdisciplinary, eclectic, self-reflexive, and "characterized by the common interests in deconstructing ideologies and power through the systematic and retroductable investigation of semiotic data (written, spoken or visual)" (p. 4).[133] Further, Wodak and Meyer (2016) note there is not "one specific methodology characteristic of research" (p. 5) within CDA/CDS but rather a diversity of approaches "derived from quite different theoretical backgrounds, oriented towards different data and methodologies" (p. 5).

But central to CDA/CDS is seeing a social perspective regarding language as being essential to analysis (Wodak & Meyer, 2016) as well as the importance of a "*hermeneutic process*" (p. 21, italics theirs) that moves beyond just descriptions of data, towards critical perspectives to complex social problems. Another summary of CDA/CDS is offered by Flowerdew and Richardson (2018) who describe the paradigm as "an inter-disciplinary approach to language in use, which aims to advance our understanding of how discourse figures in social processes, social structures and social change" (p. 1). But perhaps most widely used is Wodak and Meyer's (2016) articulation of seven core dimensions of CDA/CDS that I quote directly in Table 1 outlined below.

[132] I will utilize CDA/CDS throughout the dissertation with the exception of quotes or references where I have tried to honour the author's original intent as much as possible and will use either CDA or CDS.
[133] I will address the complex notion of "semiotics" and modes of communication later when focusing on MCDA.

Table 1

Seven Core Dimensions of CDA/CDS Approaches (Wodak & Meyer, 2016, p. 2, italics theirs)

An interest in the properties of *'naturally occurring' language use* by real language users (instead of a study of abstract language systems and invented examples).
A focus *on larger units than isolated words and sentences*, and hence, new basic units of analysis: texts, discourses, conversations, speech acts, or communicative events.
The extension of linguistics *beyond sentence grammar* towards a study of action and interaction.
The extension to *non-verbal (semiotic, multimodal, visual) aspects* of interaction and communication: gestures, images, film, the internet and multimedia.
A focus on dynamic (socio)-cognitive or interactional moves and strategies.
The study of functions of (social, cultural, situative and cognitive) *contexts of language use.*
Analysis of a vast number of *phenomena of text grammar and language use*: coherence, anaphora, topics, macrostructures, speech acts, interactions, turn-taking, signs, politeness, argumentation, rhetoric, mental models and many other aspects of text and discourse.

In terms of the aims of CDA/CDS, Flowerdew and Richardson (2018) suggest the broader goal of the paradigm as being "to uncover hidden features of language use and debunk their claims to authority…to make the implicit explicit in language use" (p. 1). In a similar critical vein, Ledin and Machin (2017) suggest the broader project of CDA/CDS as "digging out the discourses buried in texts to reveal the kinds of power relations and ideologies that they represent" (p. 60). And while grounded in broader critical and discursive foundations, as noted above, I reiterate the diversity of approaches within CDA/CDS as noted by Wodak and Meyer (2016). Catalano and Waugh (2020) outline the main approaches as being the Dialectical-Relational Approach; the Sociocognitive Approach; the Social Semiotic and MCDA Approaches; the Discourse-Historical Approach; the Dispositive Analysis Approach; Corpus Linguistic Approaches; and finally Cognitive Linguistic Approaches.[134] Having outlined the broader paradigm of CDA/CDS, as well as some of the approaches within this paradigm, I will

[134] A fuller treatment of the range of CDA/CDS approaches is beyond the scope of this thesis but I will expand on my choice to engage the MCDA approach in a rationale provided later in this chapter.

now outline the MCDA approach that emerged from Social Semiotics that I applied to my examination of spirituality in ACP resources in Ontario.

3.2.2 MCDA

Grounding MCDA in Social Semiotics. In outlining the MCDA approach I applied to my examination of spirituality in resources found on the ACPO website it is necessary to first describe the origins of another approach within CDA/CDS that influenced the development of MCDA—specifically, the Social Semiotic approach that grounds MCDA (Machin & Mayr, 2023). Social Semiotics is connected to the work of van Leeuwen whose (2005) book, *Introducing Social Semiotics,* provided a key outline to this approach. Before going further, it is important to outline what is meant by the word "semiotics". Referencing this question "what is semiotics?" at the beginning of their work, van Leeuwen (2005) redirects the question by asking a different question—"What kind of activity is semiotics?" (p. 3). Van Leeuwen proceeds to outline a definition of semiotics as "The study of semiotic resources and their uses" (p. 285). Hence, there is an activity to semiotic resources based on meaning potentials that arise in use. Theoretically, Kress and van Leeuwen (2021) suggest the "sign" (p. 8) is at the heart of all semiotics[135] while Wodak (2008) makes the link of the sign to meaning and the suggestion that modern semiotics as meaning a sign as being meaningful based on social conventions. Hence, signs have meaning based on previous social uses. Historically, van Leeuwen (2005) provides a definition of semiology by Saussure from 1916 that links the Greek word "semeion" with "sign" and the notion of "semiology" as being "A science that studies the life of signs within society" (Saussure, 1974 [1916], p. 16, as cited in van Leeuwen, 2005, p. 3). It is this notion of "sign" that

[135] I am also mindful of a larger history of semiotics with various schools of thought dating back to the 1930s (Kress & van Leeuwen, 2021). A fuller treatment of these schools is outside the bounds of this dissertation. My focus will be on Social Semiotics as outlined by van Leeuwen (2005) and then extended to MCDA.

is often utilized in linguistics along with the linking concepts of the "signifier" that means an observable form and that of "signified" which suggests a meaning (van Leeuwen, 2005, p. 4). And while some continue to utilize the concept of "sign" in their social semiotic work, others—including van Leeuwen—use Halliday's descriptor of semiotic resources.[136]

Social Semiotics is based on the theoretical work of Halliday who introduced the notion of "semiotic resources" in his social semiotic theory focusing on "choices and meaning potentials of semiotic resources" (Ledin & Machin, 2020, p. 15). These "semiotic resources" are at the heart of this approach, described by van Leeuwen and Kress (2011) as "the actions, materials and artifacts we use to communicate" (p. 123) while holding meaning potentials "based on their past documented or collectively remembered uses" (p. 123). Van Leeuwen and Kress suggest semiotic resources can be both physiological with examples being the use of voice, gesture, posture, and expressions; and also technical, giving examples of writing, painting, photos, videos, or recordings. Kress & van Leeuwen (2001) describe the range of formal and informal semiotic resources "as a vast, maze-like storehouse of words and collocations of words, fragments of language, idioms" (p. 113) that exist "in different ways for different people and groups" (p. 113). Or put more simply, Ledin and Machin (2018) outline semiotic resources as "the kinds of things available for making meaning" (p. 16) The focus of Social Semiotics is on these semiotic resources and their meaning potential that is rooted in community.

Van Leeuwen (2005) summarizes Halliday's approach to language by suggesting: "the grammar of a language is not a code, not a set of rules for producing correct sentences" (p. 3) but quoting Halliday, it is a "resource for making meanings' (Halliday, 1978, p. 192, as cited by van

[136] I will mainly follow van Leeuwen's (2005) lead in utilizing "resource" instead of "sign" in this dissertation as they suggest "sign" seems to suggest that it stands for something in particular—like a stop sign—where the notion of resource remains open to interpretive use.

Leeuwen, 2005, p. 3). Machin (2016) summarizes Halliday's social theory that places "emphasis not on a more rigid, or formal, grammar, so much as an overall system of semantic choices or alternatives made up of layers of smaller subsystems which build into the whole" (p. 324). And rather than reflecting laws of language, Social Semiotics assumes, "meanings are made in social action and interaction" (Kress & van Leeuwen, 2021, p. xiii) with a "richness and complexity of semiotic production and interpretation" (van Leeuwen, 2005, p. xi). This will be important to my research focusing on spirituality in ACP resources in regard to questions like—what underlying assumptions around social processes regarding decision-making in end-of-life situations may be reflected in reflective resources provided in Ontario? And more, if meanings are made, the next question involves—who might be the maker of these meanings? Further, if there is a maker of meanings, what is the motivation for their choices? This will be important in examining ACP resources to discern underlying motivations of content-producers. What ideological[137] leanings might be evident in resources created by content-producers that may influence personal end-of-life choices? I turn now to this focus on meanings and makers.

Before moving to how the MCDA approach emerges from Social Semiotics, it is important to outline how Social Semiotics views meaning and the makers of meaning as this will be foundational to the MCDA approach. Given the range of social meanings that may emerge in available choices of semiotic resources, another area of focus arises in Social Semiotics—namely, how a producer of text or design might choose semiotic resources to accomplish their purpose. This will be important to my analysis of ACP resources that may employ certain modes to carry out their perspective on where spirituality may fit in the ACP process. As Kress and van Leeuwen (2021) suggest, the maker of signs "seek to make a representation of some object or

[137] I will explore meaning around ideology later in this section when I outline theoretical concepts more closely.

entity…arising out of the cultural, social and psychological history of the sign-maker" (p. 9). Within a system of semiotic choices, the producer can utilize a set of semiotic tools and alternatives available to them to shape and create desired meaning within a given context (Ledin & Machin, 2020). And here the conversation returns to meaning potential (van Leeuwen, 2005) within resources—and what van Leeuwen calls "semiotic potential" (p. 4) where resources hold all previous social and cultural meanings of the semiotic resource.[138] But considering resources do not only reflect the world, but also constitute it (Machin & Mayr, 2023), the question arises—what choices are content-producers making regarding which resources to utilize and why? Extended to ACP resources, the question becomes—what choices regarding language related to spirituality, values, and death is chosen in ACP resources that may contribute to constituting a world related to end-of-life choices that inspire choices for diverse Ontarians? Social Semiotics answers this question based on language choices and the meaning potential that exists within these semiotic choices to bring about desired meaning. With a basic understanding of Social Semiotics established, I move to the emergence of the MCDA approach that grounds this thesis—an approach that highlights a critical perspective to explore multimodal aspects of language like those found on the ACPO website that I will be exploring.

The Emergence of MCDA. Machin and Mayr (2023) are clear in suggesting "MCDA is based on a social semiotic approach to language" (p. 23) with the view of language as a selection of resources a communicator chooses to bring about their interests. And while Social Semiotics emerged to examine discourses communicated in semiotic resources through choices made by

[138] Similar to the notion of "semiotic potential", van Leeuwen (2005) notes the terminology of Gibson (1979) who uses the word "affordances" to suggest "potential uses of a given object" (p. 4). Both get at this same notion of the potential social meaning within language. Van Leeuwen here (p. 5) notes meaning potential refers to meanings previously introduced societally, while affordances as more latent and unrecognized. I will utilize the notion of meaning potential.

agents, Machin (2013) highlights a key observation made by van Leeuwen (2013) of there being "little critical work done on the way that discourses are communicated, naturalised, and legitimised beyond the linguistic level" (p. 347).[139] MCDA responded to this criticism by extending Social Semiotics with an increasingly critical focus on meaning potentials and how "semiotic resources are deployed to communicate ideas, values, and identities" (p. 348). But more, MCDA brought attention to the potentials of meaning within the various modes as they function together. Machin (2013) describes this key shift in MCDA from "monomodality" (p. 348) where modes like texts functioned in isolation, to the interplay of "multimodality" (p. 348) where many modes—like text, visuals and speech—moved together to communicate broader ideas rather than existing in isolation. Additionally, there was also a need to consolidate multimodal approaches to "develop and establish clear, robust concepts that can be used as part of CDA" (Ledin & Machin, 2017, p. 60) that would result in the emergence of MCDA and a markedly critical approach to multimodality. Described by Ledin and Machin (2018) as "a sub-field of multimodality called multimodal critical discourse analysis" (p. 28), it is this MCDA approach outlined by Machin and Mayr (2023) that I operationalized in my research that allowed for a critical examination of the integrative and multimodal aspects of the contemporary ACPO website that features more than just text but photos, design, and video content.

As the conversation moves to "modality" and related concepts of monomodality and multimodality within MCDA, a question arises regarding how "modality" fits with concepts like semiotic resources? A subtle differentiation can be made between modes or modality, and that of "semiotic resources". Kress and van Leeuwen (2021) differentiate the terms suggesting that

[139] This notion of naturalization will surface again in the section below that highlights key theoretical concepts including ideology where naturalization occurs as a characteristic.

modes are major, or "central resources for making meanings materially evident" (p. xiv) and give examples of modes being larger communicative categories of image, speech and writing. Mode then is the larger category of representation, and semiotic resources, by contrast, are the "resources used in making signs within a specific mode" (p. xv). The example they give is the many different aspects of speech sounds. The varying sounds that can be expressed in speech are "part of the semiotic resource of the mode of speech" (p. xv). For clarity, when I am using MCDA to examine spirituality in the ACP website, I am analyzing the many modes like speech, writing and visuals, while also examining semiotic resources within these modes that act as signs and hold potential for meaning making based on "the broad range of meanings of a community" (Kress & van Leeuwen, 2021, p. xv). A multimodal approach examines a variety of modes.

Highlighting a Critical Perspective in MCDA. While CDA/CDS is characterized by a critical perspective, it is important to note that not all multimodal approaches to discourse analysis feature this critical lens. Catalano and Waugh (2020) go as far as to suggest that MCDA's critical focus is an exception among contemporary multimodal approaches with many still focusing on descriptive aspects instead of seeking to reveal discourses and ideologies to inspire social change. This critical perspective is central to MCDA in what Machin (2013) suggests as "Being critical at the multimodal level" (p. 352) in its link to language. Machin and Mayr (2023) suggest a key assumption about language for MCDA is inspired by the field of Critical Linguistics in that, "language can be used not just to represent the world, but to *constitute* it. Since language shapes and maintains a society's ideas and values, it can also serve to create, maintain, and legitimize certain kinds of social practices" (p. 23). And here I return to the attention given to power for content-producers of websites like that of ACPO to constitute, shape, maintain, and legitimize certain practices. And as Machin and Mayr (2023) suggest,

attention is given to "the way the communicator uses the semiotic resources available to them…in order to realise their interests" (p. 23). Extended to ACP, the question arises with regards to what semiotic resources have been chosen by ACPO content-producers and what interests they may be attempting to realize on the ACPO website regarding end-of-life decision-making? Succinctly, Machin and Mayr (2023) describe the goal of MCDA in seeking to determine "what choices the commentators deploy and why" (p. 21) and what "taken-for-granted assumptions" (p. 24) exist that may "run through our institutions, organisations and workplaces" (p. 26). This includes what Machin (2013) describes as "epistemological commitments" (p. 354) within discourses found in resources—commitments imposed by glossing over some aspects to be hidden, while magnifying other desirable messages. But how is a critical multimodal lens applied? I move now to how the MCDA approach is applied to research.

Ways of Applying MCDA. With MCDA articulated by Machin and Mayr (2023) as the multimodal "process of revealing the discourses embedded in texts" (p. 298) and then "exposing certain ideological positions of text producers" (p. 298), as noted above, the question arises regarding the application of these approaches. Practically speaking, observing discourses within semiotic resources takes on a detective-like quality in the attempt to "discover the wider discourses they carry" (Machin & Mayr, 2023, p. 27). More precisely, this process of discovering discourses within resources involves the multimodal task of seeking a "discursive script" (Machin & Mayr, 2023, p. 31) or the "elements which comprise discourse" (p. 31) that are woven across different modes. Machin (2013) draws on the work of van Leeuwen and Wodak (1999) to suggest discursive scripts "describe the vision of what sequence of behaviour is associated with a particular discourse" (p. 352). In terms of ACP, the question arises regarding what vision or sequence of behaviour regarding end-of-life choices is being suggested to

Ontarians within the discourses presented on the ACPO website? Machin and Mayr (2023) summarize Fairclough's (2003) work, suggesting "individual texts may not reveal the full nature of a discourse. Rather, we need to look over 'chains or networks of text' to assemble the discourse" (Machin & Mayr, 2023, p. 31). Alternately, van Leeuwen (2016) uses the metaphor of a puzzle where the seeking of evidence in the text of discourse will help one "piece together a discourse" (p. 139). This echoes a similar notion they suggest, that "a single text does not provide enough evidence for reconstructing a discourse" (p. 139). After "assembling" discourses in MCDA, the opportunity then exists to explore potential ideologies in the work—a process that requires an interpretive lens focusing on these discursive hints and traces of the choices made by content-producers. These hints are revealed in observing what might be "concealed, abstracted, or foregrounded" (Machin, 2013, p. 352) and shaped in social practices as a discursive script. Further, drawing on the work of van Leeuwen and Wodak (1999), Machin (2013) note the importance of paying attention to "recontextualization" (p. 352) where semiotic resources are deployed to revise social practices based on the values and assumptions of those with power to produce resources. Van Leeuwen (2016) describes the process suggesting "practices are turned into discourses" (p. 139) and that "discourses are recontextualizations of social practices" (p. 141). Hence, through deletions, additions, and substitutions, a discursive script is constituted that recontextualizes social practices in line with the ideologies of the powerful. Extended to ACP resources found on the ACPO website, the question is—what social practices might be recontextualized regarding spirituality, death, values, and spirituality? And what does this say about how spirituality is situated? These questions are core to the MCDA approach I used.

Having outlined the paradigm of CDA/CDS that underpins my dissertation, followed by the MCDA approach I utilized to examine the "black box" of spirituality in ACP resources, I

turn now to some general strengths and limitations. In the next section I will outline strengths and limitations of both the paradigm of CDA/CDS that underpins my thesis, as well as the MCDA approach I utilized to examine spirituality within ACP. I follow this by outlining a rationale for choosing the MCDA approach grounded in CDA/CDS.

3.2.3 General Strengths and Limitations of CDA/CDS and MCDA

Having outlined the theoretical underpinnings of my research, I will now outline some of the general strengths and limitations of the methodology I applied to examining spirituality in ACP resources. But I first offer a word of clarity about the scope of this section. Considering the longevity of CDA/CDS as a paradigm encompassing multiple and diverse approaches spanning several decades, and the relative newness of MCDA as one of these interwoven CDA/CDS approaches described as being "still in its infancy" (Ledin & Machin, 2017, p. 60), this articulation of general strengths and limitations encompasses both the larger theoretical umbrella of CDA/CDS and the MCDA approach within CDA/CDS. I will address how I will build on particular strengths and limitations later in this chapter, and in Chapter 5 I will return to the topic of limitations focusing on practical aspects of the study. I begin by outlining general strengths.

General Strengths of Engaging CDA/CDS and MCDA. Having outlined a theoretical foundation of CDA/CDS and the MCDA approach that I will apply to examining the situatedness of spirituality in ACP resources, I will now outline some general strengths and limitations. I begin with the strengths of this approach including the potential of real-world application and transformation, the ability to tackle complex social issues through a discursive lens, the ability to address the multimodal turn in the social sciences, the theoretical and interdisciplinary richness of this approach, the ability to draw on qualitative approaches, the concreteness of content analysis, the opportunity to analyze ideology, and finally the freedom of this approach to

customize research to address diverse and complex topics like the "black box" of spirituality in ACP. I start with the strength of real-world application and potential for transformation.

Real-World Application and Potential for Transformation. A key strength of CDA/CDS as a paradigm is its ability to address real world situations and provide opportunities for transformative application. Wodak (2020) notes the ability of CDA/CDS to concern itself not just with "analysis, interpretation, and explanation—but also with application" (p. xxii) while Gee (2014) suggests the approach holds potential to "illuminate problems and controversies in the world" (p. 10). As Fairclough (2015) suggests, "CDA is oriented to transformative action to change existing social reality for the better" (p. 13). MCDA as an approach within CDA/CDS that provides opportunity for this same potential for transformation through critical attention aimed at multimodal resources—an approach I employed in looking at ACP resources.

Ability to Tackle Complex Social Issues Through Discourse. In addition to its ability to address real-world problems, CDA/CDS uniquely examines complex social themes through a discursive lens. Wodak (2020) describes this ability to tackle the complexity of social issues in a rapidly changing contemporary society through "entry points to understanding and explaining the many complex aspects of the rapid developments, the tensions, and contradictions, which involve all of us in different and context-dependent ways" (p. xxi). Entry points include aspects of discursive scripts that provide glimpses into complex social environments like that of spirituality in ACP. As a "black box" needing examination, a methodological approach of MCDA embedded in the paradigm of CDA/CDS can address the complex social aspects of spirituality and its intertwined notions of death and values with the depth it requires. This discursive approach allows for exploration of social dynamics of this complex relationship to fill the research gap identified regarding spirituality in ACP.

Potential to Address the Multimodal Turn. Noted as the "multimodal turn of CDA/CDS" (Catalano and Waugh (2020, p. 172), another strength of MCDA is its ability to move beyond just text in language towards "a broader framing of critical discourse analysis" (Kress & van Leeuwen, 2021, p. 16). With the massive changes in communication patterns in contemporary society over the last decade that are increasingly dependent on design and images, a multimodal approach is essential to analysis. And more, Machin (2013) suggests, where previous modes of communication were used in isolation, today's technology is integrative to "communicate complex ideas and attitudes" (p. 348) with the shift from monomodality to multimodality. MCDA is uniquely able to address how entire packages of signs working together as images and text to make meaning—a perspective which is not frequently included in analysis of bioethical resources like ACP. Taking this lens to an ACP website involving text, video, and design has potential to ascertain a fuller picture of how spirituality is situated within all modes, rather than just monomodal analysis focused on text.

Theoretical and Interdisciplinary Richness of CDA/CDS and MCDA. Another general strength in the CDA/CDS paradigm and the MCDA approach is the richness of theoretical and interdisciplinary diversity. CDA/CDS is rooted in a rich theoretical background described by Wodak (2020) as drawing on "multi-/inter-/transdisciplinary and multi-method approaches" (p. xxiii) that move beyond a single theory, while Wodak and Meyer (2016) describe the paradigm as being "problem-oriented, and thus necessarily interdisciplinary and eclectic" (p. 4). This interdisciplinarity is further demonstrated by Machin and Mayr (2023) who suggest critical, ideological, and discursive approaches in MCDA draw on other fields using critical language like sociology, cultural studies, and journalism. Further, the MCDA approach has openly drawn on the richness of other disciplines with intentionality not "reinventing the wheel" (Machin,

2013, p. 348) in terms of multimodal examination, but rather, engaging with existing fields to "provide depth to our tool kit" (p. 348) where "longer and more established traditions of visual analysis" (Machin, 2016, p. 323) have existed. As a group of linguists acknowledging the need to analyze images, there was a distinct need to borrow from other fields to accomplish their examination and this is what they have done. Further, Machin (2013) notes a broad history of research in semiotics that MCDA draws upon including fields like film studies, art, and cultural studies that have engaged topics multimodality as well as ideologically.

Ability to Draw on Qualitative Approaches. As noted above, another strength in CDA/CDS is its qualitative and normative lens. Named earlier in this thesis as drawing on Van Dijk's (1993) suggestion of being "unabashedly normative" (p. 253), there is an embracing of the stance of researcher in CDA/CDS who is expected to clearly outline their own positionality and interests as Wodak and Meyer (2016) suggest. This subjective approach also aligns with my theological roots I named in Chapter 1, including the work of Lonergan who broadly embraces a subjectivity that provides a sort of intellectual conversion involving the human person. This is noted by Gregson's (1988) reference of Lonergan's work noting, "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27) that enables a fully human engagement on questions. Additionally, Braun and Clarke (2022) describe a "qualitative sensibility" (p. 7) in their reflexive TA approach that I will utilize in coding data that is rooted in researcher-focused aspects like meaning, nuance, critical questioning, contradiction, and reflection on assumptions. And evidence suggests others in the field are intrigued by the qualitative approach of CDA/CDS with Catalano and Waugh (2020) noting the amount of critique and interest garnered in the literature demonstrates "people are reading CDA work, and it has earned a distinct place among other fields" (p. 220).

Concreteness of Analysis. While Fairclough (2003) suggests "Social structures are very abstract entities" (p. 23), a strength of the MCDA approach is also its concreteness in addressing material resources and public facing documents that are broadly accessible in the public domain. Through this approach, an analysis can happen that looks at "naturally occurring" language (Wodak & Meyer, 2016, p. 2) and can approach discursive and ideological aspects that contribute to a larger, fuller, and richer picture of the concrete choices made by content producers. In utilizing what Ledin and Machin (2018) suggest as "a practical tool kit" (p. 11) in MCDA, with an eye to meaning potentials and what "exactly is being communicated and also *how* it is communicated" (p. 10) in resources, MCDA allows for both a level of concreteness and meaning in exploration.

Opportunity to Analyze Ideology. Machin and Mayr (2023) suggest "The aim of CDA is to reveal ideologies" (p. 38) that relates to their question: "what kind of world is being created by texts and what kind of inequalities and interests might this seek to generate, perpetuate or legitimate" (pp. 36 - 37). With the complexity of ACP processes existing within an overarching medical culture being the context of my research, there are significant themes of power hovering over the discussion. These ideological themes involving power and struggle cannot sit idly unexamined in a conversation regarding how spirituality is situated. MCDA enables a lens to these ideological aspects to enter the conversation regarding spirituality's situatedness, allowing for a fuller picture of ACP resources beyond just surface levels of analysis.

Freedom of Research Approach. Finally, as noted above in the work of Wodak and Meyer (2016), they speak of "a bulk of approaches with theoretical similarities" (p. 21) in CDA/CDS, and with it there is significant freedom on the part of researchers to carry out their methods in a way that best addresses their research questions. Catalano and Waugh (2020) note

that “CDA/CDS can be used in relation to any type of topic, in any type of discourse, in any type of medium…adopting a variety of types of methodology” (p. 3). As Gee (2014) playfully observes, their approach to research includes having “freely begged, borrowed, and patched together” (p. 11) an approach to discourse analysis. Continuing, this assumes no right way, but an acknowledgment that “Different approaches fit different issues and questions better or worse than others” (p. 11). Considering the significant diversity of context regarding analysis, and the multiple modalities within these contexts ranging from text to film and websites, this freedom to organize research based on one’s research questions allows for greater contextual customization.

General Limitations of Engaging CDA/CDS and MCDA in Research. Having outlined the general strengths of the paradigm of CDA/CDS and the MCDA methodological approach I utilize, I now turn to limitations before offering a rationale for the approach I have taken. The limitations I will explore below include suggestions that observations are mundane, selective and partial; suggestions of negativity; a lack of definition of discourse; the qualitative approach being largely interpretive; suggestions of a lack of attention to real readers or listeners; an absence of context; the ambiguity of focus on activism or social research; and finally, the lack of structure. I begin by addressing MCDA’s mundane, selective, and partial observations.

Suggestions of Mundane, Selective, and Partial Observations. One of the limitations of CDA/CDS is that some have suggested it chooses to explore “easy examples” (Machin & Mayr, 2023, p. 306) resulting in simple research observations. Linked to this, Machin (2013) notes general criticisms of CDA/CDS from Forceville (2007, 2010) who suggests that extreme approaches “tended towards concealing what is taking place behind complex terminology and that dense levels of analysis have led to little more than mundane observations” (p. 349). Fairclough (2003) responds to these kinds of criticisms suggesting all analysis being “inevitably

selective" (p. 14) which addresses the partiality and selectiveness. Responding to this limitation further, Wodak and Meyer (2016) note the importance of self-reflection throughout the research process that focuses one's perspective based on research questions. Hence, findings carried out with self-reflection and a well-articulated methodology will increase the likelihood of depth and richness of analysis rather than the "mundane"—which is additionally subjective and arbitrary.

Negativity. Machin and Mayr (2023) note that some observers suggest there is a tendency toward negativity in the paradigm rather than more positive objectives of research. Catalano and Waugh (2020) reference the criticism of Breeze (2011) who observes that in seeking to unmask ideology and manipulation "it is hardly surprising that language scholars of this school find it easier to deconstruct than to construct" (Breeze, 2011, p. 516, as cited in Catalano and Waugh (2020, p. 231). In response to these notions of negativity, Flowerdew and Richardson (2017) suggest critique is done for "an emancipatory function" (p. 5), while Machin and Mayr (2023) reference the work of CDA/CDS playing "a positive role in working to improve our societies and life within them" (p. 302). The roots of CDA/CDS and MCDA are in transformation and the positive focus of the researcher in this process is key as will be outlined in a section ahead on the practical context of spirituality in ACP.

Lack of Definition of Discourse. CDA/CDS and MCDA are also challenged by the elusive definition of discourse as will be outlined in greater detail in my outline of theoretical concepts later in this chapter. Catalano and Waugh (2020) note the criticism leveled by Widdowson (1995) that discourse is not well defined, but rather just a trend being "in vogue and vague" (Widdowson, 1995, p. 158, as cited in Catalano & Waugh, 2020, p. 221). Not disagreeing, Wodak and Meyer (2016) suggest discourse includes "a hugely proliferating number of usages in the social sciences" (p. 3), while Catalano and Waugh (2020) note Fairclough's

honest response regarding defining discourse as being “a hopeless and fruitless task” (Fairclough, 1996, p. 54, as cited by Catalano and Waugh (2020, p. 222). While this criticism regarding a lack of clarity around discourse is widely noted regarding CDA/CDS, Wodak and Meyer (2016) suggest the responsibility lies in the hands of researchers to define their own meaning of discourse. I have addressed this by offering a specific definition accepted in MCDA that frames this concept and focuses the analysis solidly within the MCDA approach. Further, Wodak and Meyer (2016) suggest this lack of theoretical clarity has not stopped the explosion of interest in discourse academically, noting: “CDS has become an established discipline, institutionalized across the globe in many departments and curricula” (p. 5).

Qualitative Approach is Largely Interpretive. A concern of some quantitative researchers is the significant interpretive nature of CDA/CDS. Not unlike the limitation expressed a few paragraphs above, Machin and Mayr (2023) suggest some have noted the nature of interpretation being “too selective and partial” (p. 303). Undeterred, Machin and Mayr suggest these are typical concerns with the subjective nature of qualitative work in general, and that quantitative work too is embedded with partiality and subjectivity with regards to what will be studied and how it will be studied. But more, despite the appearance of facts embodied in quantitative research through charts and tables, the numbers may indeed be “vague, shifting and arbitrary” (p. 304). Fairclough (2003) suggests the subjectivity of the analyst is in all research, noting “There is no such thing as an ‘objective’ analysis of a text” (p. 14). But with CDA/CDS being “unabashedly normative”(Van Dijk, 1993, p. 253), as I noted earlier, and rooted in research self-reflexivity, Wodak and Meyer (2016) suggest CDA/CDS researchers need to “attempt to make their own positionings and interests explicit” (p. 4) which includes one’s self-

reflexivity in research.[140] The reflexivity is central to my own application of MCDA as I examine this "black box" of spirituality in ACP from the lens of my own experience and leanings.

Real Readers or Listeners are not Addressed. Another potential limitation expressed regarding CDA/CDS, and MCDA more specifically, is the absence of real readers and listeners. Machin and Mayr (2023) note the work of Widdowson (1998) who suggests there is a privileging of certain ideological meanings in discourse analysis without the experience of real communities. Referencing this criticism in Hall's (1973) work, Machin and Mayr (2023) consider whether "real" readers experience the same oppositional perspective in these resources, or whether CDA/CDS creates a "its own privileged readings" (p. 307). Machin and Mayr (2023) answer this by suggesting ideology in CDA/CDS takes on "complex forms across a society where there is a constant process of negotiation" (p. 307) making audience participation difficult. Others have suggested ethnographic approaches might help solve this potential issue in CDA/CDS (Catalano & Waugh, 2020). But in terms of my own approach to methodology, considering the theoretical denseness and complexity of multidimensional themes of spirituality and its interwoven concepts of values and death, as well as the philosophical dispute in the culture of medicine involving ideology and discourse, a critical perspective is essential to refining the theoretical conversation to enable future study with "real" people. There is tremendous potential for future follow-up ethnographically as a second phase to potentially test this theoretical analysis with the lived experience arising from the theoretical suggestions I am making. But I suggest these complex social themes need first to be analyzed theoretically.

[140] Theologically speaking, this also connects theoretically to the work of Lonergan I have noted above, who notes "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27). It is this personal subjective approach to inquiry that is central to this expression.

Lack of Context in Research. Catalano and Waugh (2020) note the criticism by some that CDA/CDS research suffers from a lack of context—including reference to the work of Collins and Jones (2006) who suggest a lack of linguistic connection to social history. The authors suggest that while much of the early CDA/CDS research struggled with decontextualized approaches, more work has been done more recently to increase contextualization including the social, political, and historical domains. Catalano and Waugh (2020) also broadly outline the emergence of other interdisciplinary approaches embracing context involving anthropology, gender studies, education and media, and sociolinguistics. As far as the MCDA approach that is being applied to the situatedness of spirituality in ACP resources, I am ensuring a strong context is established in the thoroughness of literature review that sets out the complex landscape of bioethics and spirituality before entering into examination of the ACPO website.

Sitting the Fence Between Political Activism and Social Research. Another potential limitation articulated by Wodak and Meyer (2016) is the criticism that CDA/CDS does not have a clear home as being either social research or political activism. I agree with the authors' suggestion of this limitation actually being a strength: "such criticism keeps a field alive because it necessarily triggers more self-reflection and encourages new responses and innovative ideas" (p. 22). Fairclough (2003) blends these two together suggesting a "critical social science" approach that is "motivated by the aim of providing a scientific basis for a critical questioning of social life in moral and political terms" (p. 15). The other danger, as expressed by Catalano and Waugh (2020) is that scholarly work stays "within the constraints of academia" (p. 224). Hence, this limitation is a strength when applied to MCDA where the transformative goal is problem oriented as in the case of utilizing MCDA to examine spirituality in ACP resources where both action and social research meet in exploring this complex intersection.

Lack of Structure and Framework to Carry Out Research. Finally, while freedom in research within CDA/CDS was listed above as a strength by providing significant flexibility to approach a variety of contexts and research questions, this freedom and flexibility can also be seen as a limitation. Gee (2014) suggests there is no set of rules or scientific method but that approaches "continually and flexibly adapted to specific issues, problems, and contexts of study" (p. 11). Responding to the need for structure specifically within the MCDA approach, authors like Machin and Mayr (2023) have articulated clearer structures and tools of inquiry that map out more clearly the options available to researchers when applying MCDA—while remaining steadfast in the importance of customizing and adapting approaches to the research questions.

In the section above I have outlined both the strengths and limitations of the paradigm of CDA/CDS and the MCDA approach I applied to the examination of spirituality in ACP resources. I note here that having addressed some of the methodologically focused limitations in this section, I will return to this discussion regarding limitations in Chapter 5 when I acknowledge some of the practical limitations of this study. I now provide a rationale for utilizing the MCDA approach to answer my research questions.

3.2.4 Rationale for Methodological Choice to Utilize CDA/CDS and MCDA

Having outlined the strengths and limitations of the paradigm of CDA/CDS and the MCDA approach I applied to examining spirituality in ACP resources, I now offer a formal rationale for this approach. Considering the refrain that I have offered throughout this thesis that the "black box" of spirituality within ACP resources has not been adequately examined, and that a territory dispute[141] exists within the culture of medicine regarding spirituality's inclusion, a

[141] I remind the reader of the source of this reference being the thinking by Stempsey (2021) who suggests in bioethics there is a "field of disputed territory" (p. 244) regarding the inclusion of religion in bioethics. Stempsey argues religion is "the soul of bioethics" (p. 250) and needs integration As noted in Chapter 1 when addressing the conflict, I extend this language of a territorial dispute beyond religion to the larger domain of spirituality.

methodology is needed that can attend to both the complexity of spirituality and its interwoven aspects of death and values; as well as an approach that can take into account the complicated social dynamics within the culture of medicine that conflict with spiritual inclusion. But most importantly, the methodology must be in service to the research questions that I have proposed. To review, and as a reminder, the main research question I am asking is: how is spirituality situated in ACP resources found on the ACPO website? And my research sub-questions are: 1) What discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website? And 2) What bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death, and values? And finally, 3) What are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization? A chosen methodology must be able to serve the transformative intention rooted in these critical questions to help optimize real-world change to ACP resources in order to deepen value-based reflection in high stakes decision-making involving serious illness and death to further patient autonomy and the good of the patient.

In reflecting on my research questions and the broader context noted above, I chose to utilize the MCDA approach that is situated within the larger paradigm of CDA/CDS. I chose this approach because CDS/CDA is not only a paradigm rooted in real-world transformation, but its critical discursive and ideological lens offers a unique ability to address complex social issues rooted in power—a theme central to the territory dispute regarding spirituality in medicine noted in the previous chapter. CDA/CDS is an appropriate methodology for my research as it provides a discursive lens that can socially examine discourses and ideologies relating to spirituality in ACP that may impact one's opportunities for spiritual reflection in end-of-life circumstances.

CDA/CDS enables research to move beyond just textual description of spirituality in ACP resources, to the broader ideas—discourses—hidden in language. Through this process CDA/CDS enables an exploration of potential ideological commitments that may be imposed on individuals that reveal how spirituality is situated from a social lens. Merely descriptive approaches do not hold the same transformative potential to critically analyze dynamics of power in medicine—a lens that is needed to explore the conflicted territory of spirituality in medicine that has been noted by many theorists (Sulmasy, 2006; Pellegrino & D'Arcy, 2011; Balboni & Balboni, 2019; and Sommerville, 2000). A CDA/CDS approach enables a deeper and fuller understanding of how spirituality is situated based not only on the complexities of language and diverse understandings of spirituality but also with the potential to analyze these intricate social dynamics of power interwoven in ACP resources that contribute to how spirituality is situated.

Additionally, I utilized CDA/CDS for its ability to address complex social relationships through discourse, including how knowledge is socially structured through discourse and language (Machin & Mayr, 2023). Considering again the territory dispute implicit in medical culture's relationship with spirituality, a discursive examination drawing on "versions of events" (p. 26) that Machin and Mayr (2023) describe helps to bring a discursive lens to spirituality. This allows potential perspectives regarding the possible "versions of spirituality" or "versions of death and values" that the ACPO website resources present. And here I observe many questions arising that a discursive approach can help answer. Is there an openness or closedness to spirituality in how spirituality is situated? What version of value reflection is being offered? What version of death and end-of-life choices are offered? And what does this suggest about how spirituality is situated? Considering the constitutive power in resources to shape a version of the world for readers, CDA/CDS opens a tremendous opportunity to evaluate struggles of power

and ideology that might shape ACP resources. By analyzing the hidden, naturalized, and buried nature of power in discursive scripts, and critically teasing out traces of ideology in discourses, I am deepening an examination of spirituality and how it is situated while taking into account both the complex notion of spirituality as well as the complexity of power dynamics prevalent in medical culture and their lack of inclusion of spirituality within practice.

But why specifically the MCDA approach? With the rapid and dynamic increase in modes of communication over the past century, van Leeuwen and Kress (2009) suggest "discourse can no longer be adequately studied without paying attention to non-verbal aspects" (p. 108). I agree with this assessment. This trend has only intensified with the advent of social media and multimodal platforms. A multimodal approach is non-negotiable in analyzing websites like the one I will examine in connection with ACP. Further, as Machin and Mayr (2023) note, language choices do not exist in isolation but are embedded in many modes of communication like diagrams, charts, and design. As a result, both the modes themselves and how they interact together need examination. It is more than just typed text on a page that needs analysis on the ACPO website but a larger analysis of layout, bullet points, design, colours, and photos alongside videos. Simply put, an examination of all of these modes together is needed to get the fullest picture regarding how spirituality is situated. Any examination addressing textual exploration alone would be incomplete. Additionally, MCDA also provides an established collection of tools for inquiry that allow for a systematic and thorough analysis of discourses and ideologies hidden in resources—hints that will help assemble a discourse to gain a clearer picture of how spirituality is situated. This critical perspective in MCDA inspires more than descriptive knowledge but provides opportunity for potentially transformative findings that can impact real-world change to ACP resources to help those making decisions regarding future care.

I will note here that other approaches within the paradigm of CDA/CDS were considered for this research but none of them offered this kind of potential to critically examine a website featuring multimodal aspects including text, video, and design. As noted above, Catalano & Waugh (2020) outline the main methodological approaches that have surfaced in the past few decades including: the Dialectical-Relational Approach; the Sociocognitive Approach; the Discourse-Historical Approach; and Corpus Linguistic Approaches. Very briefly, these approaches were dismissed for various reasons. The Dialectical-Relational Approach was less aligned because of its more "radical" perspectives (Fairclough, 2015) with a strongly neoliberal focus and capitalist critique. And while one could make an argument for this approach in ACP and the culture of medicine, it was not a central ideological theme arising in the literature. The Corpus Linguistic Approach too was not aligned because of the lack of ability to assess the nuances of more interpretive multimodal resources with its focus on computerized analysis. The Sociocognitive Approach, while extremely important in analyzing the individual cognitive element of meaning-making, was outside the scope of this theoretically oriented study that focuses on language itself and content-producer, but not the "reception of the text" (Fairclough, 2003, p. 10) that may be an opportunity for future study. And finally, while the Discourse-Historical Approach is robust in its methodology, the focus is more historical in regard to discourse (Catalano & Waugh, 2020) which was on the periphery of this study and not immediately relevant to my focus on spirituality and the culture of medicine in the context of bioethics. Hence, I chose to utilize MCDA with its potential to adequately assess multiple modes within resources with a critical lens while engaging in discursive themes involving power.

Finally, while an ethnographic approach to this topic was considered, I echo Machin and Mayr's (2023) suggestion that the complex social forms involving discourse and ideology make

this approach challenging. The theoretical complexity in the first stage of theoretical analysis like I am offering in this dissertation would make ethnography difficult. These philosophical and social underpinnings first require critical theoretical treatment before a possible phase two could emerge that might involve an ethnographic component. The strength of the CDA/CDS paradigm is in its critical take on social structures that requires a strong theoretical viewpoint that explores meaning potentials within discourse to reveal ideology. Considering the language of medicine, and the deeply ingrained philosophical and epistemological notions I have outlined within a sort of theoretical territory dispute, a critical treatment of the concrete ACP resources themselves is necessary as a first step in positioning spirituality in current resources from a discursive lens. This approach would not only address the research gap existing with ACP and spirituality, but it could provide a potential next step in a future phase of research to test these discoveries for potential follow-up through other methodologies.

With a rationale provided for my methodological approach of MCDA established, including its transformative potential to critically address the complexity of spirituality and the implicit power dynamics within the culture of medicine through discourse and ideology, I move to the next section of this chapter. In this next section I focus on several key theoretical concepts underpinning the paradigm of CDA/CDS and the MCDA approach I will apply to my research.

3.3 Theoretical Concepts Underpinning CDA/CDS and MCDA

In the section above I provided a broader understanding of the overarching paradigm of CDA/CDS and the MCDA approach I will use that emerged from this paradigm. Before outlining the methodology I will apply to examine spirituality in Ontario resources, there are some key theoretical concepts requiring articulation to increase theoretical clarity. While the paradigm of CDA/CDS is expressed in many methodological approaches like that of MCDA,

there exist a number of key theoretical concepts that underpin most of these approaches. Articulating the nuances of these key theoretical concepts and their meaning in the context of MCDA is essential for me to establish before outlining my practical methodological approach later in this section. Below I outline five key theoretical concepts underpinning CDA/CDS and MCDA including discourse, power, ideology, the critical perspective of this approach, and finally the centrality of the social domain. After laying this broader groundwork with these five concepts, I will move to the next section that outlines the practical methodological approach I used by employing MCDA to ACP resources to examine the "black box" of spirituality within these resources to deepen understanding of how spirituality is situated in Ontario ACP resources.

3.3.1 Discourse

I begin this outline of theoretical concepts underpinning the methodology I used by outlining the key concept of discourse. Before articulating the approach to discourse within the MCDA paradigm I am taking in this thesis, it will be beneficial to provide some historical background to discourse to help contrast varying theoretical uses and nuances. I begin this section with some background to discourse before moving to the social turn in discourse that frames this thesis. I follow this by exploring definitions of discourse with a focus on understandings within CDA/CDS before offering the approach I apply within MCDA. I close this section by describing how discourses operate. I begin with a historical view.

Historic Views of Discourse. As the name suggests, central to CDA/CDS is the concept of discourse[142] that can be an unwieldy term meaning many things across disciplines. Mills

[142] I note here that the use of the word "discourse" or the plural "discourses" can vary. Flowerdew and Richardson (2018) suggest discourse can be used as a non-count noun in the general sense, or a count noun for specific discourses, giving examples like racist discourse or anti-immigration discourse. Both count and non-count uses will be utilized in this dissertation depending on context and reference to various theorists.

(2004) observed that discourse is often left undefined by theorists, noting it "cannot be pinned down to one meaning, since it has had a complex history and it is used in a range of different ways to different theorists, and sometimes even by the same theorist" (p. 6).[143] Wodak (2008) notes the use of discourse across disciplines ranging from historical monuments to political strategy, to broad or narrow meanings in language. Mills (2004) also outlines some of the meanings of discourse across history, including medieval use as simply one holding a conversation, as well as use in formal professional dialogue around discipline-specific topics like legal discourse or advertising discourse. In addition to these references, other meanings of discourse in linguistics include "analysis of the text above the level of the utterance or sentence" (Mills, 2004, p. 8) or "extended samples of either spoken or written language" (Fairclough, 1992, p. 3) as well as the British use of discourse as a synonym for "authentic, everyday linguistic communication" (Wodak, 2008, p. 5). But in the latter half of the 20th century, traditional uses would be extended in the social sciences (Mills, 2004). This discursive turn I explore next.

The Social Turn in Discourse. In addition to the historic linguistic meanings mentioned above, other understandings of discourse began to emerge in the social sciences with "a new set of more theoretical meanings" (Mills, 2004, p. 2) arising from the field of cultural theory—meanings that incorporated both linguistic and cultural aspects (Wodak, 2008). Foucault[144] was one prominent theorist who helped popularize the theoretical use of discourses,[145] using the word

[143] An example of this diversity of definitions is Foucault who provided some 23 definitions of discourse according to Wodak's (2014) referencing of the work of Reisigl (2004).
[144] I note here that while Foucault's work with discourse is often closely associated with CDA/CDS, it is important to acknowledge that Foucault is only one of many theorists involved. Mills (2004) draws on the work of Macdonnell (1986) to outline the discursive work of others in the field of cultural theory that include Althusser, Volosinov, Hindes, and Bakhtin—theorists whose work intersected with Foucault. They broadly outline the significance of all these thinkers in their summary of the focus being "the institutional nature of discourse and its situatedness in the social" (Mills, 2004, p. 9). A fuller treatment of the development of discourse is not in the scope of this thesis.
[145] I note here that van Leeuwen (2005) is keen to note the plural "discourses" in describing Foucault's approach, aligning with the view that there are "different ways of making sense of the same aspect of reality, which include and exclude different things, and serve different interests" (p. 95).

to suggest "different ways of structuring areas of knowledge and social practice" (Fairclough, 1992, p. 3). For example, Foucault utilized discourses to outline the history of sexuality using the description of "a whole web of discourses" (Foucault, 1976/1990, p. 26) that emerged in constructing sexual discourses in society. Mills (2004) summarizes Foucault's approach to discourse in suggesting "the only way we have to apprehend reality is through discourse and discursive structures. In the process of apprehending, we categorize and interpret experience and events according to the structures available to us" (p. 49). Mills continues by suggesting "we lend these structures a solidity which it is often difficult to think outside of" (p. 49). And while Foucault is critiqued[146] for being overly theoretical in their approach to discourse, and for using structures that lacked real world integration, Fairclough (1992) suggests two of Foucault's concepts being particularly helpful in the work of discourse analysis: first, "the constitutive nature of discourse" (p. 55) and secondly "the primacy of interdiscursivity and intertextuality" (p. 55).[147] The constitutive nature of discourse suggests the ability for discourse to create the social domain, while interdiscursivity and intertextuality reflect the complex relational qualities of discourse that influence the social (Fairclough, 1992). Discourse analysis would be built on the work of Foucault (van Leeuwen, 2016) in what Fairclough (1992) suggests as providing "a rich set of theoretical claims and hypotheses to try to incorporate and operationalize" (p. 56).[148] Operationalizing this markedly social understanding of discourse in CDA/CDS would eventually extend to an emerging focus on language in theory, helping usher in a "linguistic turn"

[146]Fairclough (1992) suggests discourse analysis "should include actual instances of discourse" (p. 56) that will form the basis of textual focus in CDA and the analysis of real texts.
[147]Wodak (2008) notes intertextuality "refers to the fact that all texts are linked to other texts, both in the past and in the present" (p. 3) and interdiscursivity as being discourses "linked to each other in various ways" (p. 3).
[148] I note here that while other critical theorists are noted by Wodak (2008) including Habermas, Mouffe, and Laclau, it is the work of Foucault that is most influential. A broader exploration of these theorists is outside the scope of this interdisciplinary dissertation.

(Fairclough, 1992, p. 2) in social science, integrating discourse, linguistics, and social practice. At this intersection CDA/CDS emerges.

Definitions of Discourse in CDA/CDS. Despite the theoretical concept of discourse being embedded in the very name of Critical *Discourse* Studies, there are nuanced understandings of the term in CDA/CDS based on the leanings of each theorist. In focusing on the differentiation of CDA/CDS from text linguistics for instance, Wodak and Meyer (2016) note van Dijk's (1990) definition of discourse being simply "*text in context*" (p. 5, italics theirs) while Fairclough's (2001) early articulation of discourse focuses on social practices, viewing discourse simply as "language as a form of social practice" (p. 16). Other notable definitions in CDA/CDS have included an organizational focus by Wodak and Meyer (2016) suggesting discourse as "relatively stable uses of language serving the organization and structuring of social life" (p. 6) while a simpler ideational definition inspired by Fairclough (2000); van Dijk (1993); and Wodak (2001) suggests discourse as "the broader ideas communicated by a text" (Machin & Mayr, 2023, p. 26). Stemming from this understanding, it is Machin and Mayr's (2023) MCDA approach to discourse that provides my working definition because of its critical focus as well as ability to engage the integrative and multimodal aspects of contemporary resources like the ACPO website. Machin and Mayr contextualize their definition by suggesting: "The versions of events created in language… can overtly or covertly encourage us to place events and ideas into broader frameworks of interpretation…these broader frameworks are referred to as 'discourses'" (p. 26). Congruent with the MCDA approach, I will utilize their definition of discourse in this thesis as being these "broader frameworks of interpretation" (Machin & Mayr, 2023, p. 26).

The Operation of Discourses. Having provided a definition of discourse as being broader frameworks of interpretation (Machin & Mayr, 2023), another question arises in terms of

how discourses operate. And with this it is important to link discourse to the notion of meaning-making. As Blommaert (2005) suggests, "we have to use discourse to render meaningful every aspect of our social, cultural, political environment…In short, discourse is what transforms our environment into a socially and culturally meaningful one" (p. 4). But a question arises here regarding *what* meaning is being created and also by *who*? Here one can see the potential for what Wodak (2020) suggests as a "fragile and contested" (p. xxiii) world of meaning where a kind of mediation of meaning happens in social settings based on these broader discursive frameworks that guide interpretation. And contributing to the fragility of meaning-making for discourse participants is the presence of multiple pressures found in society.

Mills (2004) summarizes Foucault's view of these societal pressures, suggesting "there is a combined force of institutional and cultural pressure, together with the intrinsic structure of discourse, which leads us to interpret the real through preconceived discursive structures" (p. 49). And to complicate this fragile construction of meaning further is that discourses—these broader frameworks of interpretation—do not exist in isolation. Kress and van Leeuwen (2001) allude to the existence of "multiple and integrated discourses" (p. 36) in themes as simple as kitchen designs or child-rearing. Mills (2004) also observes a dynamic plurality within discourses, remarking "discourses do not exist in a vacuum but are in constant conflict with other discourses and other social practices which inform them over questions of truth and authority" (p. 17). Catalano and Waugh (2020) reference a quote by Kress et al. (1989) that articulates a similar notion of conflict, suggesting discourses "do not exist in isolation but within a larger system of sometimes opposing, contradictory, contending, or merely different discourses" (Kress

et al., 1989, p. 10, as cited in Catalano & Waugh, 2020, p. 43).[149] Gee (2014) suggests discourses carry social identities and when people interact, several discourses interact socially, informed by historic and longer running social conversations. With all these competing "broader frameworks of interpretation" (Machin & Mayr, 2023, p. 26) at play in our social lives, one can begin to see challenges brewing when observing the potential for discursive tumult and the difficulty of participants navigating this pressurized discursive environment.[150] Translated to ACP resources and spirituality's inclusion in medicine, one can see potential for competing discourses and implicit struggle that leads to another aspect of discourse—their very construction.

Constructing Discourses. Considering both the discursive conflicts and societal pressures noted above, one can see the high stakes involved within discourses—including the potential for constructing or constituting the social (Fairclough, 1992). With the possibility of one having opportunity to create the social environment, a question arises from Kress and van Leeuwen (2001), namely —who gets to choose what discourses are "in play" (p. 30) at any time and place? It is at this point where themes of power and influence enter the conversation with questions regarding who might decide what might be discursively foregrounded in a given communication or which discourses might rise above? As van Leeuwen (2005) suggests, an aspect of reality is being created by a producer where discourses are "developed in specific contexts, and in ways which are appropriate to the interests of social actors in these contexts" (p. 94). Linked to the interests of a text producer, Kress and van Leeuwen (2001) suggest "Discourses not only provide versions of who does what, when and where, they add evaluations,

[149] Examples of this conflict of discourses includes the clash of medical science discourses versus alternative medicine discourses (Fairclough, 1992); opposing discourses regarding the treatment of migrant workers (Machin and Mayr, 2023); or discourses of mothering practices presented in media (Kress, 2001).
[150] This description calls to mind Taylor's (2007) concept of cross-pressure that suggests the blowing winds of ideas and a similar sympathetic tone towards individuals caught in this struggle for meaning-making.

interpretations and arguments to these versions" (p. 15). Language choices become significant in contexts like health care where discourses like those present in ACP resources may be value-laden or "ideologically significant" (Machin & Mayr, 2023, p. 23) with potential to impose a certain discourse that impacts decision-making. And here, with an understanding of discourse established, I address another key theoretical concept in CDA/CDS—the notion of power.

3.3.2 Power

The Broader Notion of Power. Interwoven with discourse in CDA/CDS is the role of power, a term noted by Wodak and Meyer (2016) as "one of the most central—and contentious—concepts in the social sciences" (p. 9). In this section I will provide a brief overview of power in the social sciences before outlining its situatedness within CDA/CDS. A starting place for this conversation regarding power is Wodak and Meyer's (2016) summary of Weber's (1980) understanding of power as being "the chance that an individual in a social relationship can achieve his or her own will even against the resistance of others" (p. 10). Wodak and Meyer (2016) continue by organizing Weber's thoughts together with other theorists[151] in outlining two significant aspects of power—the source of power, and the results of power. Continuing, Wodak and Meyer suggest sources of power fall into three expressions: resources, social exchange, and the "invisible systemic" (p. 10) which can be understood as power manifesting itself with individuals holding power as the result of their own specific resources; power being implicit within the social exchange; and thirdly, the acknowledgement of invisible systems of power that constitute society. In addition to these three *sources* of power, Wodak and Meyer turn to the *results* of power by drawing on the work of Lukes (1974) to suggest three

[151] In Wodak and Meyer's (2016) summary of power they refer to numerous influential theorists including French and Raven (1959); Blau (1964); Emerson (1962, 1975); Foucault (1975); Giddens (1984); and Luhmann (1975). I name these for reference purposes but a deeper dive into the notion of power is outside the scope of this dissertation.

dimensions of results: an overt power manifest in conflict around decisions; a covert power that alludes to an aspect of influence and control regardless of detractors, and a power that can shape one's beliefs. While both sources and results of power may be present in society and important in research, it is the covert and invisible aspects of power and influence that are of interest to CDA/CDS including the hiddenness of ideology that will emerge later in this section as I begin to unpack power interests in ACP resources. I turn now to relationships of power within society.

Power and Society. Extending these notions of power into social settings, the conversation leads to Foucault's suggestion of the pervasiveness of power in society. Flowerdew and Richardson (2018), inspired by Foucault (1984), suggest that for CDS, power is "ubiquitous in society, and elites may maintain control through their exercise of power" (pp. 4 - 5). And while power is often linked to elites and potentially larger political narratives of power, Eagleton, (2007), also drawing on Foucault (1977), suggests that rather than power taking extreme forms, there is an all-encompassing prevalence of power in society where "power is not something confined to armies and parliaments: it is rather, a pervasive, intangible network of force which weaves itself into our slightest gestures and most intimate utterances" (p. 7). This "intangible network" of power is the kind of power that is woven into ACP resources for example, a power that potentially subtly influences in end-of-life situations inspired by the high stakes of death. There is a sense of a dynamic and inextricably woven presence of power present in social interactions influencing multiple dimensions in society. And in the context of ACP, the question arises—what hidden aspects of power may be embedded socially on the ACPO website?

Power and CDA/CDS. Central to CDA/CDS is the relationship between power and discourse as noted by Machin and Mayr (2023) who observe that "The question of power has been at the core of the CDA project" (p. 36). Noting the high stakes involved in power to

influence and define reality, Ledin and Machin (2018), drawing on Richardson (2006), suggest the focus of CDA reveals power "as site of social struggle—a struggle for the definition of reality" (28). These struggles situated within the social domain boil down to some important questions including—who has the power to define reality? And—how is power operationalized? Extending this once again to ACP resources, the question arises—how are ACP content-producers defining reality for Ontarians? How are they presenting spirituality and interwoven themes of values and death that may inspire one's decisions? What world of ACP are they constituting for diverse individuals facing high stakes decisions involving death? It is this inquiry that brings the conversation regarding power into the realm of language and discourse. Wodak and Meyer (2016) conclude that "power and domination are embedded in and conveyed in discourses" (p. 11) which inspires a return to the question of who might control the discursive frameworks of interpretation in society? And in the context of ACP resources regarding the situatedness of spirituality, the dialogue involves the question—what discourses inform this situatedness? And more, what ideologies might underpin these discourses within ACP resources? And in addition to the prevalence of power and control of these discursive conversations, the aspect of struggle is also very important. Fairclough (1992), quoting Foucault (1984), suggests: "Discourse is not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle, discourse is the power which is to be seized" (Foucault, 1984, p. 110, as cited in Fairclough, 1992, p. 51). Hence, the struggle is for control of discourse and how one might keep this power—a theme I address next.

Maintaining Power. Considering this interwoven presence of power exercised in discourse, another theme arising in CDA/CDS is the keeping and utilization of this power. Fairclough (2001) outlines coercion and consent as being two ways one keeps and exercises

power: “through coercing others to go along with them, with the ultimate sanctions of physical violence or death; or though winning others’ consent to, or at least acquiescence in, their possession and exercise of power” (pp. 27 - 28). It is this second understanding that is central to CDA/CDS with its more subtle persuasive aspects of power found in discourse and language that will be explored in the examination of spirituality within ACP resources ahead—and the potential for those in power to influence or coerce regarding what might be appropriate for end-of-life decisions. But it is worth emphasizing that it is the negotiation of power that becomes challenging and what can be seen as the centre of struggle, as Fairclough (2001) notes: “Power relations are always relations of *struggle*” (p. 28, italics theirs). And the site of struggle is a social one, situated within language as Machin and Mayr (2023) suggest: “The point is that power, at least in democratic societies, needs to be seen as legitimate by people in order to be accepted, and this process of legitimation is generally expressed through language and other communicative systems” (p. 37). Emerging here in CDA/CDS theory is Gramsci’s concept of hegemony, described by Machin and Mayr (2023) as a phenomenon where “dominant groups in society succeed in persuading subordinate groups to accept the former’s own moral, political and cultural values and institutions” (p. 37). Machin and Mayr continue in describing this kind of persuasion happening through discourse, suggesting, “discourse constructs hegemonic attitudes, opinions and beliefs…in such a way as to make them appear ‘natural’ and ‘common sense’, while in fact they may be ideological” (p. 37). Similarly, Hodge and Kress (1993) note: “Language is an instrument of control as well as communication…In this way hearers can be both manipulated and informed” (p. 6). Here, one can begin to see the importance of language in this negotiation of power and the presence of ideology emerging within discourse. Within the context of ACP resources, language plays a key role in these resources by naturalizing and

creating a common sense in regard to end-of-life decisions and the position of spirituality within this—common sense as defined by the interests of the content-producers. I will address the central theoretical concept of ideology next.

3.3.3 Ideology

While the concept of ideology is very important to CDA/CDS, a definition has proven very difficult to pin down. In addition to Blommaert's (2005) suggestion that "Few terms are as badly served by scholarship as the term ideology" (p. 158), Eagleton (2007) lists 16 different definitions which are not necessarily compatible inspiring the conclusion that "Nobody has yet come up with a single adequate definition of ideology" (p. 1). Regardless, in acknowledging the long history and many uses, Hodge (2017) playfully uses the metaphor of a genie for ideology, concluding "it is too late to put the genie back in the bottle" and that despite its elusiveness semantically, "this 150-year old genie still does magic" (p. 168). This "magical" ideological lens can provide a helpful theoretical approach to examining complex relationships of power in social settings that has become core to CDA/CDS, as Machin and Mayr (2023) suggest: "The aim of CDA is to reveal ideologies, showing how and where they might be buried in texts" (p. 38). But here lies a potential tension for the researcher. Considering a key aim of CDA/CDS is to reveal ideologies—how does one navigate the disagreement of definitions for this key notion underpinning CDA/CDS aims? In the paragraphs to follow I will provide a brief overview of the scope of the conversation regarding ideology before clarifying the direction I take with MCDA.

Origins of Ideology. Ideology is a concept that has evolved over more than two centuries. The term "ideology" was coined in 1790 by Destutt de Tracy, a French aristocrat studying moral and political science who sought to ambitiously examine "the process through which human beings interact with their material surroundings" (Hawkes, 2003, p. 60) while

tracing ideas "to their roots in matter" (p. 60). Originally supported by Napoleon Bonaparte, de Tracy's ideological approaches were soon dismissed as "unrealistic theories" that led to "unwarranted interference of philosophical theory in political practices" (Strath, 2013, p. 6). Strath shares that the term continued to have a life, eventually extending into the writings of Marx and Engels in the 1840s who understood ideology as "the instrument of the ruling classes" (p. 8) that instilled false beliefs while disguising reality. By the early 1900s, the term had evolved further, transcending narrow associations with Marxism "to become a general and rather value-neutral term in philosophy and sociology…infused through amendments like socialist, liberal, conservative, nationalistic, false, and right" (p. 10). But it was from 1914 – 1989 when approaches to ideology intensified politically. Noted by some as "the age of ideologies" (p. 17) this time was marked by extremes that included force and terror together with tumultuous political dynamics playing out in global conflicts including World War II and the Cold War. It was in response to these global events that Critical Theorists[152] like Adorno theorized ideology merging with reality in a powerful way "as the force that shapes society and reality" (p. 12) requiring a critical perspective.[153] By the late 20th and 21st century, a shift to a pluralistic view of ideology occurred, including themes of neoliberalism, racism, modernity, globalization, freedom, solidarity, citizenship, and religion (Strath, 2013). It is here that I insert ideology into CDA/CDS.

Situating Ideology in CDA/CDS. Amidst this complex background emerges the CDA/CDS paradigm that holds ideology as being pivotal to engaging in discourse analysis. But

[152] I will briefly address Critical Theory in the section below focusing on the critical aspects of CDA/CDS. But I note here that Sherratt (2006) suggests that while "Critical Theory" is "used very loosely" (p. 175) to include a broad swath of critical thinkers they remind the reader the term does refer to a specific tradition coined by Horkheimer and expanded outward in the social sciences (p. 177). I will use "Critical Theory" when addressing this formal movement and lowercase when referring to a broader sense of the critical in theory.

[153] It is noteworthy that Critical Theory, as I will discuss in a section ahead, intersected with World War II and analysis on: "how and why Nazism had arisen in a developed, supposedly civilized society" (Sherratt, 2006, p. 176). Critical theorizing allowed them to analyze this through interrogating cultural aspects of knowledge (Sherratt, 2006). The influence of critical inquiry continues in CDA/CDS as to be discussed ahead in focusing on critical aspects.

what might ideology mean in the context of CDA/CDS? Wodak and Meyer (2016) name the tension in utilizing the concept ideology with its historically "bad" (p. 8) categorical connotations including totalitarianism, fascism, communism, and even capitalism. Referencing Knight (2006), Wodak and Meyer (2016) acknowledge the difficulty in freeing ideology from negative understandings, iterating the interest of CDA/CDS being "not that explicit type of ideology…it is rather the more hidden and latent inherent in everyday-beliefs, which often appear disguised as conceptual metaphors and analogies" (p. 8) and "the functioning of ideologies in everyday life" (p. 9). I appreciate Freeden's (2013) call for examining "roughly identifiable patterns" (p. 127) that are less about recognizable political patterns, but more on the hidden general ideologies reflected by the powerful. This approach allows for a broader understanding of ideology and its influence beyond global political systems. Aligning with this broader understanding of ideology, yet still linked with power relationships, Machin and Mayr (2023) provide a simple articulation of ideology for MCDA that I will use in this dissertation as being "an overall world view that reflects the interests of the powerful in society" (p. 37). This definition enables analysis of ACP resources with an eye to territory disputes I have mentioned regarding bioethics and spirituality, namely, that spirituality has been largely neglected by mainstream medicine in the West characterized by a medical culture focusing on physical aspects of care. With a definition of ideology established for this thesis, I will now briefly outline several qualities of ideology before articulating the relationship between discourse and ideology.

Characteristics of Ideology. Drawing from broader social and critical traditions, some qualities of ideology have emerged in the literature that are helpful in the context of CDA/CDS and my analysis of ACP resources in Ontario. One characteristic linked with ideology is its hiddenness. Hodge and Kress (1993) suggest ideologies "are not normally fully declared in a

given text, but if they are effective in a text they will normally leave their traces" (p. 210). Fairclough (2001) suggests a similar notion in saying "Texts do not typically spout ideology" (p. 71) while Eagleton (2007) notes ideology as being "always most effective when invisible" (p. xvii). Machin and Mayr (2023) also talk about how ideology "might be buried in texts" (p. 38) and it is this hiddenness that requires some detective work to discover what world view or value system of the powerful might be buried in a resource. In my examination of ACP resources in Ontario I will be seeking to examine these hidden and invisible traces of ideology that might reveal how spirituality is situated more broadly and with any subtle leanings that may influence individuals in how they carry about their value-based reflection.

In addition to a hidden nature, Eagleton (2007) suggests "Successful ideologies are often thought to render beliefs natural and self-evident—to identify them with the 'common sense' of a society so that nobody could imagine how they might ever be different" (p. 58). As Fairclough (2001) suggests, "There is a constant endeavor on the part of those who have power to try to impose an ideological common sense which holds for everyone" (p. 71). This common sense normalizes assumptions of social behaviours and suggests to individuals what might be broadly appropriate in a given situation. Intersecting with the notion of common sense is that of naturalization. Fairclough (2003) suggests "Naturalization is the royal road to common sense. Ideologies come to be ideological common sense to the extent that the discourse types which embody them become naturalized" (Fairclough, 2001, p. 76). In my examination of ACP resources, I will be seeking to explore how the treatment of spirituality and interwoven concepts of values and death in resources may reveal an overarching common sense that imposes a certain suggestion for individuals to follow in making decisions involving death. It is my hypothesis that ACP resources in Ontario favour a certain epistemology regarding spirituality, death, and values

that is imposed by medical culture, and is not necessarily privileging patient-centred reflection that may impact autonomy and one's fullest decision-making for the future. Having outlined discourse above, and now ideology, I move next to the relation between these two terms.

Relationship Between Ideology and Discourse. Before moving on to the next section focusing on the "critical" quality of CDA/CDS, some clarification is needed in differentiating the notions of ideology and discourse that I have addressed thus far. Named by Chouliaraki and Fairclough (1999) as a theoretical problem, the relationship between discourse and ideology takes different approaches in research. While Eagleton (2007) suggests that Foucault would choose to abandon ideology altogether in favour of discourse, Freeden (2003) sees the value of both and makes a distinction between discourse and ideology by suggesting "discourses are the communicative practices through which ideology is exercised" (p. 105). Fairclough (2001) expresses a similar notion, suggesting "discourse is the favoured vehicle of ideology" (p. 30) and that discourse can "embody ideological assumptions" and that ideology becomes "embedded in features in discourse which are taken for granted as matters of common sense" (p. 64). Hence, with this nuanced relationship, there is a sort of teasing out of the ideological that needs to happen within discourses. It is this approach—where discourses reveal ideologies—that I take in my research in alignment with MCDA that necessitates analysis of both discourse and ideology that I outline in a section ahead on methods. Having explored the concepts of discourse, power, and ideology, I arrive at a fourth key concept underpinning CDA/CDS—a critical perspective.

3.3.4 A Critical Perspective

Embedded in the very name of CDA/CDS is the word "critical". In this section I will briefly distinguish descriptive approaches that serve to simply describe, from a critical perspective, that seeks transformation and change. I will then outline some of the origins of the

critical perspective I will be using and how it is integrated broadly into CDA/CDS. To begin, I note the observation of Gee (2014) who suggests that some discourse analysis aims to "describe how language works in order to understand it, just as the goal of the physicist is to describe how the physical world works in order to understand it" (p. 9). They note that while these approaches may have some real-world application, they are "not motivated by those applications" (p. 9), rather, any real-world application is almost like a secondary by-product. It is this explicit motivation to problem-solve that makes a critical perspective in CDA/CDS so important—CDA/CDS is actively seeking change. Extended to examining spirituality in ACP resources, I am not seeking to simply describe spirituality's current situatedness, but rather, I am seeking transformation to fully realize the potential of spirituality in ACP reflection and decision-making. As Gee (2014) puts it, a critical perspective seeks to "speak to and, perhaps, intervene in, institutional, social, or political issues, problems and controversies in the world" (p. 9). Gee goes as far as to say that "all discourse analysis needs to be critical, not because of discourse analysts are or need to be political, but because language itself is…political" (p. 9). Simply put—the critical motivation for social change is at the root of CDA/CDS with a goal of transformation. But before outlining how this critical perspective is integrated, it is worth briefly outlining where this critical spirit emerges from historically and it provides a transformative lens to ACP.

Background to Critical Perspectives. While the field of philosophy has a long tradition of being critical, including ancient philosophers utilizing Socratic thinking that included "internal questioning" (Sherratt, 2006, p. 179), Wodak and Meyer (2016) suggest the critical motivation in CDA/CDS has a theoretical lineage that emerges from three main sources: literary criticism, Marxist theory and Critical Theory. It is this third source, that of Critical Theory, that is most relevant to my dissertation because of its theoretical connections to van Leeuwen's Social

Semiotic approach (Catalano & Waugh, 2020) that grounds the MCDA methodological approach that I will apply to ACP resources. Critical Theory emerged out of the Frankfurt School, an interdisciplinary group of academics rooted in ancient philosophy and German philosophical traditions focused on critical thinking and rational thought while being influenced in diverse directions regarding aspects of Marxism (Bronner, 2017). But as Bronner suggests, the Frankfurt School's approach to Marxism was different, among other things in that, "They highlighted its critical method over its systematic claims" along with "its emphasis upon the role of ideology" (p. 2). It is this focus on ideology that will influence the paradigm of CDA/CDS and the MCDA approach in exploring how ideologies might be buried in texts (Machin & Mayr, 2023) like those of ACP resources that will be my research focus. Wodak and Meyer (2016) specifically note the importance of Horkheimer's work in suggesting, "social theory should be oriented toward critiquing and changing society as a whole, in contrast to traditional theory oriented solely to understanding or explaining it" (p. 6). This transformative aim, beyond just description, aligns with the aim of my research in analyzing spirituality in ACP resources. Bronner (2017) elaborates on this critical perspective of unearthing what is buried, suggesting Critical Theory "questions the hidden assumptions and purposes of competing theories and existing forms of practice" (p. 1) while utilizing "withering interrogation" (p. 3) to "cast new suspicions on universal claims, philosophical foundations, and the fixed narrative" (p. 6). Eventually extending to CDA/CDS more formally, Wodak and Meyer (2016) articulate the critical perspective moving its way into language studies slowly under the banner "Critical Linguistics" inspired by the work of Fowler et al. (1979) and Kress and Hodge (1979) with a key tenet being "the use of language could lead to mystification of social events which systematic analysis could elucidate" (p. 7).

This critical perspective is embedded in the paradigm of CDA/CDS and the MCDA approach I will utilize in interrogating ACP resources and what they reveal about spirituality's situatedness.

A Critical Perspective in CDA/CDS and MCDA. Next, I articulate what a critical perspective might look like in the paradigm of CDA/CDS and the MCDA approach. Wodak and Meyer (2016) emphasize an attitude of critical interrogation being central to all CDA/CDS, quoting van Dijk's (2013) description of what it means to be critical in discourse analysis: "Being critical, first of all, is a state of mind, an attitude, a way of dissenting" (p. 3). But it is important to note here that a critical perspective within CDA/CDS is rooted in a positive wish for change and transformation in society inspired by a set of values. Flowerdew and Richardson (2018) suggest approaches to being critical in CDA/CDS need "to be based upon sound ethical values, such as democracy, honesty, integrity, transparency, accountability, objectivity, respect for others, lawfulness and loyalty to others" (p. 5). This is the transformative potential of a critical perspective that grounds CDA/CDS and how I endeavor to carry out my work as well. But how is a critical perspective carried out in research? And specifically, how is it utilized in my work in examining the "black box" of spirituality in ACP resources? Machin and Mayr (2023) focus the meaning of engaging with a critical perspective within MCDA, suggesting, "The term 'critical'…does not so much meaning 'criticising' than 'denaturalising' the language used in order to reveal the kinds of ideas, absences and taken-for-granted assumptions in texts. In this way we can draw out the power interests buried in these texts" (p. 9). They continue by suggesting that by "looking at the choices of language and grammar in texts in order to discover the wider discourses they carry" (p. 27) one can discover "what kind of world is being created in texts" (p. 36). But more, one can analyze the potential for discourses to be "infused with ideologies which define power relations and many forms of social organisation" (p. 45). This is

important to my work because ACP resources may be infused with ideologies that impact how spirituality is situated within reflection resources. In extending this examination of the world being created by texts to ACP resources in my research, I seek to explore how a world relating to spirituality might be situated in ACP resources—beyond simple semantics to the complex and embedded taken-for-granted assumptions that may be imposed on individuals potentially impacting one's options for value reflection in ACP. But central to this critical examination is exploring the social context that I will explore next.

3.3.5 Social Aspects of Language

So far in this section that outlines the key theoretical concepts that underpin the paradigm of CDA/CDS, I have articulated the concepts of discourse, power, ideology, and in the last section the implicit critical perspective. The final theoretical concept I will outline that undergirds CDA/CDS is the social dimension and its interwoven relationship with language. Considering the importance of language in ACP and the navigating of Ontario resources, this domain is also central to my examination. Flowerdew and Richardson (2018) open their collection of essays on CDA/CDS by articulating the pervasive social presence in discourse intersecting with "social processes, social structures and social change" (p. 1). Noting the all-encompassing social aspect of discourse, Blommaert (2005) too suggests "There is no such thing as a 'non-social' use of discourse…What concerns us here is how discourse can become a site of meaningful social differences, of conflict and struggle" (p. 4). The centrality of the social domain in CDA/CDS is also expressed with Wodak and Meyer's (2016) reference in their definition to discourse as being the "organization and structuring of social life" (p. 6) and also Fairclough's (2001) definition of discourse noting "language as a form of social practice" (p. 16).

Concisely put, the social dimension is core to the notion of discourse. But more, there is an inextricable relationship between the social and that of language. Hodge and Kress (1993) describe language as a "social phenomenon" (p. 1) which is "an absolute precondition for nearly all of our social life" (p. 1) as well as describing it as "a key instrument in socialization, and the means whereby society forms and permeates the individual's consciousness" (Hodge & Kress, 1993, p. 1). Flowerdew and Richardson (2018) draw on Austin (1962) and Wittgenstein (1965) to note this extension of language into the social domain with a sense of action, suggesting, "language as always doing something" (p. 1) as it interacts and relates to social spheres like interpersonal relationships and institutions. Machin and Mayr (2023), as noted earlier in this chapter, outline the centrality of language by noting discourse as "versions of events created in language" (p. 26). It is here that the potential social ramifications of language emerge, along with notions of power that are embedded in chosen discourses to inspire versions of events. And again, the theme of power arises—who gets to produce language? And in terms of ACP resources for Ontarians, the question becomes—who chooses the language in the ACPO resources that may inspire different social ramifications and versions of events? Who might outline how death, values, and spirituality should be treated?

Social Agents Producing Texts. Fairclough (2003) introduces the profound influence of the language producer into the equation by simply suggesting "Social agents texture texts" (p. 22). Machin and Mayr (2023) suggest, "choices of words carry certain taken-for-granted assumptions which themselves suggest a set of ways of doing things" (p. 24). Hence, there is a lot at stake socially for the agent who engages in the social structuring of texts. They are helping shape actions through the offering of certain possibilities and assumptions represented through discourse (Fairclough, 2003). Taking this further into the realm of language and text, Machin and

Mayr (2023) draw on van Leeuwen (2008) to suggest the use of discursive scripts entering into language that "comprise elements such as participants, actions, settings, times, causalities, solutions, aims, priorities, evaluations and resolutions" (p. 30) and that these scripts are influential in presenting a worldview or ideology regarding a given situation. And while the language may not be explicit, when looking at a network of language in text and graphic, one can begin to "assemble the discourse" (p. 31) of what Machin and Mayr (2023) note as the primary question in MCDA: "what is *really* being communicated?" (p. 1, italics theirs). And it is the hidden and naturalized discourses that are sought after, in what Flowerdew and Richardson (2018) describe as the aim of CDS: "to make the implicit explicit in language use" (p. 1). My research focusing on language that informs how spirituality is situated within ACP resources will focus directly on what choices of words, images, and design help create a version of the world as it relates to spirituality, death, and values through discourse. And echoing Machin and Mayr (2023) above, I am asking—what is really being communicated regarding spirituality in ACP resources? And more than what is being communicated in language regarding spirituality's place in ACP—is there an aspect of control of this language that is needing to be addressed?

Language as Social Communication and Control. And once again, this exploration returns to the primary motivation of CDA/CDS that seeks more than just a descriptive analysis of language utilized in social life, but a critical one that seeks a deeper examination of language's potential power and control. Hodge & Kress (1993) observe that "Language is an instrument of control as well as of communication" (p. 6) while Fairclough (2001) takes this even further suggesting that language is "perhaps the primary medium of social control and power" (p. 2). Linking concepts of ideology and power with language, Fairclough notes the centrality of language in the simplest of terms: "Ideologies are closely linked to language, because using

language is the commonest form of social behavior, and the form of social behavior where we rely most on 'common-sense' assumptions" (p. 2). Echoing this same connection regarding the role of language in furthering ideology, Catalano and Waugh (2020) cite Kress and Hodge's (1979) suggestion that use of language "has society's ideological impress" (Fowler & Kress, 1979, p. 185, as cited in Catalano & Waugh, 2020, p. 36). And extending language to both texts and images, Machin and Mayr (2023), inspired by van Dijk (1993), suggest the goal of CDA as being "to reveal what kinds of social relations of power are present in texts both explicitly and implicitly" (p. 36) with the suggestion that "language is not simply a vehicle of communication or persuasion, but a means of social construction and domination" (p. 37). Linking this to ACP resources, the question in my research becomes—what approach to spirituality, and the interwoven notions of values and death, is being constructed by language in these resources? How is spirituality situated? These questions are important because of the diversity of spiritual beliefs that are important to many in making high stakes decisions surrounding death. If potential for engagement in spiritual aspects of their life is minimized, they may be unable to make decisions at end-of-life with the fullness of value reflection.

The Centrality of Social Practice. But probably the most important element relating to the social aspect of CDA/CDS is the notion of social practice and its relation to discourse. The notion of "practice" is outlined by Gee (2014, p. 5) as being the social conventions, rules, and activities where meaning is established. Hence, language gets its meaning from "practices they are used to enact" (p. 7). Ledin and Machin (2017) articulate social practices as including elements like "participants, ideas, values and attitudes; activities; social relations; objects and instruments; time and setting and causality" (p. 64). But what is the link from social practices to discourse? Fairclough (2003) suggests social practices "articulate discourse" (p. 25), while van

Leeuwen (2016) suggests “discourses are ultimately modelled on social practices” (p. 138) and that through recontextualization in resources “practices are turned into discourses” (p. 139). Hence, by inserting certain social practices of medical culture in resources like ACP, discourses are established that Machin and Mayr (2023), inspired by Fairclough (2000), suggest as projecting “certain social values and ideas” (p. 34). Social practices become recontextualized in alignment with discourses and then constitute life based on the ideologies of the powerful who are creating these resources. In this one can see the high stakes involved in the production of resources and the importance of a critical view in analyzing what discourses are being created and whose purposes they serve. In particular—how is spirituality situated in ACP resources and whose purposes are being met in regard to value-based decision-making?

After providing an understanding of the paradigm of CDA/CDS and MCDA approach that grounds my methodology, I outlined the key theoretical concepts that underpin my research—that of discourse, ideology, power, as well as the critical and social aspects of language. I now outline the MCDA methodological approach will utilize in my research.

3.4 The Methodological Approach to My Thesis

In the previous sections of this chapter I provided a theoretical overview of both the broader paradigm of CDA/CDS and the MCDA approach including some general strengths and limitations, as well as a rationale for choosing this direction in my research. I then articulated some key theoretical concepts underpinning these approaches including discourse, ideology, power, the critical perspective, and finally, the social dimension. Having established this theoretical foundation, I now move to outlining a specific methodological approach I employ in my research before ending the chapter by outlining the methods I utilize—including the MCDA tools of inquiry I will use inspired by Machin and Mayr (2023) and an articulation of how I

extend Braun & Clarke's (2022) reflexive thematic analysis (reflexive TA) method to coding and generating discursive and ideological themes. I begin with an introduction to the methodology.

3.4.1 Assumptions Underpinning the Methodological Approach

The MCDA methodological approach I apply is rooted in the paradigm of CDA/CDS that emerges from the soil of a transformative philosophical worldview (Creswell & Creswell, 2018) in seeking social change. Applied to ACP resources, I seek to help inspire opportunities for the integration of spirituality for individuals making high stakes value decisions involving ultimate themes like death and values to increase autonomy and the good of the patient in medical decisions. Utilizing a critical perspective through the MCDA approach, my research seeks to take a significant step towards my transformative goal by examining the current state of the "black box" of spirituality within Ontario ACP resources with an eye to discourses that may reveal assumptions, principles, and ideologies, demonstrating spirituality's inclusion or lack there-of. This MCDA approach aligns with the interdisciplinary focus of my program of study that aspires to solve complex real-world problems requiring a multidimensional approach (Repko & Szostak, 2021, p. 4). Considering the strongly social lens utilized in MCDA, the focus also leans towards a constructionist[154] worldview that suggests language both reflects and constitutes reality through the social creation of "versions of events" (Braun & Clarke, 2022, p. 165)—or in the case of this project focusing on ACP resources, the potential "versions" of how spirituality is situated in bioethical resources like an ACP website in Ontario. I stand with Fairclough's (2003) critical stance suggesting "texts have social, political, cognitive, moral and material consequences and effects" (p. 14) and that a discursive lens can help explore some of these

[154] I am aware of different approaches to constructionism, but I utilize it broadly as expressed by Creswell and Creswell (2018) who describe this worldview as seeing constructed meanings as contextual, subjective and "varied and multiple" (p. 8) and often "negotiated socially" (p. 8) that aligns well with the MCDA approach.

layers and provide a potentially transformative perspective. In ACP resources this discursive lens can provide a helpful perspective in analyzing tensions in order to help explore how spirituality is currently situated in resources with the goal to make recommendations for future change to optimize decision-making in end-of-life planning.

Acknowledging the inherent complexity of both spirituality and its nuanced expression in ACP resources within bioethics, my application is grounded in a critical realist lens, as noted in the first chapter, that assumes a knowledge of reality that is "contingent, shifting, and partial" (Fairclough, 2003, p. 14). I work with the assumption that there are aspects of reality beyond human perception that require critical subjective interpretation (Hiebert, 2008) and that "our experiences and understandings of reality are theorized as *mediated* by language and culture" (Braun & Clarke, 2022, p. 170, italics theirs). Hence, in critically analyzing resources, a discursive lens is utilized, acknowledging findings as being "inevitably partial" (Fairclough, 2003, p. 14). Within this approach that acknowledges the complexity of language there is also a central role of interpretation and a "*hermeneutic process*" (Wodak & Meyer, 2016, p. 21, italics theirs) to CDA/CDS, and with it the acknowledgment that findings are *"inevitably* subjective" (Braun & Clarke, 2022, p. 201, italics theirs) with the researcher bringing their unique perspectives while engaging in self-reflexivity and naming biases they bring to interpretation.

3.4.2 Broader Contextual Positioning of MCDA and ACPO Website

I have suggested above that the "black box" of spirituality in ACP has been inadequately explored. I sought to help fill this gap by examining how spirituality is situated in Ontario ACP resources to help provide opportunities for individuals to access their fullest ultimate values when making high stakes end-of-life decisions. Specifically, I sought to address the gap in research in spirituality and ACP by analyzing the current state of how spirituality is situated in

ACP resources in Ontario by examining a public-facing ACPO website featuring instruction, stories, photos, design elements, videos, and other resources. I carried out this research on a website in response to my research questions noted above by engaging the MCDA approach. Considering the multidimensional nature of spirituality with its interwoven aspects of values and death that are present in ACP reflection, together with the bioethical territory dispute that I have referenced regarding the culture of medicine and its resistance to spirituality, an approach to examination was needed that could examine both the more obvious surface-level references to spirituality in ACP resources—but more, could explore my observations of what was "really" being said in the multimodal resources and their integrated relationship across the website regarding spirituality. By exploring discourses that may have been embedded in the resources, MCDA provided a critical social lens to analysis that could then reveal potential assumptions, values, and ideologies present in the resources that demonstrated how the interests of content-producers inform the resources, thus providing a fuller picture of how spirituality is situated—or put differently, what world related to spirituality, values, and death was being shaped by content producers in ACP resources based on the Ontario website?

While a thin and compartmentalized approach to examining spirituality on the ACPO website may reveal surface references to the word spirituality, the multimodal perspective of MCDA has potential to go deeper in the critical process of piecing together discourses based on semiotic resources within the varying modes that reveal a larger picture. This approach includes examining modes of text, image, and speech across the ACPO website that reveal the specific and plentiful semiotic resources that inform discourse. Hence, a broad inventory of semiotic resources will be examined on the ACPO website including the analysis of 27 unique pages of content utilizing different modes of communication. These unique pages of content on the

website include expressions like text, font, colour, design, bullet points, charts, diagrams, photos, and symbols—resources that express larger categories of character stories, frequently asked questions (FAQ), reflection exercises and workbook, educational videos, links to other parts of the website and external organizations, links to social media platforms, and an Indigenous-focused brochure, poster, and video. Within all of these semiotic resources there resides nuances of meaning potential and the "reach" of these expressions as potential social meanings connected to the broader community (Kress & van Leeuwen, 2021, p. xv). Rather than a partial and selective examination of the website for how spirituality is situated by single reference to words, the methodology I will utilize includes examination of nuances on every page of the ACPO website to ensure a fuller and deeper analysis of how spirituality is situated.[155] Congruent with MCDA focusing on a collection of modes to examine discourse and ideology, I recognize the ACPO site is more than just these elements in isolation but the integrated and diverse interaction of semiotic resources. A full examination of the website through MCDA requires engagement on every page to avoid a partial glimpse into spirituality's presence.

3.4.3 Applying MCDA to Examining Spirituality on the ACPO Website

With my research questions centred on spirituality's situatedness on the ACPO website, along with implicit discourses and ideologies relating to spirituality, values, and death, I am seeking to observe how spirituality might "really" be situated on the website through the MCDA approach that enables a multilayered and concrete examination of these themes. Reviewing some of the foundations of the MCDA approach, the goal is in "revealing the discourses embedded in texts" (Machin & Mayr, 2023, p. 298) and "exposing certain ideological positions of text

[155] I note here that external links on the ACPO website directed to external organizations as well as social media platforms linked to the website were outside the scope of this analysis. My research focused on resources attached to the website domain itself and nothing further.

producers" (p. 298). And more, MCDA focuses on the choices content-producers make in utilizing semiotic resources that may reveal traces of possible buried power interests. And drawing on theorists mentioned above, some key questions arise in MCDA that I apply in research such as, what meaning potentials exist in the semiotic resources presented on the ACPO website? And if language not only reflects the world but *constitutes* it, what world is being created by language? Additionally, what world related to spirituality is being created by language on the ACPO website?

Applying these questions to spirituality's situatedness in ACP resources means asking questions like—what social practices regarding spirituality, values, and death are being maintained or legitimized by language put forth in the ACP resources? How are meanings around spirituality, death, and values recontextualized in ACP resources to align with the views of the content-producers? What kind of epistemological commitments from a bioethical lens are evident in the content or design? And what version of spirituality, death, and values is being presented to individuals engaging in ACP? All these questions dovetail towards the larger research question I am answering— how is spirituality situated in ACP resources found on the ACPO website? Echoing Flowerdew and Richardson (2017) again, the MCDA process means making "the implicit explicit in language use" (p. 1). For MCDA this means revealing what is hidden or "concealed, abstracted, or foregrounded" (Machin & Mayr, 2023). It is this kind of detective work that seeks hints, traces, and glimpses of discourses that I will apply to my MCDA examination of the ACPO website in order to seek transformation for the good of the patient.

Having established the goal of the MCDA approach in revealing discourses found in language along with the ideologies they carry, and the application of this to the ACPO website to reveal how spirituality is situated in ACP resources through discourse and ideology, I will now

outline how this methodology was carried out. I begin with the intention of assembling discourses. As noted above, single texts and references fall short of revealing a larger discourse. This is a strength of MCDA in that it works across semiotic resources within modes to reveal a larger picture. As van Leeuwen (2016) suggests, evidence in semiotic resources helps "piece together a discourse" (p. 139) rather than looking at a single reference in a text. As I will outline in detail in the section below focusing on MCDA tools of inquiry, this piecing together of discourses means critically examining lexical aspects on the ACPO website—including word choices, connotations, adjectives, adverbs, evidence of over-emphasis, how people are represented, what oppositions are created, genre and tone, pronouns, metaphors, grammatical positioning, and hedging. And secondly, it means a multimodal examination of visual and auditory aspects of the ACPO website including attention to aspects like pictures, fonts, gaze, poses of social actors, how people are represented, visual metaphors and symbols, design elements, sounds, as well as the presentation of data through tables and graphs.

By critically examining the entire website, I sought to assemble discourses that demonstrated how spirituality is situated. And as noted earlier—to carry out an examination that considers "how language and visuals come to operate as coherent wholes" (Ledin & Machin, 2018, p. 29). A helpful lens to assembling discourses in MCDA is the seeking evidence of a "discursive script" (Machin & Mayr, 2023) as mentioned earlier in this section. This involves gathering evidence of elements and references in social practices on the website, as well as the potential absence of certain elements in the ACP resources that may reveal subtle script of a discourse and the taken-for-granted and common-sense expectations created by those who have created the resources. In outlining discursive scripts further, Machin and Mayr (2023) draw on van Leeuwen's (2008) work to suggest discursive scripts as being "the 'doings' of a discourse"

(p. 30) that "comprise elements such as participants, actions, settings, times, causalities, solutions, aims, priorities, evaluations and resolutions" (p. 30) that arise from discursive analysis.

Regarding spirituality on the ACPO website, more specifically, I examined the multimodal resources across the site to examine what discursive script regarding spirituality and the interwoven aspects of death and values may be present, and what potential bioethical assumptions, values, and ideologies may be infused in these discourses that shape how spirituality is situated. In the section below focusing on tools of inquiry, I outline in greater detail the MCDA methods I incorporated to observe discourses and ideologies, as well as the reflexive TA approach I extended to coding the data and generating discursive and ideological themes. Next, I return to the strengths and limitations outlined earlier in the chapter to articulate how the MCDA approach I use builds on these strengths to answer the research questions I am proposing.

3.4.4 Building on Strengths and Limitations in the MCDA Approach

In the first part of this chapter, after providing a theoretical outline of the paradigm of CDA/CDS and an overview of the MCDA approach I am applying to my research, I offered an outline of some general strengths and limitations of both CDA/CDS and MCDA. In this next section I will articulate how I will build on these strengths and limitations with a focus on the MCDA approach I am using to explore how spirituality is situated in the ACPO website. Following this section, I will move to an exploration of the MCDA tools of inquiry I will employ in carrying out this analysis. I begin next with how I build on the strengths of MCDA.

Building on Strengths in the Methodological Approach I will Utilize.

MCDA and the Opportunity for Real-world Application in ACPO. The opportunity in MCDA for real-world application holds great potential to create change. And for research like

mine that focuses on helping transform ACP with an increased inclusion of spirituality, the real-world application involves critical analysis of ACP resources to gain a glimpse into the current state so future recommendations can optimize engagement of diverse communities facing high stakes value-based decisions involving the potential of death. In my introduction I outlined statistics regarding the diversity of in Canada including 100 religions represented and many cultures (Statistics Canada, 2022b). An approach is needed to ACP that can embrace all cultures and belief systems in value reflection. The MCDA approach can provide a comprehensive view to how spirituality is currently situated in Ontario in order to create spiritually integrated opportunities in the future that take into account the diversity of spiritual expression.

Addressing Complex Issues with Theoretical Richness and Interdisciplinarity. MCDA provides a unique opportunity to tackle complex social issues through a discursive and ideological lens. Considering the multidimensionality of spirituality, coupled with the undercurrents of bioethical conflicts I named earlier in this thesis, a fuller analysis of spirituality needs an approach like MCDA that can address complex power dynamics and social undercurrents. It is this theoretical richness of MCDA that can examine this "black box" of spirituality in the ACPO website from multiple angles. Adding to this theoretical richness, MCDA also integrates numerous theoretical approaches in its tools of inquiry, allowing for other perspectives. One example of this is Machin and Mayr's (2023) reference to Barthes (1972) and the examination of connotations of images focusing on what the objects, settings, and people may signify. Additionally, the theoretical context I have provided in my application of MCDA extends into other disciplines as well to add context including bioethics, theology, psychology, anthropology, history, and philosophy. These integrated interdisciplinary and theoretical

perspectives allow MCDA to examine complex themes from diverse angles adding to the fullness of the analysis of spirituality's situatedness.

Embracing the Potential for Ideological and Philosophical Examination. Another strength of the MCDA approach is its ability to dig into deeper layers of analysis involving assumptions, values and ideology. I have described in this thesis a territory dispute involving philosophical and ideological notions in bioethics that may impact how spirituality is positioned in ACP resources. MCDA provides opportunities for deeper engagement with layers of analysis to offer an observation of what potential world is being currently created by the ACP resources regarding spirituality, so that once again, recommendations can come forward to enhance these resources for the good of the patient involved. MCDA enables a lens to spirituality within ACP that can reveal more than surface assessments of spirituality and interwoven concepts of values and death, but deeper discursive and ideological themes impacting individuals—themes involving cultural tensions, views on autonomy reflecting diverse spiritual perspectives, and how death and values may be approached.

Taking Advantage of the Freedom Within the MCDA Approach. The MCDA approach functions with the same freedoms as outlined in my description of the MCDA approach. While the methodological approach I utilize is rooted in MCDA, there is an accepted flexibility to utilize tools of inquiry that fit specific research questions. While the majority of the tools of inquiry that I will employ originate with Machin and Mayr (2023), other questions related to specialized areas of ACP were added to the tools that uniquely addresses the complex social dynamics named above through MCDA. Further flexibility is offered in MCDA with the coding and generation of discursive and ideological themes. This flexibility has allowed me to extend

the “theoretically flexible method” (Braun & Clarke, 2022, p. 5) of reflexive TA to ensure a process is followed that can integrate with the MCDA methodology.

Building on Limitations in the MCDA Methodological Approach.

Moving Beyond the Partial and Mundane Towards Fullness and Depth. One of the limitations of MCDA named earlier in the chapter suggested partial, limited, and mundane observations. Considering the research I conduct seeks to analyze the entire 27-page ACPO website with a thorough approach using a broad selection of MCDA tools of inquiry, I am mitigating the chance of a partial review by not only examining every page of the website but also in the utilization of multiple tools of inquiry that are grounded in established MCDA theoretical processes. And more, the approach I take to coding data and generating themes uses the reflexive TA method to analyze discourse and ideology—a method that ensures a process and structure while also inviting self-reflexivity in helping make biases transparent. Further, the thorough context I have provided in my literature review in Chapter 2 provided a level of depth to the topic that was carried into MCDA examination to ensure a substantial analysis occurs.

Moving from Negativity to Transformation. A limitation noted earlier in this chapter suggested a negative view for approaches like MCDA. I build on this limitation by reiterating the approach I take is transformative. I utilized a critical perspective that aligns with the MCDA approach with the positive goal of making helpful gains by helping integrate diverse and complex expressions of spirituality into ACP resources in order to truly serve the good of the patient. By engaging in this project of examining spirituality in ACP I am filling a research gap and taking a very positive next step in deepening spiritually integrated resources that increase patient autonomy and values-based alignment in decision-making. I am helping bring forward a decision-making process in ACP where all spiritual expressions are welcome and the fullest

decisions based on the unique ultimate values of each patient are honoured—this is indeed positive work actualized by the MCDA approach to examine the current state.

Purposeful Engagement of Self-Reflexivity. Considering both the territory dispute I have outlined in bioethics related to spirituality's inclusion and my own positionality that includes a career in spiritual care provision and multifaith support to patients, I have been transparent in my own social, theological, and philosophical leanings; as well as my own normative take on the lack of spiritual integration and exclusion in ACP within the dominant medical culture. I also chose to examine the entire ACPO website instead of portions to ensure a comprehensive examination rather than a partial glimpse. I recognize the need to be self-reflexive regarding biases but I also recognize the normative strength of a spirit of critical inquiry that guides transformative research. This self-reflexiveness is central to both the examination of the website in MCDA and also to the approach to coding through the extension of reflexive TA to MCDA.

Ensuring Context in Research. Another broader criticism has been a lack of context in some research. Once again, I have transformed this limitation into a strength with the contextual approach that I have taken. Within interdisciplinary studies more broadly the goal is to understand "the complex phenomenon or behavior as a whole" (Repko & Szostak, 2021, p. 16) and this requires contextualization and "integrating insights from the relevant disciplines" (p. 16). In my research, I have sought to provide adequate context to complex layers of bioethics, spirituality, values, and death through a lengthy and thorough literature review that includes the historical, philosophical, and social aspects of medical culture and spirituality that are central to a fuller theoretical conversation with a clear context. I have also sought to integrate this context in the methodological approach of MCDA to ensure a thorough and contextual treatment.

Living in the Tension Between Structure and Freedom. I have chosen to address the lack of structure in CDA/CDS by utilizing both Machin and Mayr's (2023) tools of inquiry they suggest as helping "carry out a more systematic analysis" (p. 11) and by extending Braun and Clarke's (2022) reflexive TA method to bring thematic structure to my discursive analysis, ensuring a rigorous interpretive process aligned with my research questions. Considering the eclectic description of CDA/CDS described by Wodak and Meyer (2016) as including "no accepted canon of data sampling procedures" (p. 22) and no "well-defined empirical method but rather a bulk of approaches with theoretical similarities" (p. 21), I have drawn on the strength of a single approach in MCDA that is seeking increasing systemic analysis. I also apply the freedom and structure of reflexive TA in the coding and theme generation phase that celebrates core values of being both theoretically flexibility and also systematic (Terry and Hayfield, 2021). This demonstrates a balance within this tension by embracing freedom to approach unique contexts and diverse research questions while providing an adequate structure rooted in MCDA.

Before moving to the next section focusing on the MCDA tools of inquiry that were utilized in this methodological approach, I pause to articulate the importance of researcher self-reflexivity in carrying out research that is central to both MCDA and the reflexive TA method.

3.4.5 Self-Reflexivity

Within both the data collection phase of MCDA that utilized tools of inquiry inspired by Machin and Mayr (2023), Fairclough (2003), and Ledin and Machin (2020), as well as my extension of reflexive TA (Braun & Clarke, 2022) in coding data and generating themes, I was mindful of the importance of self-reflexivity. Braun and Clarke reference Berger's (2015) description of reflexivity as "turning of the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have"

(Berger, 2015, p. 220, as cited in Braun & Clarke, 2022, p. 13). As suggested by Braun and Clarke, I kept a reflexivity journal across all stages that I updated regularly during my research, mindful that researchers are "all deeply embedded in our values and experiences" (Braun & Clarke, 2022, p. 14). This reflection will be addressed at the end of Chapter 4 with a summary of reflections provided in Appendix B, providing valuable perspective that integrates my theoretical leanings, commitments, biases, and perspectives. This self-reflexivity included disciplinary reflexivity that reflected my own training and institutional affiliation, as well as personal reflexivity that revealed my own commitments and privilege, and finally, a sense of functional reflexivity with any practical considerations (Braun & Clarke, 2022). Self-reflexivity will also be integrated in Chapter 5 as I address my research questions once again, including discussion related to my third sub-question: what are the potential implications of these discourses, values, principles, and ideologies related to openness to spirituality in individual value reflection?

Having provided an introduction to the methodological approach I utilized, as well as an outline of how I build on these strengths and limitations in this approach, and the importance of self-reflexivity, I move now to a focus on the MCDA tools of inquiry that were utilized that I have divided into Part 1 and Part 2. I begin with an introduction to these tools of inquiry.

3.5 Methods

3.5.1 Introduction to Tools of Inquiry and Methods

Having outlined the broader methodological underpinning of my research as well as how I build on strengths and limitations in this MCDA approach, I now turn to the specific tools of inquiry and the methods I utilized to carry out this project. In an online publication, CDA/CDS originator, Van Dijk (2013) argues "A good method is a method that is able to give a satisfactory

(reliable, relevant, etc.) answer to the question of a research project" (para. 2). And for the paradigm of CDA/CDS that includes questions related to discourse. This means a range of diverse and flexible methods is needed to answer a broad scope of research questions. Acknowledging the diversity in CDA/CDS once again, Wodak and Meyer (2016) suggest: "CDS does not constitute a well-defined empirical method but rather a bulk of approaches with theoretical similarities" (p. 21). Gee (2014) echoes this range of approaches in discourse analysis by suggesting that rather than a step-by-step guide or recipe, the focus is on the utilization of a patchwork of "tools of inquiry" (p. 11) taken from different theoretical traditions by cooking by "taste" through taking from others and then adapting and mixing ingredients as a fine broth (p. 11). Gee suggests these tools of inquiry are not an isolated set of linear rules, but rather, thinking devices utilized by the researcher. I took this same eclectic approach in assembling tools of inquiry to answer my research questions with a two-part approach. While rooted in MCDA and the analytical methods of Machin and Mayr (2023), I also drew on the tools of others including Fairclough (2003), as well as Ledin and Machin (2018), and also Ledin and Machin (2020), before extending the coding and theme generation processes drawn from Braun & Clarke (2022) to help answer my research questions related to how spirituality is situated in ACP resources, as well as what discourses and ideologies may be present in these resources.

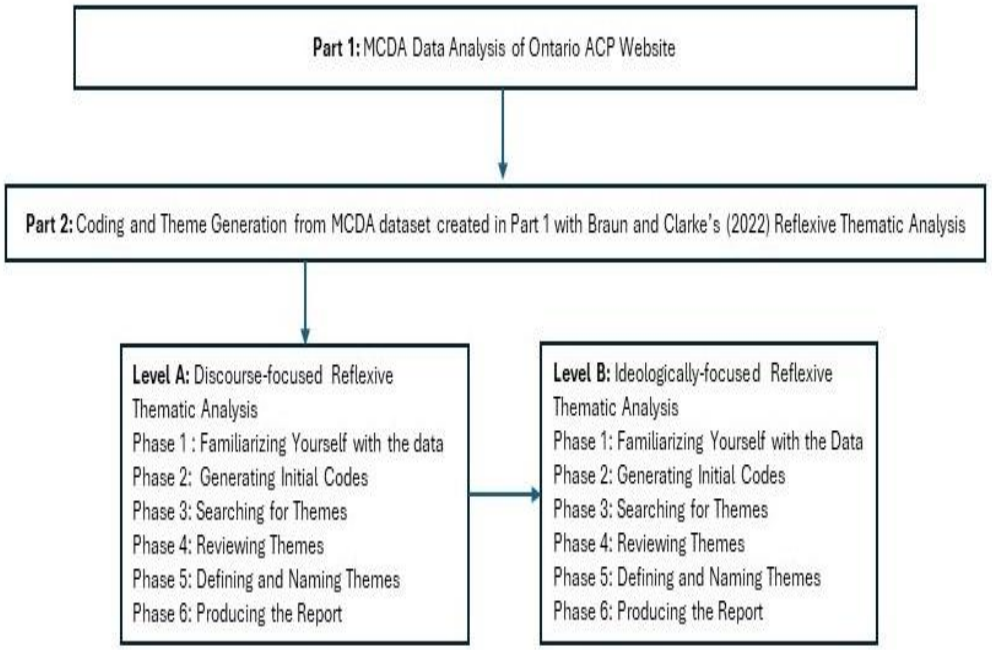
As I will articulate in greater detail in the section on methods ahead, in Part 1 of this MCDA approach I carried out an initial examination of the entire ACPO website focusing on both lexical choices and visuals through the tools of inquiry I list below. Through this process in Part 1 I sought to identify discursive elements related to spirituality, death, and values throughout the broader website before collecting them into a manageable dataset that was then analyzed in Part 2. In the coding and theme generation process in Part 2, I analyzed this dataset of elements

discovered in Part 1 by extending Braun and Clarke's (2022) reflexive TA to MCDA with a goal of assembling potential discourses and ideologies aligning with my research questions.

Before outlining in the section ahead in Part 1 the MCDA tools of inquiry that I utilized and the approach I took to coding and theme generation with reflexive TA in Part 2, I offer a diagram to help clarify for the reader the overarching process of this two-part MCDA approach.

Table 2

Overarching Outline of Part 1 and Part 2 of MCDA Approach



3.5.2 Articulation of Part 1: MCDA Data Analysis of ACPO Website

Having provided a diagram to help articulate the path I took in Part 1 and Part 2 of the MCDA methodological approach I used, I begin by articulating Part 1 that focused on the examination of the Ontario ACP website through the MCDA tools of inquiry. As Wodak and Meyer (2016) note, there is no standard way of collecting data in CDA/CDS with many

researchers not even mentioning their methods in this regard and no "accepted canon of data sampling procedures" (p. 22). Hence, researchers in CDA/CDS utilize tools of inquiry to create their own approach, or "soup" as Gee (2014, p. 11) would suggest, and MCDA is no different. Considering the many resources on the ACPO that I sought to examine, I created a summary of MCDA tools of inquiry based largely on the work of Machin and Mayr (2023) with additional ingredients from Ledin and Machin (2018) and Fairclough (2003) to deepen analysis. Before analyzing the data I digitally captured the raw website data as it existed on the last week of April of 2024,[156] before cataloguing the pages for examination to ensure organization. I utilized the site map[157] provided on the ACPO website as a checklist to ensure each page was archived and date stamped to ensure that the website pages I was analyzing remained unchanged even if the broader website incurred changes in months to come. Within the 27 unique pages existing on the website there included text, design, photos, six educational videos, as well as several Indigenous-focused resources including a downloadable brochure, a poster, and a video. Following the MCDA approaches demonstrated by Ledin and Machin (2018) for analyzing video content, each short video on the site was storyboarded frame by frame to capture the fullness of semiotic resources. All resources were examined utilizing the MCDA tools of inquiry noted in the table below. Consistent with the detective-like approach noted by Machin and Mayr (2023), and a goal to observe buried discourse, I identified both explicit and implicit references to spirituality in the ACPO webpages using MCDA tools of inquiry, paying special attention to interwoven aspects of death and values. Each resource on the website was analyzed utilizing the MCDA tools of

[156] As I will note in Chapter 5 in noting some of the limitations in my research, pages for analysis on the website were observed to be missing in July of 2024 forcing me to capture some pages at a later date. And while this dissertation is not an empirical one, I have attempted to maintain consistency of when the website was analyzed in case of dynamic changes to the website over time. I will address this in the limitations of the thesis in Chapter 5.
[157] The site map with the numbering system I added for increased organization is available in Appendix A.

inquiry with findings carefully catalogued. Catalogued evidence of discursive scripts gathered from the larger database in Part 1 was then set aside as a unique dataset to be analyzed in Part 2 with a focus on coding and theme generation using Braun and Clarke's (2022) reflexive TA.

Before moving to an articulation of Part 2, I briefly outline below the MCDA tools of inquiry I utilized in Part 1 with the first table summarizing tools focused on the lexical analysis of word choices, and the second table focused on analysis visual and other multimodal choices in the ACPO website. In these tables I provide only a brief description of each tool along with reference to the theorist that is linked to the tool of inquiry. By providing an outline of these tools of inquiry I outline the depth and breadth of the MCDA approach.

Table 3

MCDA Tools of Inquiry Focusing on Lexical Analysis of Word Choices

Inquiry Tool	**Brief Description**	**Key Question**	**Theorist**
Word Connotations	Choices of words carry connotations placing events into discourses with meaning potentials.	What world do words build?	Machin and Mayr (2023)
Overlexicalization	Any over-emphasis, excess in description, or attempts to over-persuade can hint at discourse.	Any hints of over emphasis?	Teo (2000, p. 20); in Machin and Mayr (2023, p. 54)
Adjectives	Words that dress up sentences and "raise the emotive value of what is being claimed" (p. 56).	Adjectives? Do they heighten?	Machin and Mayr (2023)
Word Choice and Recontextualization	What is "going-on" can become recontextualized by removing or adding elements or creating abstractions.	Are word choices unclear?	Machin and Mayr (2023)
Lexical Choices and Genres of Communication	How do formal or informal word choices "package information" (Machin, 2023, p. 59)? Are there hints of genre?	Are there hints of authority or genre?	Machin and Mayr (2023) and Fairclough (2003)
Structural Opposition	What concepts are opposed? Van Dijk (1998) refers to "ideological squaring" including young and old; or us and them. Fairclough (2003) asks what differences are accentuated?	Are there hints of opposition? Openness to different ideas?	Van Dijk (1998), cited by Machin & Mayr, 2023, p. 63) Fairclough (2003)
Intertextuality	Overlapping with the above, Fairclough (2003) asks if other voices are included or excluded, referenced indirectly or directly, and how other voices may be textured vs. authority.	Are other voices included in the dialogue?	Fairclough (2003)

Quoting Verbs	Verbs are chosen with implicit meaning potentials, like neutral verbs (said), meta-propositional (grumbled), prosodic (muttered), or para-linguistic verbs (giggled).	What quoting verbs are used? Do they give glimpses of meaning potentials?	Machin and Mayr (2023) notes Austin (1975), Coulthard (1994), and Fairclough (1995)
Representation of People and Classification of Social Actors	Are there hints of otherness that reveals "us and them" thinking? Splitting could include personal vs. impersonal; individual vs. collective; or specific vs. generic. Notions also include honorifics; anonymization; suppression; aggregation; and objectivization.	How are people referenced in resources? Is there evidence of otherness within lexical choices?	Machin and Mayr (2023)
Social Events	This relates to Fairclough's (2003) suggestion that texts are a part of a larger network of social practice that frames usage. Fairclough (2000) asks how social relationships are suggested.	Are social practices referenced? How are social relations portrayed?	Fairclough (2003, p. 191 - 194) and Fairclough (2000)
Pronouns	Pronouns like "you" and "we" and "us" can suggest vagueness. Power can also be used with "we" which refers to an unknown group.	What pronouns are used and with what meaning potentials?	Machin and Mayr (2023) refers to Fairclough (2000).
Representations of Action	Machin and Mayr (2023) extend Halliday's (1978) processes like mental (cognition, affection and perception), behavioural (psychological or physiological), relational (presented as fact or opinion), and existential (being).	Are there processes of action? How is agency noted? Are people noted as passive or active?	Machin and Mayr (2023) reference Simpson et al. (2018) section and Halliday (1978)
Adjuncts	Adjuncts are "lexical items that can be used to modify circumstances" (Machin, 2023, p. 156) like swapping words to evoke agency or power.	Any words hint at circumstantial change?	Machin and Mayr (2023)
Grammatical Positioning of Actions	Prepositional phrases can reveal dominant clauses and actions being downplayed when engineered to be buried later in a sentence.	Evidence of downplaying with positioning?	Machin and Mayr (2023) references van Dijk (1991)
Actions Represented in Abstraction	Actions are abstracted and generalized with vague notions and words like "appears" suggesting a lack of clarity.	Do words create abstraction?	Machin and Mayr (2023)

Nominalization	Verb processes take the form of a noun, increasing ambiguity, removing people from thinking, and decreasing responsibility.	Do choices remove people?	Machin and Mayr (2023)
Presupposition	Assumptions where "meanings that are presented as given, yet which are actually contestable" (Machin, 2023, p. 197).	Is there assumed knowledge?	Machin and Mayr (2023); and Fairclough (2003)
Rhetoric and Metaphor	Devices can utilize metaphors or rhetorical tropes to communicate a deeper principle, assumption, or even ideology.	Do choices suggest metaphors with meaning?	Machin and Mayr (2023)
Hyperbole, Metonymy or Synecdoche	Hyperboles utilize exaggeration; metonymy suggests swapping a close concept with another; and synecdoche exchanges a part for the whole.	Do hyperboles, metonymy or synecdoche arise?	Machin and Mayr (2023)
Personification	Choices made can give inanimate objects human qualities while objectification suggests a similar notion when something is objectified physically.	Any reference to human qualities in abstract ways?	Machin and Mayr (2023)
Metaphor Signaling	By using phrases like "so to speak" or "as it were" producers increase emphasis on metaphors.	Are metaphors signaled to bring out presence?	Machin and Mayr (2023)
Modality	The level of commitment in expressions suggests high modality with strong commitment while low modality notes low commitment and hedging.	Any references to commitment or doubts?	Machin and Mayr (2023)
Evaluation	This relates to Fairclough's (2003) notion asking what values are realized by the authors and hints of them being desirable?	Are there traces of values suggested as desirable or not?	Fairclough (2003)
Hedging	Tentativeness in words can add to ambiguity often connected with lower modality as noted above with words that express doubt.	Are there hints of hedging or choices that downplay?	Machin and Mayr (2023)
Modals and Authority	The role of authority is suggested in language that includes high modality or low modality, including suggestions of the imperative or mere suggestions.	How might authority be referenced? Any modality?	Machin and Mayr (2023)
Mood	Verbs with indicative, imperative, interrogative, or conditional tenses impact mood, or with Fairclough's (2003) factual or hypothetical tone.	What mood or tone is created through verb inflections?	Machin and Mayr (2023); and Fairclough (2003)

Table 4

MCDA Tools of Inquiry Focusing on Semiotic Analysis of Visual and Other Modal Choices

Inquiry Tool	Description	Questions	Theorist
Font and Typeface	Fonts highlight qualities including formal, informal, or casual representations, and can also be brought together with photos or video for additional meaning potentials.	What fonts are chosen? How do they interact with images?	Machin and Mayr (2023)
Denotation and Connotation	Denotation of images relates to documenting of people or things, while abstractions suggest meaning connotations. Machin (2023) draws on Barthes (1972) to examine connotations of visuals of "objects, settings and people" (p. 68), and what they signify.	What worlds do images and settings imply? What objects are present; do they suggest meanings?	Machin and Mayr (2023), drawing on Barthes (1972)
Gaze	One way people are represented is through their gaze and where people may be focused in their eyes that may invite relationship or a sense of distance.	Where do people represented in photos look toward?	Machin and Mayr (2023)
Poses	Poses of people in photos reflect different meanings including formality, informality, controlled posture, or more relaxed poses.	Are poses relaxed, open or closed or distanced?	Machin and Mayr (2023)
Ways of Talking	Machin (2023) references Schaffer (1977) who notes loudness invokes power or danger. Other audible aspects include meaning potential with breathiness, pitch, roughness and smoothness, tension, nasality, vibrato, reverb/echo, and articulation that all hold nuances.	How are audible voices or sounds reflected in video portions on the website?	Machin and Mayr (2023) draws on Schaffer (1977)
Representing People	Images too can reflect people including the individual vs. collective; generic vs. specific; anonymous; or notable absences of people. Other aspects related to how people are represented include distance and angles of photos.	How are people represented? What meaning potentials may exist?	Machin and Mayr (2023)
Visual Representation of Transivity	Similar to above but applied to images; transivity is the "study of social action" (Machin, 2023, p. 322) and draws on Halliday's (1978) processes like material aspects of what is concrete; the mental revealing emotions; the behavioural showing actions; the existential invoking being; and the relational showing comparison to others.	What processes are being suggested in the images provided? What processes are foregrounded?	Machin and Mayr (2023) draws on Halliday (1978)
Visual Metaphor	This describes images chosen for their "persuasive function" (Machin, 2023, p. 242) and may not be obvious to the viewer through meaning potentials.	Are images being foregrounded? Any meaning potentials?	Machin and Mayr (2023)

Metaphorical Associations and Experiential Metaphors	Machin (2023) refers to visual aspects that invoke shared solidarity to larger social projects through an image, becoming popular in social media imagery.	Are there hints that metaphors imply a meaning or lean to social causes?	Machin and Mayr (2023)
Metaphorical Associations and Diagrams	Diagrams can communicate metaphorical associations including the size of the boxes, spacing, framing, and privileging of certain content.	What is foregrounded in diagrams?	Machin and Mayr (2023)
Visual Metonyms	Metonyms visually involve the substitution of one image for another icon or image that may invoke other meaning potentials or foreground themes.	Is there evidence of metonymy in imagery or visuals?	Machin and Mayr (2023)
Modality and Certainty	Modality notes levels of commitment to ideas. Visually, Machin (2023) note "markers of visual modality" including the degree to which something is articulated in clear detail, inclusion of background, and light, shadowing and tone.	Are there hints of modality and commitment to ideas or visual hedging?	Machin and Mayr (2023)
Document Design	Ledin and Machin (2018) suggest interfaces on a phone or tablet can show what is segregated, and if functions have the same size on the screen.	Are aspects of design segregated or set a part?	Ledin and Machin (2018)
Film Clips	This tool evaluates narratives including entertainment narratives, possible world narratives, and narratives recounting events. Included are narrative stages of clips starting with orientation to setting, and content that may be a series of events and then a coda.	What narratives are present in clips? What narrative arch may be prevalent?	Ledin and Machin (2018)
Scene Analysis Through Settings & Characters	Ledin and Machin (2018) suggest the analysis of individual scenes through a focus on settings and characters may include cultural aspects as well as notions like individualization vs. collectivization.	What do settings and character portrayals suggest regarding culture or the social?	Ledin and Machin (2018)
Rhythm and Sound in Scenes	Ledin and Machin (2018) suggest film clips carry a rhythm that can be dependent on music that speaks to moods of intensity or intimacy, that depend on the even or uneven nature, fast or slow pace, or even a lack of rhythm.	What do sounds imply in film clips about the mood of this resource?	Ledin and Machin (2018)
Language and Evaluations	Film clips may have voiceovers or text that suggest a guiding narration and motivation of an individual.	Is there a voiceover or authority guiding?	Ledin and Machin (2018)
Data Presentation and Tables, Line Graphs and Bar Charts	Ledin and Machin (2018) note data presented in bullet points can reference what Kress and van Leeuwen (1996) suggest as technical modality where the producer has privilege in offering main building blocks of persuasion. Graphs and tables hold the same potential for influence.	What is highlighted in bullets, graphs and tables? Is it high or low modality?	Ledin and Machin (2018); Kress et al. (1996)

Colour	Ledin and Machin (2020) suggest colour holds meanings and metaphorical values including ideas, attitude and coherence. Dimensions include brightness, saturation, purity and modulation, hue, luminosity, and florescence.	What colours are utilized? What meaning potentials might exist?	Ledin and Machin (2020)
Causality	Ledin and Machin (2020) suggest graphics suggest a certain flow between elements that invite intentional movement.	Are graphics and modes linked that invite direction?	Ledin and Machin (2020)

Having outlined the MCDA tools of inquiry I am utilizing in Part 1 of the examination of spirituality's situatedness in the ACPO website, I turn now to Part 2 and the utilization of the reflexive TA method to code and generate discursive themes from the dataset produced in Part 1.

3.5.3 Articulation of Part 2: MCDA Coding and Theme Generation Utilizing Reflexive TA

Having applied the MCDA tools of inquiry listed above to the examination of resources on the ACPO website in Part 1, a smaller dataset of specific discursive elements and examples was now ready to be analyzed in Part 2 focusing on discursive coding and theme generation. It is important to circle back to my research questions at this point to ensure clarity around what exactly I would be coding for, and what themes would I be seeking to generate in this process. My main research question focused on how spirituality was situated in ACP resources in Ontario; and my sub-questions included—what discourses related to spirituality, death, and values might be both present and absent in ACP resources on the Ontario website? And secondly, what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death and values?[158] It is these questions that would frame the Part 2 coding and theme generation process.

[158] My third sub-question is—what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization? This reflective question will be dealt with in Chapter 5 in response to findings.

Mindful of my research questions wading into discursive and ideological themes, I sought an analytic method to coding and the generation of themes in Part 2 that offered flexibility and theoretical openness to addressing the complexity of spirituality and the interwoven themes of death and values, as well as an approach that could enable discursive and ideological themes to arise in alignment with MCDA. Further, I observed a need for a strong overarching structure for coding and generating themes from the data gathered from Part 1. In response to this theoretical and structural need, and in acknowledging Braun and Clarke's (2020) suggestion that there is "*rarely* one ideal method" for research (p. 38),[159] I sought to use an approach to coding that was adequate and justifiable—and as these authors suggest, fit to the purpose of the research and ensuring alignment and coherence towards the approach being utilized. Congruent with the spirit of CDA/CDS where the researcher gathers ingredients from different methods to season their own methodological "soup" as Gee (2014, p. 11) suggests, the method chosen for coding and theme generation for Part 2 of this analysis was Braun and Clarke's (2022) reflexive TA. I will outline this method now.

Terry and Hayfield (2021) outline the core values of reflexive TA as being theoretically flexible; procedurally focused with a rigorous and systematic approach to data; self-reflexive; and as characterized by focusing on "framing of 'themes' as multifaceted, conceptual, meaning-based patterns" (p. 4). Extending the reflexive TA method of coding and theme generation to MCDA demonstrated strong alignment with these values—as well as offering strong overarching theoretical congruency. First, the explicit critical realist approach espoused by Braun and Clarke (2022) aligned both with the CDA/CDS paradigm as a whole and also Lonergan's theological

[159] Further in regard to this choice of method, I appreciate Braun and Clarke's (2021) perspective on the search for a coding method and their suggestion of an illusionary temptation of the existence of a "hallowed method" where "there is a perfect qualitative analytic approach waiting…if you can only identify it" (p. 37).

lens that informs my larger perspective. Further, reflexive TA also aligned with both MCDA and Lonergan, once again, by embracing subjectivity and the importance of a chosen approach being "guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied" (Braun & Clarke, 2022, p. 13). The researcher's central role in the interpretive process was that important—and MCDA aligned with my own leanings.

In terms of analyzing thematic patterns, while typically focusing on themes related to psychology, Braun and Clarke (2022) iterate the flexibility of applying their method of analysis in reflexive TA to other datasets generated by multiple forms—including data "sampled from material that exists out there in the world" (p. 27). This inherent flexibility provided latitude for analysis of the dataset emerging from the ACPO website that included a diverse range of modalities and expressions. Further to flexibility, the authors suggest there is no code book provided for coding in advance in reflexive TA, but rather, a focus on "adventure, not a recipe" (Braun & Clarke, 2019, p. 592) that is "fluid and recursive rather than rigid and structured and requiring the use of a codebook" (p. 591). And perhaps most importantly, the reflexive TA method also had precedent not just in identifying themes and patterns but could also be extended to "identify discourses" (Terry & Hayfield, 2021, p. 82). Further in this regard, Terry and Hayfield suggest that "Researchers have combined TA with discourse analysis to produce *thematic discourse analysis*" (p. 81, italics theirs). Hence, considering reflexive TA has been "shackled by few constraints" (Braun & Clarke, 2022, p. 26) regarding research questions, datasets and theory, as well as the encouragement of blended approaches that may be "messy and organic, complex and contested" (Braun & Clarke, 2022, p. xxvi"), the method was chosen as for its potential to be extended to the equally diverse and flexible paradigm of CDA/CDS and the MCDA approach that I have described above. Overall, utilizing the reflexive TA approach

within MCDA allowed me to maintain "methodological integrity"[160] (Braun & Clarke, 2022, p. 26) by applying a systematic coding method to a multimodal dataset drawn from the ACPO website—aligning both with the methodological approach of MCDA, as well as the contextual focus of my research questions in examining spirituality's situatedness in ACP resources through discursive and ideological lenses. Engaging reflexive TA in Part 2 of my application of MCDA enabled a more systemic approach to coding discursive and ideological themes from the dataset produced by the MCDA tools of inquiry employed in Part 1, thus enabling a thorough and more structured analysis of how spirituality is situated in the ACPO website.

Practically, in extending the reflexive TA method to the MCDA approach in Part 2 of this analysis, I sought to examine discursive and ideological themes arising in the coding process as "patterns of shared meaning underpinned by a central organizing concept" (Braun & Clarke, 2019, p. 39). And in the case of the methodological approach I took, the central organizing concept included themes of discourse and ideology related to spirituality and the interwoven concepts of death and values. Further, in analyzing the dataset gathered in Part 1 for both discursive and ideological themes, I extended Braun and Clarke's (2022) suggestion of "multiple interpretive 'takes' on the data" (p. 205) through their phased approach outlined below. I drew on Braun and Clarke's (2022) suggestion noting a dataset consists of "often deeply connected" (p. 213) levels. In the case of my research rooted in CDA/CDS, the discursive themes contained within them ideological themes as outlined in the section above. Moreover, reflexive TA allowed for flexibility for both deductive and inductive coding as well examining explicit, latent, hidden, and unconscious themes, as well as critical frameworks like the one I used (Braun & Clarke,

[160]Braun and Clarke (2021) suggest methodological integrity involves a coherence of research design and procedures that integrate with the research questions that result in a trustworthy study. It is this coherence I seek to demonstrate in my articulation.

2022).[161] Hence, not only were discourses assembled in this process in Part 2 through reflexive TA, but ideologies could emerge in a second layer of analysis.

Further to inductive versus deductive approaches, the reflexive TA method enabled an interpretive blend of both in analysis. And while I took an inductive approach and one not utilizing an explicitly theoretically informed codebook to code discourses and ideologies, I was also very mindful of the presence of "existing theory and concepts" (Braun & Clarke, 2022, p. 208) that were present with my interpretation that included the broad range of theoretical concepts in bioethics, theology, and spirituality that I highlighted in the literature review. I acknowledge here that, as Braun and Clarke (2022) articulate, that an inductive analysis like mine can be "strongly informed by existing theoretical constructs" (p. 208). Hence, while preexisting theories are present in my research, and there is an unintended element of "theory-directed interpretation" (p. 210) regarding what themes are given "greater analytic priority" in interpretation (p. 210), my research is inductive with theory informing the process of interpretation in a way that is "unavoidable" (p. 211) as Braun and Clarke (2022) suggest. But this inspires the central need for self-reflexivity that I outline next.

Finally, it is important to emphasize the centrality of the researcher in the process of reflective TA that aligns with CDA/CDS more broadly in being unapologetically researcher centered. Braun and Clarke (2021b) suggest, "the importance of the researcher's subjectivity as analytic resource, and their reflexive engagement with theory, data, and interpretation" (p. 330) as well as noting "the inherent and inescapable subjectivity of the method…and the researcher's

[161] Specifically, Braun and Clarke (2021) suggest reflexive TA is appropriate when "the data source is something other than interviews" or "the analytic focus is solely on identifying themes across the data set" as well as the actionable intent of the research (p. 42). All these factors resonate in the approach I am taking to MCDA and the need to analyze data across an entire website.

active role in knowledge generation" (Braun & Clarke, 2024, p. 3). Because of the subjectivity of reflexive TA and the centrality of the researcher, a key to this process is keeping notes on self-reflexivity including naming values and bias.

Having provided a broader overview of reflexive TA, I now move to outlining the method. The coding method in reflexive TA revolves around six recursive phases: 1) familiarizing yourself with the data; 2) coding; 3) generating initial themes; 4) developing and reviewing themes; 5) refining, defining and naming themes; and 6) writing up (Braun & Clarke, 2022, p. 35 - 36). I outline the six phases in the table below with a brief description.

Table 5

Braun and Clarke's (2022) 6-Phase Reflexive TA Process

Phase	**Description**
Phase 1: Familiarizing yourself with the dataset	This phase involves immersion into the dataset to become "deeply and intimately familiar with the content" (Braun & Clarke, 2022, p. 35) and making analytic notes with insights.
Phase 2: Coding	This section involves a fine-grained systematic approach to the dataset to "identify segments of data that appear potentially interesting, relevant or meaningful for your research question" (p. 35) and the addition of code labels with meaningful descriptions.
Phase 3: Generating initial themes	In this section patterns of meaning spanning the dataset are observed and one will "compile clusters of codes that share a core idea of concept" and create "candidate themes" (p. 35) with collated data organized with each of them.
Phase 4: Developing and reviewing themes	Here one assesses the initial themes by comparing with the dataset to see if revisions are needed, the collapsing of themes must happen, or creation of new themes.
Phase 5: Refining, defining and naming themes	This stage involves a fine-tuning of themes and the story that a theme might tell and the decision regarding a name for a theme.
Phase 6: Writing Up	This involves the coherent weaving of dataset and themes.

Having outlined the phases of reflexive TA that I utilized, I now outline how I applied this method. With my focus in Part 2 on analysis of the discursive and ideological themes arising from the dataset gathered in Part 1, I chose to apply reflexive TA in two unique layers of analysis—Layer A focused discursively, and Layer B focused ideologically. In the paragraphs below I outline the two layers of analysis in greater depth. First, I outline Layer A of reflexive TA where I examined the initial dataset from Part 1 with a focus on discourses related to spirituality, death, and values within the ACP resources. Secondly, I outline layer B that examined what bioethical values, principles, assumptions, and ideologies might be embedded within the discourses named in Layer A. I outline these layers in greater depth below.

Layer A: Coding Discursive Themes Related to Spirituality, Death, and Values. The first component of my analysis utilizing reflexive TA related to my first research sub-question: what discourses related to spirituality, death, and values might be both present and absent in ACP resources on the Ontario Website? At this stage of coding and theme generation process, I followed the six-phase reflexive TA process by Braun and Clarke (2022) with an eye to discursive themes that I observed in the dataset produced in Part 1 that are related to how spirituality is situated in in the ACPO website—specifically, what discourses related to spirituality, death, and values might be both present or absent?[162] Simply put, this thematic exercise sought to assemble discourses that I observed from evidence in the dataset using the phased process above for analysis. This involved analyzing the dataset that emerged in Part 1 with the MCDA tools of inquiry to assemble possible discourses and discursive scripts through what Wodak and Meyer (2016) call discourse strands and discourse fragments. These strands and fragments were coded and then assembled into discursive themes as per the six-phase process.

[162] It is important to note that an analysis of discourses that may be absent on the site will be addressed in Chapter 5.

After Layer A of the process that included my identification of a variety of thematic discourses in the dataset, I then brought these discourses to Layer B for further analysis.

Layer B: Coding Themes Regarding Values, Principles, Assumptions, and Ideologies.

Layer B is the second interpretive layer of analysis in my extension of reflexive TA to MCDA. This layer responded to my second research sub-question: what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death, and values? In this component of analysis, I examined the thematic discourses I "assembled" in Layer A, but this time with a different lens—a lens that sought to uncover possible values, assumptions, and ideologies within the discourses that emerged in Layer A, in order to answer my second research sub-question related to ideology. Similar to the process of analyzing the dataset in Layer A that focused on discursive themes, Layer B followed the same reflexive TA phases as above; but with a focus on identifying bioethical assumptions, values, and ideologies that emerged from the discourse in response to my research question focusing on ideologies embedded in discourse.

Finally, having outlined my application of the reflexive TA approach to coding and generating themes that I took in this analysis in Part 2, I take a moment to briefly outline some of the overall strengths and limitations of utilizing a reflexive TA method with an MCDA approach.

Strengths and Limitations of Utilizing Reflexive TA for Coding and Theme Generation.

I close this section by offering some of the strengths and limitations of using the method of reflexive TA in the MCDA approach. Broadly speaking, Braun and Clarke (2022) suggest several strengths to utilizing reflexive TA for coding and theme generation including "potential for wide ranging application" (p. 260) giving reasons that it is "Flexible with regard to theory,

research question, data collection method, method, dataset size and generation strategy, and analytic orientation…and purpose" (p. 260). This makes it ideal when applied to MCDA data like the ACPO website. But further, it is a method that can be extended to critical discourse analysis where the process can be flexibly utilized to focus on discursive themes and as well as ideologies. Further, Braun and Clarke continue by suggesting their work can be integrated as a method with many methodologies rather than being an "off-the-shelf" (p. 260) methodology with narrower parameters for usage—but this, they suggest, requires the researcher to be intentional in articulating their theoretical and philosophical underpinnings which is exactly what I have done in the sections above in articulating my application of the MCDA approach to ACP resources and the next step of coding and generating discursive and ideological themes related to the data. The authors also note the method is well-suited for emerging qualitative researchers because of its flexibility and systemic approach. Other strengths include its ability to interpret both social and psychological aspects within data, the potential to produce "complex, nuanced, sophisticated and conceptual analyses" (p. 260) and finally, linking to my transformative goal in my research, reflexive TA "Can be used to produce analyses with actionable outcomes and that can inform policy development" (p. 260) which is exactly what I am hoping to do with the transformative aim of the current study in examining spirituality ACP resources in Ontario.

Limitations of Utilizing Reflexive TA. In terms of limitations, or what Braun and Clarke (2022) suggest as limitations and challenges, the authors note the "Flexibility and wide range of potential applications can lead to 'analytic paralysis'" (p. 260) where new researchers can long for some additional structure. Braun and Clarke also note the reliance on substantial theoretical knowledge that is required before engaging in data analysis. Considering a thorough articulation of theory within MCDA I have provided, and the broad theoretical overview of bioethics,

spirituality, death, and values that I have outlined, I believe this limitation is actually an opportunity for the complexity of this research project. And further to theory, Braun and Clarke also suggest here the challenge of not having "recipe-like guidance" (p. 260) in higher level interpretation, something that requires a level of maturity of the researcher to bridge theory, their analytic orientation and purpose. Again, this aligns with the approach I have taken in MCDA. Because of the uniqueness of the MCDA approach that I am applying to examining spirituality in ACP resources, I have already offered significant theoretical articulation, as well as a concise outline of how I will bring together theory related to MCDA and interpretive theme generation through reflexive TA with a strong purpose rooted in transformation of ACP resources for the good of the patient. Finally, the authors note the approach is not appropriate for "fine-grained analysis of language practice" (p. 260) which aligns with the two-part approach I took to engage first in Part 1with a multimodal analysis of texts with the MCDA tools of inquiry to create a dataset, and then secondly, utilizing reflexive TA to analyze the dataset discursively and ideologically in Part 2 with the broader interpretive strengths as noted above. Again, this limitation aligns with the methodological plan I have outlined in a layered approach.

Having provided an outline of the tools of inquiry I employed, including an outline of Part 1 MCDA tools of inquiry, and Part 2 that includes the reflexive TA approach I took including strengths and limitations. I outline the validity of the methodology to end the chapter.

3.6 Validity of Methodology

Catalano and Waugh (2020) summarize questions around validity in CDA/CDS as an "academic cottage industry" inspiring questions around its ability to produce valid knowledge (p. 219). With the underpinning of my understanding of validity rooted in the assumption of critical realism where the subjective task of analyzing texts is notably "limited and partial" (Fairclough,

2003, p. 15) and where "understandings of reality are theorised as *mediated* by language and culture" (Braun & Clarke, 2022, p. 170, italics theirs), I align with a movement away from an understanding of validity grounded in a positivistic view of knowledge as truth and accuracy with its "stable, static meanings" (Clement et al., 2023, p. 799) towards one involving interpretivist and constructionist assumptions that involve different questions of what might be valid. And while historic approaches were based in this positivist thinking utilizing the scientific method, there has been a transformation of the notion of validity in critical qualitative research with different concerns including authenticity, trustworthiness and relationships of power (Clement et al., 2023). And in this debate a struggle emerges with regards to the notion of validity in the CDA/CDS paradigm—but a struggle not unique to discourse analysis but one that has "continually vexed so-called 'qualitative research'" (Gee, 2014, p. 141). But what is at stake?

The heart of this struggle is one of objectivity versus subjectivity—a struggle Machin and Mayr (2023) observe as being "rather misguided" (p. 304) considering seemingly objective notions in quantitative research are hardly neutral with "vague, shifting and arbitrary" (p. 304) findings beneath the numbers. This aligns again with the thinking of Lonergan (1972/2017) who suggested a view where objectivity arises from one's authentic engagement in subjectivity. Addressing validity in CDA/CDS research processes, Macgilchrist (2021) articulates the challenge, noting, "Scholars of critical discourse studies (CDS), and most other social sciences, are today perched on the rope in a tug-of-war" (p. 387) between scientism focused on indicators like reliability, validity and an evidence-base, and the "unscientific" (p. 387) use of story and narrative. While positivistic approaches focus on "objective" notions rooted in measurement, qualitative research seeks "not to measure but rather to understand, represent or explain something, usually some fairly complex social phenomenon" (Pyett, 2003, p. 1170).

So how do I assess validity? Pyett (2003) asks questions of confidence in one's accounting of representation, while Schwandt (2007) names credibility regarding one's interpretations, and finally, Lincoln and Guba's (2007) suggest notions of trustworthiness and authenticity. With this backdrop, I articulate validity in my MCDA research within the bounds of these notions of instilling confidence, credibility, trustworthiness, and authenticity. Integrating these aspects more intentionally, I articulate the validity of my research in four distinct ways: my attention to self-reflexivity as a researcher, my use of multiple theoretically grounded tools of MCDA inquiry, the thorough theoretical grounding of my research within the paradigm of CDA/CDS, and finally, through my ability to articulate my research through the writing process. Through these approaches to validity I inspire trust, credibility, authenticity and confidence. I begin with self-reflexivity.

3.6.1 Researcher Self-Reflexivity

The first indicator of validity in my research is my self-reflexive approach as researcher. With CDA/CDS suggesting an "unabashedly normative" (Van Dijk, 1993, p. 253) approach that seeks transformation in real-world problems with a critical lens, there exists a strong interpretive stance rooted in the subjectivity of the researcher. Fairclough (2003) notes that analysis of discourse is "inevitably selective" (p. 14) and "inevitably limited and partial" (p. 14) while Gee (2014) suggesting one's discursive tools of inquiry being "designed to describe and explain what the researcher takes to exist and to be important in a domain" (p. 11). There is an explicitness to one's research aims centering on the researcher that is unavoidable. Further, as a "hermeneutic process" (Wodak & Meyer, 2016, p. 21) the researcher brings their own experiences, biases and perspectives to examining ideologies and discourses interwoven with social perspectives that are open to interpretation. This critical focus requires unapologetic transparency regarding the values

and positionality I bring to research as Wodak and Meyer (2016, p. 7) suggest. It is transparency and self-reflexivity that contributes to credibility and trust. And in extending this interpretive lens to coding and theme generation, this need for transparency and self-reflexivity is no different. The reflexive TA approach that grounds my thematic analysis also positions the researcher as offering a "*mediated* reflection of reality" and a "coherent and compelling interpretation of the data" (Braun & Clarke, 2022, p. 170).[163] And in answering the question "how do I ensure my coding is accurate?" (Braun & Clarke, 2019, p. 590), the authors return to the theme of subjectivity of the researcher and "an orientation to researcher that was fully qualitative—qualitative with regard to both philosophy and procedure" (p. 591). Braun and Clarke (2022) continue elsewhere suggesting, "Paradigmatic, epistemological and ontological assumptions *inescapably* inform analysis" (Braun & Clarke, 2021, p. 331). I too bring my own unique theory and experiences to research and commit to Wodak and Meyer's (2016) suggestion of a process including "self-reflection at every point in one's research" (p. 22). And along with self-reflexivity is Fairclough's (2003) acceptance in analysis that "our categories are always provisional and open to change" (p. 15). This spirit of discovery frames the MCDA approach. I address self-reflexivity again in Chapter 4 with a summary of journal entries in Appendix B.

3.6.2 Broad Utilization of Methods

In addition to self-reflexivity, another indicator of validity is my broad utilization of multiple and diverse MCDA methods. Considering the multiple modes represented on the ACP website—including text, video, design, and photos—an approach that can utilize multiple lenses to analyze the website from different angles increases validity. In this, I echo (Gee, 2014)

[163] So important is the researcher's particular and unique views to analysis that the authors "do not recommend using multiple coders" as there is no "accurate" analysis (Braun and Clarke, 2022, p. 55), but rather, the researcher brings their unique experiences and perspective.

approach to validity in discourse analysis by seeking to demonstrate credibility through the use of a broad collection of exploratory questions and diverse tools of inquiry that provide multiple perspectives. Focusing on their own interpretive model that includes dozens of critical questions, Gee suggests validity in discourse analysis includes convergence among the many interpretive questions being utilized that support their analysis as well as suggest agreement between the tools of inquiry and the larger context (pp. 141 - 144). Turning to the research methods I will outline in the next section, the approach includes a broad usage of 20 multimodal tools of inquiry to analyze images and design, and another 25 tools to analyze lexical aspects of the website. Similar to Gee's (2014) suggestion above, validity is demonstrated through this multifaceted approach to analysis involving multiple tools of inquiry addressing not just textual features but visual, design, and video components as well. And while Fairclough (2003) notes there is "no such thing as a complete and definitive analysis of a text" (p. 14), the strength in my use of multiple tools of inquiry inspires confidence, especially with its rootedness in CDA/CDS bringing me to a third indicator of validity, a strong theoretical grounding.

3.6.3 Strong Theoretical Grounding

In addition to self-reflexivity and my broad utilization of methods, a third indicator of validity in my research is the strong theoretical approach I have taken. As Gee (2014) says, "There can be no sensible method to study a domain unless one also has a theory of what that domain is" (p. 11). And it is this approach I have taken through both my strong interdisciplinary engagement with literature regarding bioethics, spirituality, values, and death, as well as the rootedness of my study in an attempt at a thorough understanding of CDA/CDS theory that underpins MCDA. The strength of this theoretically grounded approach is in its situatedness within a larger community of CDA/CDS. This aligns with Gee's (2014) suggestion that "tools

and strategies ultimately reside in a ‘community of practice’ formed by those engaged in such research” (p. 11). It is this broader approach involving the body of CDA/CDS and MCDA theoretical research that informs my practice and the variety of methods I will use. I have intentionally grounded my research in the paradigm of CDA/CDS with “its own principles and procedures” (Machin & Mayr, 2023, p. 304) and specifically the field of MCDA with its multidimensional tools of inquiry grounded in established theory. I take this same approach in my choice to utilize Braun and Clarke’s (2022) reflexive TA for coding and theme generation. In choosing a strong well-established and theoretically sound approach, I root my research in the strength of integrative theory that enables the fullest interpretive process to increase validity.

3.6.4 Articulation Through the Writing Process

Finally, a fourth and final aspect that inspires validity is my ability to articulate the integration of this theory and research through writing. As Pyett (2003) argues “trust must be earned in the writing-up process, by demonstration of the researcher’s honesty, reflexivity, discipline, and rigor” (p. 1171). In my CDA/CDS research this means outlining with clarity my strong theoretical base that coherently links my project to the broader research context. This means articulating both the contextual landscape of bioethical, theological, and philosophical themes related to ACP, as well as the theoretical base of CDA/CDS and MCDA. This ability to articulate will enable the bringing together the varied and complex theoretical threads in my interdisciplinary study and contribute to increased validity.

Having outlined my approach to validity in the research above and the expression of this through self-reflexivity, the use of multiple MCDA tools of inquiry, rootedness in a theoretical base, and through the articulation of this project with words, I now offer a chapter conclusion.

3.7 Conclusion

I began this chapter by offering a broader understanding of the paradigm of CDA/CDS and the MCDA approach I applied to my examination of how spirituality is situated in Ontario ACP resources. This included an outline of strengths and limitations of CDA/CDS and MCDA, as well as a rationale for my choice to use this methodological approach. I then provided an outline of key theoretical concepts that underpin CDA/CDS and MCDA—including discourse, power, ideology, a critical perspective, and finally, the social domain. After laying this theoretical foundation, I outlined my application of the MCDA approach in greater detail, including how I applied this approach to analyzing the ACPO website and how I built on the strengths and limitations named above to answer my research questions. Finally, I noted how I address self-reflexivity in the methodology I use before moving to a discussion on methods. Here, I first articulated Part 1 of the methods I utilized by outlining a summary of the MCDA tools of inquiry I used to examine multimodal aspects. I then articulated Part 2 of this approach that focused on methods of coding utilizing Braun and Clarke's (2022) reflexive TA. I then offered an outline of a two-layer approach to coding I utilized by extending Braun and Clarke's (2022) method to discursive and ideological themes that relate directly to my research questions around the situatedness of spirituality, death and values in ACP resources. Finally, I briefly offered some overarching strengths and limitations specific to the method of reflexive TA before closing the chapter with a focus on the validity of my approach. I now move to Chapter 4 and an outline of my findings.

Chapter 4

Findings

4.1 Introduction to Chapter 4

In the previous chapter I provided an overview of the methodology I utilized in this dissertation. In outlining the transformative approach I am taking to help deepen spiritual inclusion in Ontario ACP resources, I noted the importance of a critical perspective in carrying out research on spirituality in ACP that has been considered a "black box" needing examination. I outlined how an approach was needed that could critically explore both spirituality in its complexity, its multidimensionality, as well as addressing the implicit territory dispute with bioethics that has been outlined in the literature. I also provided a theoretical outline of the paradigm of CDA/CDS as well as the MCDA approach rooted in Machin and Mayr's (2023) work before introducing several key theoretical concepts that underpin this approach and how they integrate with MCDA. After providing this outline, I articulated in greater depth the MCDA approach in assembling elements of discourse and potential discursive scripts that may be present as well as some tools of inquiry—both lexical and multimodal—that I utilized in the examination. I then outlined the process I used for coding the data and the process of generating discursive themes and ideologies through Braun and Clarke's (2022) reflexive TA. I closed the chapter by outlining the validity of this approach before concluding the chapter.

Chapter 4 focuses on the findings related to my examination. I begin Chapter 4 by providing an introduction followed by an outline of the components of the ACPO[164] website that were examined. I follow this with a brief articulation of how the MCDA tools of inquiry were

[164] I remind the reader that ACPO is an acronym for Advance Care Planning Ontario.

operationalized to examine the website and gather evidence of discursive scripts for analysis. After outlining components of the website and the process utilized in the MCDA examination that led to the findings I will present, I will articulate the findings of my analysis, framing them in the two parts I outlined in Chapter 3 that align with my research questions.[165] In Part 1, I outline MCDA findings focusing on elements of discourse related to spirituality, death, and values that are present on the website. In Part 2, I outline the findings produced by the process of coding and generating themes through reflexive TA—a two level process with Level A findings outlining discourses related to spirituality, death, and values present on the website; and Level B findings focusing on bioethical values, principles, assumptions, and ideologies embedded in these discourses of spirituality, death, and values. In Level A, I will outline my findings of eight different discourses I observed on the website as at it relates to spirituality, death, and values; and in Level B, I will articulate my findings of eight ideological assumptions I observed to be embedded in these discourses. Discussion around what discourses may be absent on the website will be reserved for reflection in Chapter 5 along with discussion around potential implications of these discourses and ideological assumptions for individual value reflection and prioritization. I begin with an overview of website components examined in the MCDA analysis.

4.2 Overview of Website Components Examined with the MCDA Tools of Inquiry

I begin by offering a brief scan of the components of the ACPO website that were a part of my MCDA exploration. My examination of the ACPO website utilized the MCDA tools of

[165] I review my research questions here for the reader for reference. My main question is: how is spirituality situated in ACP resources found on the ACPO website? My sub-questions are: 1) what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website?; 2) what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death, and values?; and 3) what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regards to an openness or closedness to spirituality in individual value reflection and prioritization?

inquiry outlined in Chapter 3 to explore the website involving both lexical and multimodal lenses. Additionally, I also critically examined any resources that were housed on the website including videos, a brochure, and poster.[166] External links that left the ACPO website domain, along with social media links provided on the website, were not examined as they were outside the formal website platform. The ACPO website map situated on the "Home" webpage was used as an organizing tool for examining each separate webpage. A number system was added to order these pages[167] to help in organizing data and tracking MCDA observations across all pages and to help catalogue examples of elements of discursive script. The multimodal analysis of the website included an initial scan of every page on the website followed by multiple assessments of data focusing on different dimensions—first utilizing the lexical analytical tools of inquiry as noted in Chapter 3 and then utilizing the multimodal tools of inquiry. Detailed notes captured evidence of discursive scripts across all elements of the resources focusing on potential discourses related to spirituality, death, and values. Consistent with MCDA practices (Machin & Mayr, 2023; Ledin & Machin, 2018) each of the seven videos situated on the site were storyboarded with both text as well as multimodal observations including my descriptions of sound, music, photos, and design elements to ensure modes were uniquely captured and examined. In terms of the website content examined, I explored the four main sections of "Home", "Resources", "Advance Care Planning", and "Substitute Decision Makers". Below I briefly outline the web content observed in each of these four main sections before moving to the website analysis. I begin with the "Home" section.

[166] I note here that the only aspects of the website that were not examined were the ACP postcards (HPCO, n.d.-y) available in Chinese, Spanish, French, Italian, Punjabi, and Tagalog because of the language barrier.
[167] See Appendix A for the website map that was utilized in the MCDA examination.

The "Home" section of the website I analyzed (HPCO, n.d.-j)[168] included an introduction with a welcome and invitation to watch an educational video created by *Hospice Palliative Care Ontario* and *Speak Up Ontario* entitled "Advance Care Planning In Ontario" (HPCO, n.d.-h).[169] Also situated on this page were instructions for utilizing the website, options for browsing the site, links to other parts of the site including the "Online ACP workbook", "Glossary", a "Frequently Asked Questions" (FAQ) section, and a link to the "Healthcare Practitioner Site". The page also provided an introduction with pictures to the stories of six characters that were featured at length across the website. The main "Home" page also included a bar on the bottom of the site to access additional pages including "About", "Videos", "Accessibility", "Privacy", "A Legal Disclaimer", and "Sitemap". Additional links on the bottom of the page included a link to "Contact Us" through two icons including "CALL US" with a phone number listed and a link to an external "CLINICIANS' SITE".[170] Finally, a bottom bar of options unique to this page invited connection to four external social media channels—Twitter, Instagram, Facebook, and Vimeo—and additional opportunity to access the "Health Care Provider Site", "ACP Workbook", the "5 Steps of ACP" page, and finally, a "Newsletter Signup". This "Home" section also linked to the "About Us" section that provided more information about the institutional home of ACPO, its purpose, and its connection to HPCO.

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[168] I offer an additional note here with a reminder that I will be using the acronym HPCO for *Hospice Palliative Care Ontario* throughout this chapter. I note here as well that in accordance with APA guidance, each separate webpage I cite in this chapter has its own reference with the URL link provided in the References section.

[169] This is the first reference to four videos created by HPCO and *Speak Up Ontario* that are situated on the ACPO website. These videos include "Advance Care Planning in Ontario", "Confirming Your Substitute Decision Maker in Ontario", "I'm a Substitute Decision Maker…" and "Understanding Consent & Capacity in Ontario". In congruence with guidance from an APA Style Guide consultant, in addition to citing these four videos in regard to their place on the ACPO website, I am also crediting the producers of these four videos here by acknowledging they were created by "HPCO" and "Speak Up Ontario". For brevity, in future references to these four videos in this dissertation, I will only cite the videos and not the creators mindful that the reader is now fully aware of the creator.

[170] I note here again that external sites and social media channels listed in this section were considered outside the scope of this dissertation because these links meant leaving the formal ACPO website. My focus was solely on resources housed on the ACPO website itself.

The "Resources and Educational Support" (HPCO, n.d.-p) section of the website that I analyzed offered a "Glossary", a link to "FAQ", a link to the "Resource Guide", and finally, a link to "Character Stories" that featured the stories of six characters facing health challenges and an exploration of their values. Further, "Additional Resources" were listed with a link to "Videos", an empty link to "Paper Copy of ACP Guide", and finally a link to "ACP Postcards in Seven Languages". There were two other icons on the page that invited readers once again to "CALL US", and finally, a link once again to the external "CLINICIANS" SITE". The same offerings of social media and the link to the "Newsletter" were included in a similar way to the "Home" section listed above. The videos situated on this page included two created by Advance Care Planning Ontario entitled "Five Steps" and "A 5 Step Process for Future Planning for Families & Children with Medical/Developmental Conditions",[171] and four other videos entitled "Advance Care Planning in Ontario" that walks through the basics of ACP; "Confirming Your Substitute Decision Maker in Ontario" with a focus on the SDM; "I'm a Substitute Decision Maker…" that articulates the role of the SDM; and "Understanding Consent & Capacity in Ontario" that looks at legal aspects of capacity. Links on the "Resources and Educational Support" page also included access to an "ACP App" to aid in the ACP process, as well as a "Resource Guide" with detailed focused on three main categories of information including "Consent", "Substitute Decision Makers", and "ACP".

[171] I will reference these two animated videos throughout this chapter and offer two notes regarding citations. First, while the full title of the second video is "A 5 Step Process for Future Planning for Families & Children with Medical/Developmental Conditions", I will, for the sake of brevity, abbreviate this title to "A 5 Step Process for Future Planning". Also, similar to the note above referring to the four videos produced by HPCO and *Speak Up Ontario*, in congruence with guidance from an ACP Style Guide consultant, I have noted the creator of these two animated videos as "Advance Care Planning Ontario" but for the sake of brevity, I will only provide a citation and not include the name of the producer in future references, mindful that the creator has now been fully acknowledged.

The "Advance Care Planning" section of the website (HPCO, n.d.-a) that I examined provided an overview of ACP with brief examples from the character stories introduced earlier. The page outlined additional information regarding ACP and how planning relates to future health care needs. A diagram on the page that outlined planning in the present and the future also linked to information about mental capacity and circumstantial needs, as well as additional opportunity to access the "FAQ" section. Additional links on the page were available to access major topics in ACP including "5 Steps of ACP" that included a focus on the words "identify", "learn", "think", "talk", and "include"—as well as interwoven stories of the six characters mentioned earlier. This section also provided opportunity to access the section, "Who is ACP for?" that focused on different groups that ACP may be for—including "children and teenagers", "healthy adults", "adults living with chronic illnesses", and "adults who are not mentally capable". Finally, three resources in this same section focused on First Nations, Indigenous, and Métis participants. In addition to the six videos featured in the "Resources and Educational Support" section that I named above, this page on the website included a seventh video, "The Time is Now", that was produced by the Improving End-of-life Care in First Nations Communities (EOLFN) research team at Lakehead University (HPCO, n.d.-y) as well a poster and brochure.[172] Finally, this page of the website included links to "ACP Conversation Starters" and the "ACP Workbook" with four distinct sections focusing on the SDM, questions for one's

[172] I note here that while situated on a webpage of the mainstream ACPO website, these First Nations, Indigenous, and Métis resources were not created by the ACPO, but rather, were produced by the *Improving End-of-Life Care in First Nations Communities* research team from Lakehead University, as noted in the video, brochure, and poster credits. Additionally, the poster and brochure acknowledge joint partners including the Government of Canada, *The Way Forward*, *Quality End-of-Life Care Coalition of Canada*, *Canadian Hospice Palliative Care Association* and the *Canadian Institutes of Health Research* who provided a grant focused on "Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development". Like my note regarding the previous six videos mentioned earlier in this chapter, in congruence with guidance from an APA style guide consultant, I am duly crediting the creators of these resources here. But for brevity, I will not be repeating this information regarding the producer with each reference in the chapter. Rather, I will simply cite the webpage where the resource is located, mindful that the creator of the video has been fully acknowledged.

health care team, a values reflection exercise, and a final section related to ACP questions. Finally, opportunity existed on this page to answer the "Six Questions" addressing themes including health, important information, concerns, worries, values, and meaning at end-of-life.

The final section "Substitute Decision Makers" (HPCO, n.d.-r) that I examined was focused on the SDM role in ACP. The page outlined some background information about the SDM role and a link to a video, "Confirming Your Substitute Decision Maker in Ontario". The page also invited participant engagement through access to several links including, "Making Decisions for Others", "Who is My SDM", "When do SDMs Make Decisions", "How do SDMs Make Decisions", exploring "Attorney for Personal Care", and finally the link "I am an SDM". Opportunities were provided to click on a link, "If you are an SDM", and another link inviting one to "Go to My Substitute Decision-Maker Card", and finally "Go to the five steps of ACP". This section offered information about who, when, and how the SDM would make decisions, including a hierarchy of decision-makers defined by legislation. Having provided an overview of the website components examined with the MCDA tools of inquiry, I move next to the findings of my examination focusing on elements of discursive scripts that were identified within these sections I analyzed related to the interwoven themes of spirituality, death, and values.

4.3 Part 1: MCDA Findings

In Chapter 3 I outlined the MCDA tools of inquiry that would be utilized in this examination of the ACPO website with a focus on my main research question: how is spirituality situated in ACP resources found on the ACPO website? And secondly, my analysis also responds to my first research sub-question—what discourses related to spirituality, death, and values might be present or absent on the website? Below I present the findings of my MCDA

examination focusing on these questions.[173] Congruent with my research question focusing on the three interwoven aspects of spirituality, death, and values, I divided my MCDA examination into three sections that I articulate below including sections addressing findings of discourses related to spirituality, discourses related to death, and discourses related to values. I offer my findings in Part 1 of this chapter by reflecting on some of the elements of potential discursive scripts I observed across the website. I then outline in Part 2 of this chapter the findings that I observed in the coding and theme generation process utilizing reflexive TA. I begin with my findings regarding discourses related to spirituality.

4.3.1 Hints of Discourses Related to Spirituality on the ACPO Website

Explicit References to Spiritual/Spirituality. I begin my presentation of findings by focusing on explicit discursive references related to spirituality. It is important to acknowledge that the words "spiritual" and "spirituality" are only explicitly mentioned in the text three times on the entire ACPO website. The first mention is in the preamble to the "Values Exercise" (HPCO, n.d.-u) where the word "spiritual" is situated in the context of an ACP workbook where the content-producers reference "spiritual beliefs" (para. 1) among a longer list of factors related to one's "personal experiences" (para. 1). Secondly, the exact same paragraph that references "spiritual beliefs" here is duplicated verbatim on the "Think About What's Important to You" page (HPCO, n.d.-t, para. 1). This second reference has a different context within a five-step process that is presented in the ACPO website that I will refer to later in this section. Finally, the third reference is related to the word "spirituality" and listed among a longer list of values in the

[173] I note here again that I will address my second research sub-question, "What bioethical values, principles, assumptions, and ideologies might be embedded within these discourses", later in this chapter. My third research sub-question, "What are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization?", will be addressed in Chapter 5.

"Values Exercise" section (HPCO, n.d.-u, section 2, bullet 8). Here "spirituality" is listed among a "brief list of personal values" (section 2, para. 1) with an invitation to consider which value would be of most importance to the participant. These are the only explicit textual references to "spiritual" or "spirituality" across the ACPO website.[174] Having located these words as starting places, I share my findings regarding what hints of discourse and meaning potentials that might be present in these explicit references.

Drawing on the MCDA tools of inquiry outlined in Chapter 3, I examined these three explicit references to "spiritual" and "spirituality" as starting points to explore meaning potentials, focusing on how spirituality might be situated and what discursive hints may be present contextually. As noted above, two of the three mentions of the words "spiritual" and "spirituality" occur on the same webpage in the online workbook page "Thinking About Values" (HPCO, n.d.-u) under the main heading "Think about what is important to you". This section includes a short introductory paragraph where the first reference to "spiritual beliefs" is found in the second sentence amidst a list of other aspects of life. The brief paragraph reads as follows:

> Who we are, what we believe, and what we value are all shaped by our personal experiences. Our cultural and personal values, family traditions, spiritual beliefs, customs, work, and those close to us affect us deeply. This is important whether you are healthy or if you are living with a health condition (HPCO, n.d.-u, para. 1).

[174] I also note here that while I suggested in Chapter 2 that my approach sees spirituality as encompassing religion, because of the closeness of these words to spirituality in the public sphere, I did scan the website for explicit lexical references to "religion" and "religious" as well, mindful they can be key aspects to spirituality for many Canadians. Evidently, I found one mention of "religion" in the ACP section of the "Resource Guide" (HPCO, n.d.-b, question 10, para. 6) in relation to the potential source of one's values and beliefs—a reference that I will discuss later in this chapter when I address the presence of values on the website. Additionally, I found the word "religious" referenced one time in relation to a conversation around ceremonies and readings at the end-of-life in the "Six Questions" section (HPCO, n.d.-q) that I will address in the section ahead in my findings related to death.

Engaging in an MCDA examination of this paragraph as a starting point, I explored what hints appear in this short paragraph that might reveal how spirituality is situated more broadly. I outline my findings in the paragraphs to follow beginning with evidence of a sort of overlexicalization.[175]

Examining the Context of Explicit References to Spiritual/Spirituality. Applying the MCDA tools of inquiry to this paragraph above with the explicit reference to "spiritual beliefs" reveals several elements that hint at a potential discursive script. In analyzing the first sentence of the paragraph (HPCO, n.d.-u, para. 1) that serves as a pre-cursor to the reference to "spiritual beliefs" found in the second sentence of this same paragraph, there are several flags that arise. The first flag is the presence of the pronoun "we" repeated three times in succession to begin the sentence: "Who we are, what we believe, and what we value". This repetition invites several questions regarding what might be accentuated here with this obvious repetition. The second flag is at the end of this same sentence with a suggestion that one's beliefs, values, and identity are "all shaped by our personal experiences". I outline my reflections around these references in the paragraphs to come beginning with an analysis of the repetition and potential overlexicalization of "we" in the first part of the sentence.

Overlexicalization signifies a repetition, overemphasis, or over-persuasion of some kind, and the three-fold use of "we" as a pronoun in this short sentence (HPCO, n.d.-u, para. 1) could suggest that "we" is overly emphasized. This repetition could imply a potential commitment by the content-producer regarding their beliefs, values, and identity. And then a question arises—what commitment is potentially being suggested? There is a discursive possibility that the three-

[175] As alluded to in Chapter 3, overlexicalization refers to overly repetitious use of words or excess describing that may suggest "over-persuasion and is normally evidence that something is problematic or of ideological contention" (Machin & Mayr, 2023, p. 54).

fold "we" presented here suggests an implicit structural opposition[176] where "we" may be subtly contrasted to the "other" that creates poles of "us" and "them". And this begs the question—who might be the "us" and who might be "them"? The second half of this short sentence provides some possible clues. After outlining the three-fold pronouns of "we" in relation to one's beliefs, values, and identity, the second half of the sentence suggests they are "all shaped by our personal experiences". One understanding of this could be that this segment could signify a subtle foregrounding of a philosophical commitment to seeing one's identity, values, and beliefs as being *only* shaped by "personal experience" rather than an openness to other spiritual belief systems rooted in ontological perspectives that include other beliefs—including an omnipotent creator involved in shaping, or even creating, the entirety of one's life and human identity.[177] This conversation around the shaping of one's identity, beliefs, and values matters to ACP because one's understanding of identity may include theistic beliefs of life being divinely created which may impact one's health care decisions based on values related to respecting the sanctity of their divinely created self.[178] Utilizing another tool of inquiry, one could also describe the possibility of a subtle recontextualization[179] happening here with the vague suggestion of spirituality being rooted only in one's personal experience rather than openness to other ontological perspectives. This view is foregrounded while an openness to other unnamed

[176] Structural opposition is noted by Machin and Mayr (2023) as the introduction of "opposing concepts" by the author. Examples of this could include suggestions of "us and them" or "good and bad".
[177] I will touch on themes of epistemological closedness and openness in my discussion in Chapter 5. But I will suggest here that Taylor (2007) alludes to a modern shift from an openness to the supernatural and transcendent, to a closed "self-sufficient immanent order" that emerges "without reference to God" (p. 543). Further, Taylor suggests this immanent frame in the modern age "will accept no transcendent hope beyond history" (p. 586). This dovetails with the closed statement I am naming here in the ACP resources that names only "personal experiences" as shaping one's identity—a subtle choice of words that may reveal a philosophical leaning while potentially excluding spiritual belief systems that include a transcendent force like a divine creator.
[178] The Roman Catholic tradition is an example of the sanctity of a divinely created human life that would impact decision-making significantly. I address other Catholic themes like meaning and quality of life later this chapter.
[179] Recontextualization suggests "language is used to transform events and practices with elements being changed, replaced, simplified or removed" (Machin & Mayr, 2023, p. 321).

creation-oriented ontologies and beliefs systems are backgrounded—or even non-existent, like that of Roman Catholic belief systems where there is a belief that through a creative divine act, "God imparted to human beings…a spiritual soul, which was made to be 'in the image' of God" (Moraczewski, 2009, p. 3). Hence, much may be philosophically missing, omitted, or simplified in this brief sentence, "Who we are, what we believe, and what we value are all shaped by our personal experiences" (HPCO, n.d.-u, para. 1), including the view of spiritual traditions that suggest one's identity is not only formed by personal experience but something divinely "imparted" to humans.[180] This is important to my research question in assessing how spirituality is positioned because these hints of language found in the ACP resources contribute to an overall assembling of a discursive script that helps reveal how spirituality is positioned discursively. And this examination of spirituality's current positioning will help to identify areas for future development to enrich patient-centred approaches to ACP that help deepen one's decision-making opportunities in alignment with one's spiritual beliefs.

Another subtle hint of a discursive script found in this first sentence of this opening paragraph that I have been examining (HPCO, n.d.-u, para. 1) involves the word "experiences". With the sentence suggesting, "Who we are, what we believe, and what we value are all shaped by our personal experiences" (para. 1), there may be evidence of limitations being placed on who might be able to *experience* life. In focusing on personal experiences to shape one's identity,

[180] Also missing here is acknowledgment of any sort of tension experienced by humans regarding beliefs around how the human is shaped—whether only by personal experiences, as noted by the ACP content-producers, or through other options like theistic perspectives of a divine creator. With the suggestion of one poll (Ipsos, 2017) that 27% of Ontario respondents considered themselves "spiritually uncertain", there is a sizeable group accessing ACP resources who are in a space of uncertainty of where they position themselves spiritually. I link this to Taylor's (2007) reference to a tension in the modern individual where, despite a larger "spin of closure" (p. 549) regarding a larger transcendent picture, there is the presence of cross pressures involving personal debate between this closed immanent order, and a sense of cosmic meaning and belief, "in some transcendent source or power" (p. 600). I will return to these themes intersecting with moral reflection and decision-making in the discussion in Chapter 5.

there is a backhanded implication that one must experience life cognitively and socially which may exclude those with less capacity for experience or those at different stages of development as humans. This intersects with work by Liégeois (2021) who advocates for those with disabilities and without rational capacity, as well as Catholic perspectives, as noted above, where the dignity of the human person is connected to one being made in God's image. In naming only experience, I see hints of a subtle socio-cognitive perspective being foregrounded that may demonstrate closure to some beliefs and therefore be limited in its applicability to a broad audience. Having examined only the first sentence of the first paragraph thus far, I now expand the conversation to include the second sentence of the opening paragraph of this section that contains the word "spiritual" and with it an exploration as to how it is positioned.

Examining the Positioning of the "Spiritual" Within a Larger List. Having identified hints of a potential discursive script related to the limited ontological positioning of how one's identity, beliefs, and values "are all shaped by personal experiences" (HPCO, n.d.-u, para. 1), and how this may omit some theistic perspectives from the conversation, I move the conversation to the inclusion of "spiritual beliefs" within a larger list within this paragraph. In the second sentence of the paragraph the content-producers provide a list of examples—presumably connected to these personal experiences that provide one's shaping. And here the phrase "spiritual beliefs" is encountered for the first time, tucked into a larger list of one's experiences with a summary statement at the end of the sentence declaring that all these factors "affect us deeply". Before addressing the meaning potential in this concluding phrase, "affect us deeply", I want to examine the content-producer's choice to situate "spiritual beliefs" within this larger list of factors that have this kind of "deep" influence. I provide the quote again for convenience: "Our cultural and personal values, family traditions, spiritual beliefs, customs,

work, and those close to us affect us deeply" (HPCO, n.d.-u, para. 1). In examining this list, one can see the items named include a broad selection of influences on one's life including values, culture, one's work, family, as well as those living close to us. But what can be made of "spiritual beliefs" being inserted in the middle of this larger list of diverse influences like this? On the surface, it is vague and unclear what is meant by "spiritual beliefs" as there is little elaboration. And more than the vagueness of this reference without additional explanation, I also observe that the reference to "spiritual beliefs" is not lexically positioned in a place of prominence in this sentence, but rather, buried in a larger pack of other influences including factors like one's work and people living close by. This suggests to me a subtle backgrounding of spirituality—a tendency to bury spirituality in the pack without giving it much attention. Additionally, one could also point to the length of this paragraph (3 sentences) as well as the abstract reference to "spiritual beliefs" that has little elaboration that could suggest a level of hiddenness, or a suggestion that the topic is needing to be named, but not one that the content-producers are wanting to highlight or discuss at length. There seems to be a peripheral quality to the spiritual that is presented. But in moving my analysis to the end of this second sentence, a peculiar phrase is used that suggests these miscellaneous factors—that includes this reference to spiritual beliefs—indeed "affect us deeply". But once again there is no elaboration given. What could this arbitrary reference to depth without explanation mean to how spirituality is situated? I will address this question next.

The Utilization of "Deeply" in Relation to Spiritual Beliefs. Having presented the reader with a brief list of the personal experiences that *shape* one's identity, beliefs, and values—that includes one's spiritual beliefs—the sentence ends with a summary phrase suggesting that these factors "affect us deeply" (HPCO, n.d.-u, para. 1). Considering the paragraph is a total of three

sentences with little elaboration, one must ask what the content-producers might be suggesting here lexically with a brief reference to this depth of influence without any deeper articulation. In my multimodal examination of other parts of the website, it appears that lexical precision and elaboration is frequently offered to explain key concepts,[181] as well as the frequent use of bullet points to clarify the arguments they wish to lay out more succinctly. But here they have chosen a short three-sentence narrative paragraph without addressing the "deeper" complex and multidimensional themes they suggest as affecting us deeply. I see evidence of the MCDA tool of inquiry named as "presupposition" in this phrase where assumptions are being made regarding the meaning of this depth they refer to. There is an implication that the meaning of what affects us "deeply" has already been established and not needing elaboration—this despite the diversity of beliefs that may be present in ACP participants that would suggest a need for more dialogue. Additionally, focusing on how actions are represented in this case, I observe an abstraction present in the word "deeply" that implies a mental or even an existential process they are seeking to put in motion without naming it. This implies a larger expansive conversation that is not elaborated upon. Additionally, the reference to "deeply" raises the emotive value of this section and signals another dimension below the surface that is not being addressed despite significant personal impact. But it is not addressed further. Despite the weighty implication of the spiritual, little detail is given in such a short and abstract paragraph of three sentences suggesting the content-producers do not need to, or do not wish to, address it further—instead, choosing to move on to issues they seemingly *do* wish to address. Contrary to the suggestion of Churchill

[181] See the "Advance Care Planning" section of the "Resource Guide" (HPCO, n.d.-b) for examples that includes five of the questions with "wish" in the title, including significant medical-legal detail about wishes in numerous situations like whether one can put their wish in writing (Question 7), how "wishes" are not decisions (Question 10), or the nuances of general versus capable wishes (Question 12). I will explore the focus on wishes as opposed to values in greater depth later in this chapter focusing on hints of discourses related to values.

(2015) of the importance of the deep reasons being underneath ACP processes, there appears in this reference on the ACPO website only a brief and peripheral flash of a deeper dimension—with little elaboration as to how one might acknowledge, engage, or integrate this depth into their ACP planning. And what do the content-producers wish to address if not what affects one deeply? The brief paragraph ends with a third and final sentence that abruptly provides a strong indicator of modality[182] with a level of authority suggesting: "This is important whether you are healthy or if you are living with a health condition" (HPCO, n.d.-u, section 1, para. 1). I observe the fulfillment of the two abstracted sentences above with another abstraction suggesting, "This is important" without clarity around what "this" might be referring to—be it the depth of the conversation, the spiritual beliefs, or the larger list of factors. There is simply a lack of elaboration I observe in this brief three-sentence treatment of spirituality. What meaning potentials could these hints of a vague and brief treatment of spirituality without elaboration suggest? Additional context and hints of a possible discursive script are found in the "Values Exercise" on the same webpage. I will examine this section next.

Examining the Explicit Reference to Spirituality in the "Values Exercise". Having outlined some of the potential threads of discourse found in the short three-sentence introductory paragraph featuring the explicit mention of "spiritual beliefs" together with the unaddressed phrase "affect us deeply", I now turn my attention to further multimodal findings in helping uncover meaning potentials. I move to the second explicit mention of spiritual/spirituality that is found on the same page of the website—this time tucked into a larger bullet list of values that follows this three-sentence introductory paragraph referenced above. The bullet list of values is located within a graphical section of the "Values Exercise" that encourages readers to "think

[182] Modality in MCDA is "an author's commitment to the truth of a statement or necessity" (Machin & Mayr, 2023, p. 319). High modality would suggest an author is strongly committed to a perspective.

about common values" (HPCO, n.d.-u, section 2, bullet 1) and invites participants to choose which one is most important. The section includes a list of values, presumably chosen by ACPO content-producers, that are listed in the following order: "Dignity", "Independence", "Wellness", "Clear-mindedness", "Family", "Hard work/dedication", "Strength", "Spirituality", "Not being a burden", and "Relationships"—as well as a space in a text box to identify "Others".[183] In assessing the layout of the bullets and their ranked order by the content-producers, it may be revealing that "spirituality" is listed as just another value alongside other values like "strength", "hard work" and "not being a burden". Examining further, one can see by the absence of alphabetization, that the content-producers had a choice to privilege any one of these values through their positioning in the order of listing.[184] It is with this ranking that I see potential for a subtle nudge by content-producers of a preferred "sequence of behaviour" in ACP as Machin (2013, p. 352), inspired by the work of van Leeuwen and Wodak (1999), would suggest. There is a higher level of modality and commitment regarding the ranking of values here and the subsequent evaluative leanings that are seemingly demonstrated. The word "spirituality"—while named and included—is simply not high on the list (named 8th out of 10 values in the list of tick box options).

Further, when given an empty graphic text box on the webpage that invites further reflection with prompting questions spirituality is not chosen as something needing elaboration with its own box. Despite suggesting earlier in the page how factors like identity, beliefs, and values "affect us deeply" (para. 1), there is no explicit space given for exploration of this depth

[183] I note here that this list will be examined here in the context of "spirituality" while later in this chapter I will return to this same list in the "Values Exercise" and examine the list from a "values" perspective.
[184] As Ledin and Machin (2018) suggest, an institution that is creating lists has power to "be in control of the knowledge involved" (p. 166) which in this case may be to prioritize what might be higher on the list and what they choose as worthy of highlighting by placing it in a position of prominence.

for the very category—spirituality—that may invite this very depth they reference. In contrast, space in the design privileges two reflective questions about the value of dignity, two questions inviting thoughts on the value of independence—and finally a single question regarding family (HPCO, n.d.-u, section 3, text box 7). Again, this suggests to the reader a sequence of suggested behaviour that is linked to values focusing on dignity and independence. Fairclough (2003) would name this kind of privileging as a dynamic that reveals hints of evaluation, where what is desirable for the content-producers is evident in the resource provided. In terms of assembling a discourse, the situatedness of spirituality here is not unlike the previous discussion regarding "spiritual beliefs" (HPCO, n.d.-u, section 1, para. 1) outlined in the paragraphs above with spirituality being vaguely positioned on the periphery of a larger group of influences without need for elaboration or additional reflection. Further, the categorization of spirituality as a value among a list of other values in this section provides an additional hint of how spirituality is viewed. It is this finding I address next.

Exploring the Positioning of Spirituality as a Value Among Other Values. An additional element to the discursive script related to spirituality in the "Values Exercise" on the ACPO website is the explicit positioning of spirituality as a value. This section expresses this in no uncertain terms when it introduces spirituality as part of a "brief list of common values" (HPCO, n.d.-u, section 2, para. 1) alongside values like "hard work", "strength", and "independence". Why is this positioning of spirituality as a value important? As I noted in Chapter 2, the definition of spirituality is complex and the interplay between values and spirituality is critical as one's values can be rooted in one's spirituality. I reiterate McPherson's (2015) suggestion that spirituality is not a value itself but "a practical life-orientation *towards what is seen as being of great value*" (p. 336, italics theirs) and a movement towards what we see

as good that connects to a larger "vision of spiritual/ethical fullness" (p. 337). Spirituality is seen not as a value per say but a larger "project of life-integration" as Schneiders (2003, p. 166) suggests—a complex domain that includes one's orientation to ultimate values. Additionally, considering the website is sponsored by HPCO, which is rooted in a palliative care philosophy, their approach to spirituality seems like it may be incongruent with a larger body of thinking regarding spirituality in palliative care circles. The international consensus definition from the field of palliative care, as noted in Chapter 2, by Puchalski et al. (2014) suggests spirituality as being "a dynamic and intrinsic aspect of humanity" that is "expressed through beliefs, values, traditions and practices" (p. 646).[185] What is important in this palliative care definition is that spirituality is not considered a value in itself—but rather spirituality is *expressed* through one's values and beliefs. But in the "Values Exercise" I observe that rather than one's "ultimate meaning, purpose and transcendence" being *expressed* in one's values and beliefs, as reflected in the palliative definition, the positioning of spirituality on the ACPO website seems to portray spirituality as simply one value among other values.

Finally, in addition to the inclusion of spirituality as one value among many on this list in the "Values Exercise" (HPCO, n.d.-u), another finding is the absence of any reference to potential challenge or struggle regarding value reflection and prioritization—especially regarding spirituality. While end-of-life research suggests many complications regarding values and spirituality, including Ontario research by Sibbald and Chidwick (2010) that observe God and religious values were the main theme in eight of twelve of the cases taken to the Consent and

[185] I repeat here the entirety of the definition of spirituality agreed upon by the international palliative care community: "Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices." (C. M. Puchalski, Vitillo, et al., 2014).

Capacity Board; and research by Bandini et al. (2017) suggesting 25% of conflict at end-of-life involves religion as the main factor, there is an uncomplicated picture of values reflection and spirituality presented. The mainstream pages on ACPO website seems devoid of acknowledgement of the conflicts looming in family discernment and prioritization of choices.[186] While the ACPO website seems to be alluding to a dimension of value reflection that indeed "affects us deeply" (HPCO, n.d.-u, para. 1), as noted above, there seems to be instead the exact opposite in the tool, an almost superficial quality to this exercise that ignores the more challenging themes related to ultimate beliefs and the potential complexity of spirituality by not inviting more reflection. And further to this apparent simplicity, the website tools of discernment do not seem to acknowledge the emotional and intuitional aspects of values that might intersect with this desired depth—rather, the questions seem to be reason-focused with instrumentally focused tick boxes suggesting an ease of cognitive choice. This positioning is in contrast to work by Nullens (2017) I noted in Chapter 2, who suggests that orienting values are "not primarily known cognitively, but intuitively and emotionally" (p. 41). I observe no reference to these aspects of discernment in the "Values Exercise" that touch a deeper place in the human journey. Having addressed the first two explicit references to the spiritual/spirituality, I now move the conversation to the third and final explicit reference to spiritual/spirituality on the website—a lexical duplication of the earlier paragraph that again includes the phrase "spiritual beliefs" but in a different context revealing additional hints of spiritual discourses related to wellbeing, meaning, and quality of life.

[186] Lazenby et al. (2014a) describe some of the struggles surrounding death quite evocatively: "The waters of death are treacherous, and navigation is perilous. Clinical, psychological, social, economic, political, and spiritual currents all converge on death" (p. 257). It is the naming of these challenges I observe to be absent on the ACPO website.

The Positioning of Spirituality with Wellbeing, Meaning, and Quality of Life. Having examined the first two explicit mentions of spiritual/spirituality in the paragraphs above, I now move to the third and final explicit reference of "spiritual" and with it some additional hints of a possible discursive script. This third reference to "spiritual" occurs in a paragraph that is identical to the one referenced above that includes one's "spiritual beliefs" and that phrase I have been highlighting—in what may "affect us deeply.[187] The difference in this third reference to "spirituality" is that this identical paragraph to the one located in the "Thinking About Values" section (HPCO, n.d.-u), is positioned with a different context focusing on the "thinking" aspect of the "Five Steps" section (HPCO, n.d.-t) of the ACP process—a context that may provide additional discursive hints of a larger script. The context of this paragraph includes the heading "Think about what's important to you" (HPCO, n.d.-t) and invites individuals, once again, to think about what is important to them. But in this reference, the context of the same sentence examined earlier—"Our cultural and personal values, family traditions, spiritual beliefs, customs, work, and those close to us affect us deeply" (HPCO, n.d.-t, para. 1)—includes a bullet point before the paragraph, that frames the context differently by noting: "Think about what is important to you when it comes to your health and wellbeing" (HPCO, n.d.-t, bullet 1). In this context I observe a few additional hints of a potential discursive script related to spirituality including the apparent link with one's health and wellbeing. This is important to this examination of spirituality because it seems to hint at spirituality being understood more in terms of physical health and wellness instead of the more transcendent understandings of spirituality

[187] For convenience I offer the paragraph referenced above once again here for easy reference: "Who we are, what we believe, and what we value are all shaped by our personal experiences. Our cultural and personal values, family traditions, spiritual beliefs, customs, work, and those close to us affect us deeply. This is important whether you are healthy or if you are living with a health condition" (HPCO, n.d.-u, para. 1; HPCO, n.d.-t, para. 1).

that are common in many mainstream spiritualities including Abrahamic faiths of Christianity, Islam, and Judaism (Balboni & Balboni, 2019). But what are the meaning potentials here?

In exploring this reference to "health and wellbeing" further in the context of its positioning on the same page alongside references to phrases like "spiritual beliefs" and what may "affect us deeply" (HPCO, n.d.-t, para. 1), another potential hint of discourse is observed. In these phrases being grouped together in proximity there appears to be a subtle suggestion of spirituality being related to more physical aspects including one's health and wellbeing, rather than the potential for deeper ontological aspects of identity, values and belief that many would connect to dimensions that "affect us deeply" (para. 1). While this reference provides only a hint of a meaning potential, when broadening the examination further to include the entire page where these messages are found, there are additional hints that suggest these elements may be woven together in a cohesive whole. Additional examples of spirituality being connected to physical aspects like health and wellbeing occur a few lines lower on same webpage where there is an additional invitation for individuals to reflect on two linked questions combined in a single thought bubble graphic that asks: "What gives your life meaning?" and "What brings quality to your life" (HPCO, n.d.-t, section 2, box 1). It would appear the spiritual landscape is getting increasingly crowded in this small section with references to spiritual beliefs that "affect us deeply", to "health and wellbeing", to "meaning"—and finally to "quality". But how might it all fit together? While there is once again no elaboration, I observe some hints of a larger discourse related to spirituality with the close relationship between meaning and quality of life in the thought bubble graphic. This link is important because it appears that the content-producers have boiled the conversation around the depth of one's spiritual beliefs and wellbeing down to these two questions in a pop-out box focusing on meaning and quality in one's life. But once again, as

noted above in other references to spirituality, there is no elaboration on how meaning and quality are understood individually—or in relation to each other. There seems to be only a presumption that previous knowledge of these terms is well understood. With meaning being so central to many understandings of spirituality, the relationship between meaning and quality is an important connection to distinguish. How are meaning and quality of life understood in this section? There is no elaboration. But are there other hints in other areas of the website that can provide other hints of a discursive script? These questions are essential to my dissertation because the spiritual notion of meaning is unique to individuals of different spiritualities and can include physical aspects, but understandings of meaning can often include aspects of transcendence for many belief systems[188] that can be an important aspect of discernment of values that is central to ACP reflection. These terms—meaning and quality of life—are deserving of more examination in the ACP website. I start by exploring hints of possible meaning of references to meaning in the ACP resources and will then address quality.

Exploring Discursive Hints Interwoven with Meaning. Still exploring the explicit reference to "spiritual beliefs" on this page and the possible larger context that may bring more understandings of a discursive script on this page, I focus the conversation to the notion of meaning and how it may be understood more contextually on the website. Mindful of the potential link between meaning and quality of life that I observe in the "Thinking about what's important to you section" (HPCO, n.d.-t), and the possible meanings regarding spirituality, I begin by unpacking hints of meaning potential of the word "meaning" across the website to provide greater context. When explored more broadly on the website, understandings of the word

[188] Taylor (2007) explores the notion of cosmic meaning within an ordered universe, suggesting, "The dawning sense in modern times that we are in a meaningless universe, that our most cherished meanings find no endorsement in the cosmos" (p. 587). This question of meaning is at the heart of patient-centered care.

"meaning" seem ambiguous and unexplored. There is no definition presented in the "Glossary", "FAQ", or "Resource Guide". And while the palliative care consensus definition noted above (C. M. Puchalski, Vitillo, et al., 2014) suggests one's *ultimate* meaning is a significant part of spirituality, no reference or allusion to ultimacy in meaning seems to be found on the website. But rather, what appears is a vague link of one's meaning to one's immanent physical health and wellness. For example, in examining the "Six Questions" section (HPCO, n.d.-q), there are two reflection questions asked, "What do I value most?" and "What brings quality or meaning to my life?" (Section 3, question 3). Here again I observe hints of meaning potential. Not only do the words "quality" and "meaning" seem linked closely in this reference but there are some additional clues provided in an answer to the question offered by content-producers in the text. The answer provided by the content-producers regarding the question of "What brings quality or meaning to one's life" is: "Most people have an idea of what a 'good life' is. Take some time to think about the things that make your life good and enjoyable" (HPCO, n.d.-q, section 3, question 3, para. 1). Here it would seem the content-producers are providing their preferred answer to their own question about meaning in the description in the second sentence of this paragraph where it notes: "the things that make your life good and enjoyable". This phrase would suggest both a possible conflation of meaning with quality—and more, an articulation that meaning and quality might mean to them what is "enjoyable". This is important to my dissertation because it positions the spiritual dimension of meaning in the realm of the experiential or even physical aspect of life rather than opening potential diverse understandings of meaning that may include transcendence. In contrast to a deeper *ultimate* definition of meaning suggested by M. Puchalski, Vitillo, et al. (2014) in the international palliative care definition, this understanding of meaning presented in the ACPO website appears more

physically-oriented based on life enjoyment rather than understandings of ultimate meaning found in some spiritual belief systems like Muslim spiritualities where expressions of meaning may be tied to non-physical domains related to death and the afterlife including aspects of one's righteous deeds and suffering (Al-Shahri, 2014), or Roman Catholic suggestions of there being meaning in suffering that includes spiritual, emotional, and psychological aspects (Gross & Hilliard, 2009) to one's faith. These understandings of meaning are not necessarily linked to in-the-moment "enjoyment" that the ACPO understanding of meaning might suggest. Rather, examples from Abrahamic faiths[189] as noted above tend toward transcendent expressions of spirituality that may include challenges like suffering rather than in-the-moment enjoyment—aspects of meaning that may be missing from ACP resources.

Further hints of a more physically oriented understanding of meaning can be found once again in the "Six Questions" section (HPCO, n.d.-q) where another question hints at an understanding of meaning related to a physically oriented notion of time: "If you were near the end of your life, what would make this time meaningful?" (section 3, question 6). Not only is this reference to meaning focused on in-the-moment aspirations in making the time one has as a meaningful experience within the present moment, the options provided by content-producers also place meaning more immanently.[190] The information provided in the bullet points that are connected to these questions seem to provide options that place meaning into the realm of in-the-moment enjoyment and comfort including options like "Religious reading or ceremonies you want to have" (bullet 4) and "Music you want to listen to" (bullet 5) or "Where you might want

[189]Balboni and Balboni (2019) explore some of the perspectives of Abrahamic faiths in relation to healthcare and the focus on the transcendent aspects in contrast to the immanent focus in Western medicine. I will return to this conversation later in this chapter in focusing on discourses and ideological assumptions.
[190]Balboni and Balboni (2019) utilize this word immanence to describe a focus on bodily and physical aspects of humanity. I will return to this notion later in this chapter and discuss immanence further in Chapter 5.

to spend the last days of your life" (bullet 6). Meaning seems to be connected to immanent time at the end-of-life, as well as interventions that are task-focused rather than opportunities for a more transcendent sense of meaning or time[191] that takes on other understandings of time and meaning related to spiritual notions like suffering, duty, or connection to the afterlife. As there are no other articulations of meaning across the website one is left to piece together an understanding through discursive hints. And with meaning being a central aspect to spirituality, it would appear that the ACPO website seems to present a rather closed understanding of meaning focused on one's immanent physical experiences rather than an openness to the diversity of expressions of ultimate meaning connected to transcendent spiritual orientations. Having noted the explicit references to "spiritual beliefs" and how the spiritual notion of meaning may be positioned in the ACPO website using the contextual examples above, I now address the reference to "quality" on the website and explore its situatedness with meaning.

Exploring Discursive Hints Related to Quality. Having examined potential understandings of "meaning" in the section above that provide context to possible meaning potentials to the explicit mention of "spiritual beliefs", I now focus on the second question arising alongside meaning in this section—the reference to "quality" and the question raised: "What brings quality to your life?" (HPCO, n.d.-t). With quality connected closely with meaning in this website, the question remains—what is meant by this word quality? Quality, like meaning, is left similarly vague, requiring further examination more broadly on the website to discern possible meaning potentials. Discursive hints on the website seem to connect quality to

[191] The notion of "time" is a larger conversation beyond the scope of this dissertation, but I share briefly the transcendent perspectives on time by Taylor (2007) who inserts eternity into the conversation around time, suggesting it is "the philosophically and theologically consecrated term for higher time" (p. 55) that connects humans with "an impressible craving for eternity" (p. 57). Larger theological notions of time like those offered by Taylor seem to be missing from this perspective of time given by ACP content-producers that is rooted in what Taylor (2007) refers to as "the horizontal flow of secular time" (p. 59).

physical notions of health and wellness—a connection that may limit spiritual expression to quality-focused aspects of meaning, rather than open opportunities for transcendent understandings. In addition to the above example that highlights quality focusing on what may be "enjoyable" (HPCO, n.d.-q, section 3, question 3), I observe again the tendency toward the experiential aspect of life that seems linked to the physically oriented understanding of quality of life with a focus on one's experiences. For example, a story regarding one of the characters named Priya references an invitation for their daughters to reflect on what their mother might "consider to be a good quality of life" (HPCO, n.d.-n, para. 5). While little elaboration is given in this example, there is a reference in the same paragraph to physical and in-the-moment notions like walking and swallowing that suggest a physical understanding of quality. The character story focusing on the character Jacob also references physical aspects like sleeping during the day, utilizing a feeding tube, being uncomfortable, and not being able to be with his friends (HPCO, n.d.-l). Additionally, reference to the parents' decision-making in this character story is focused on the physical aspects of health with no mention of spiritual components of what quality might be. Resources like the "FAQ" section, "Glossary", or "Resources Guide" have no questions related to what quality of life might be.

Drawing from the MCDA tools of inquiry I outlined in Chapter 3, I examined the notion of "quality" further and noted other intertextual voices missing in the dialogue as it relates to quality and the connection to meaning. For instance, there is no mention of contested views regarding quality including the Roman Catholic perspective on quality of life. In *Catholic Health Care Ethics: A Manual for Practitioners,* that serves as a guide for health care in the USA, for instance, Furton (2009a) suggests the phrase "quality of life" (p. 179) as being a "much-abused phrase" (p. 179) and suggests jettisoning this term because of the concern that, "Talk about

quality of life should never suggest that the life of any patient has no value. Life itself is an intrinsic good and so always possesses values". (p. 179). Instead, there appears to be in the ACPO website, a presumptive discourse and assumption of quality of life as a central component as noted in these examples above—without elaboration, and without broader external understandings like a Roman Catholic perspective. In returning to the link between meaning and quality that seems to be presented on the ACPO website, there is a physically oriented perspective regarding quality that I observe that might suggest hints of a broader discourse of meaning and spirituality as being physical and in-the-moment as opposed to something potentially transcendent. But overall, this notion of quality of life that emerges from the section that explicitly references spiritual beliefs contains little elaboration. One is left with hints of discourse to piece together regarding what is meant by quality of life in the context of spirituality.

Having explored the references, context, and potential discourses related to the three explicit references to spiritual/spirituality on the website using the MCDA tools of inquiry and the possible meaning potentials that flow from these references including aspects of meaning and quality, I now move the conversation to implicit hints of discourses related to spirituality.

Implicit Hints of Discourses Related to Spirituality on the ACPO Website. Having examined the three explicit references to spirituality/spiritual on the ACPO website and the larger contexts where they were situated that revealed hints of discursive scripts, I now highlight my findings related to implicit references to spirituality on the website. Here the discursive exploration moves to the more nuanced and possibly hidden references on the ACPO website beginning with the lexical references and then followed by multimodal references. I start with the key words of religion/religious before examining references to "hope" that may link with

spirituality. These words are important because of their close link to many institutional expressions of spirituality that include diverse understandings that have potential to impact value reflection and decision-making. I begin by looking at references to religion/religious.

Implicit Spiritual Discourses Found in Religious References. I turn now to implicit findings related to discourses of spirituality—beginning with the spiritually oriented notion of religion/religious. Across the entire ACPO website there are only two mentions of religion/religious, including one of "religion" and one of "religious". The "religious" reference, as noted above in my examination of meaning, is an end-of-life reference to meaning and the invitation for one to consider "Religious reading or ceremonies you want to have" (HPCO, n.d.-q, section 3, question 6). The second mention of religion/religious is in the "Resource Guide" related to the origins of one's wishes with the suggestion: "The values and beliefs may be from a particular faith or religion or may be opinions of that person about the value of life and how life should be lived" (HPCO, n.d.-b, question 10, para. 6). Similar to the lack of context and elaboration regarding "spiritual beliefs" and the reference to the origins of one's beliefs that I noted earlier in this chapter, this section too introduces the origins of one's values through the mention that one's values "may be from a particular faith or religion"—but, again, with no elaboration as to how this might be relevant to ACP processes and value discernment.[192] Considering the importance of religion in Canadian society, and polling suggesting 68% of Canadians have a religious affiliation (Statistics Canada, 2021), I observe a hint of a discursive script here again with the peripheral and vague addressing of religion in regards to ACP decision-making processes. With only two mentions in the entire website there seems to be a discourse that suggests some gatekeeping around these themes and a potential closedness

[192]Additionally, I note there that I will address the nuances of this mention of religion later in this chapter in relation to how values and wishes are presented.

regarding integration. And knowing, once again, of the prevalence of conflict related to religious beliefs intersecting with end-of-life decisions in the literature as noted above (Bandini et al., 2017; Sibbald & Chidwick, 2010), it seems odd that spiritual themes, while named vaguely and without elaboration, are seemingly being kept to the periphery. Connected to conflicts related to end-of-life, I examine next another hint of discourse related to spirituality—the theme of hope.

Implicit Hints of Spiritual Discourses Related to Having Hope. Having addressed the lack of inclusion of religion as it relates to spirituality with only two references to religion/religious with little elaboration, I now turn to a related theme that appears rather abruptly in the "Six Questions" page of the website (HPCO, n.d.-q, section 3, question 2)—the theme of hope and the link to miracles. While I have suggested a peripheral inclusion of spirituality in the list of values on the website and the allusion to religion above, the implicit spiritual theme of hope arises in the "Six Questions" section related to ACP under the question, "What information would I like to find out" section (HPCO, n.d.-q, section 3, question 2). The text reads as follows:

> Some people feel it is very important to always maintain hope. This may even be when a person is very, very sick. It is possible to be hopeful and believe in miracles and at the same time think about, talk about and prepare for the future. Remember that ACP is about preparing your SDM(s) in the event that you are unable to make decisions for yourself…Let your healthcare team know if it is important for you to stay hopeful through this conversation. Also, let your health care team know how you would prefer to be given 'bad news' (HPCO, n.d.-q, section 3, question 2).

While this paragraph does not mention spirituality, it seems to reveal a positioning of spirituality with the suggestion of the spiritual notion of hope that is seemingly linked here to religion. With

the reference, “It is possible to be hopeful and believe in miracles and at the same time think about, talk about and prepare for the future” there seems to be an abrupt lexical connection being introduced between one’s understanding of “hope” and that of “miracles”. My analysis reveals some apparent presumptions regarding the word “hope” here and what I see as a curious leap to that of physical miracles. There seems to be an intertextual undercurrent here where additional dialogue seems to be missing. There seems to be assumptions present in this section but the content-producers do not elaborate more. This move from “hope” to “miracles” seems abrupt and unexplained, and again, the lack of elaboration might suggest an undercurrent of a contested dialogue that is not being disclosed. It could appear, in my opinion, that instead of addressing “hope” as a spiritual aspiration towards a larger transcendent reality that may include beliefs around heaven, or even hopeful aspirations that many spiritual traditions may take, in this case, “hope” seems to be explicitly connected to the solely physical aspects of healing and a miraculous physical intervention—and I suspect with possible links to religious conflicts in landmark bioethical cases.[193] But it is the randomness of this reference and the lack of context that makes the reference noteworthy and a signal of a larger discourse that may be present.

Another hint that a discourse may be present here in this paragraph involving “hope” and “miracles”, as quoted above, is the utilization of “very” two times to mention a patient being “very, very sick” (HPCO, n.d.-q, section 3, question 2)—a repetition and potential overlexicalization which may suggest a discourse that may be present. The inclusion of “very” twice could possibly suggest the need for content-producers to persuade an unbelieving reader, or possibly an emphasis on articulating a higher level of sickness where “miracles” would

[193] I reference the work by Bandini et al. (2017) here once more and their finding that 25% of conflicts at end-of-life involve themes of religion and miracles. This suggests miracles may be a larger theme than the ACPO resources acknowledge and may be deserving of greater attention.

certainly not be possible. It is unclear what is happening here from a meaning perspective. Additionally, there is some clear hedging[194] in this paragraph with phrases like "This may" and "It is possible" that may introduce some doubts or unnamed beliefs. Also, the reference to "Some people feel" at the beginning of this paragraph does suggest a possible structural opposition being set up, that in my opinion, might suggest the "other" regarding beliefs and the potential for "us" and "them" language that could possibly have some powerful undertones with a possible explanation as the "us" being medical culture, and "them" being those who believe in miracles. Again, there is no elaboration. To further this potential structural opposition, there is in my opinion, a hint of authority and perhaps a paternalistic suggestion in the saying, "Remember, that ACP is about preparing your SDM(s)" (HPCO, n.d.-q, section 3, question 2) that could potentially be viewed as a chastisement or warning—especially in light of some of the conflicts regarding religious beliefs involving the SDM and the Consent and Capacity Board as noted by Sibbald and Chidwick (2010). While it is suggested in one study that 25% of conflict at end-of-life surfaces around religious beliefs regarding miracles (Bandini et al., 2017) there is only a vague reference here to some potential conflict or dynamics regarding spiritual belief and decision-making involving medical culture—a dialogue that appears to remain below the surface.

Further, in terms of authority and paternalism, as noted above, the same paragraph invites the suggestion that "Some people feel it is very important to always maintain hope" (HPCO, n.d.-q, section 3, question 2). This may be an understatement in considering research by Balboni et al. (2019) who suggest almost 50% of participants in a study suggested they believe "a great deal" that "God could perform a miracle in curing me of cancer" (p. 1531) while 61% of participants in another US study (Jacobs et al., 2008) believed someone in a persistent vegetative

[194] Hedging refers to language used to "soften the impact of what we have to say, or to mitigate the force of an utterance" (Machin, 2023, p. 261).

state “could be saved by a miracle” (p. 733) compared to 20% of professionals surveyed. I am not aware of data on this question in the Ontario context, but applying these potential numbers to the example in the ACPO website above, that suggests that “some people” feel it is important to “always maintain hope” in reference to miracles, that number could be more than just “some” and potentially referenced as “most people” or even “many people” believing in miracles. This may offer another potential hint of a discursive script of how spirituality is situated and the potentially contested dialogue that exists below the surface in this section. Additionally, a suggestion in the bullet point that immediately follows suggests, “Let your healthcare team know if it is important for you to stay hopeful through this conversation” (HPCO, n.d.-q, section 3, question 2)—a reference that suggests a narrow view of hope that relates seemingly only to physical healing or miracles. But again, there is no elaboration.

Further, this reference to hope seems to suggest the health care team would not be offering hopefulness unless asked, which is an absurd notion in the caring professions. All told, there is a lack of elaboration around the potentially spiritual word “hope” and a presumptive dialogue underneath this section seemingly about physical belief in miracles that is left vague and unaddressed. Not unlike the references to “spiritual beliefs” (HPCO, n.d.-t; HPCO, n.d.-u) above, where the reference seemed vague and without elaboration, I observe this same kind of reference here with a seemingly untold presumptive conversation underneath that suggests an aspect of a discursive script may be present regarding spirituality. Having examined implicit hints of discourse related to spirituality in the ACPO website, I now move to multimodal hints of discourse related to spirituality that may be found in videos, images, and character stories.

Multimodal Hints of Spiritual Discourses in Videos, Images, and Character Stories.

Returning to my main research question regarding how spirituality is situated on the ACPO

website, I now offer my findings with a specific multimodal focus on the seven videos posted on the ACP website—six main videos as part of the "Educational Videos" section, and one video situated on a different page that is focused on First Nations, Indigenous, and Métis participants. What might the seven videos suggest about the presence of discourses and the situatedness of spirituality? Is there an openness or closedness to spirituality? I begin with the six main videos positioned on the "Resources and Educational Support" section of the website. Overall, the images in the six main videos include pleasant images featuring some nature scenes including a sunset in the "I'm a Substitute Decision Maker…" video (HPCO, n.d.-h, 0:56) that could be construed as spiritual—as nature is considered a key element of many understandings of spirituality (C. M. Puchalski, Vitillo, et al., 2014; Fisher, 2011). But there are no additional lexical or multimodal links that I observe that might obviously extend the meaning towards spirituality. In addition to nature, relationships have also been noted as an aspect of spirituality (C. M. Puchalski, Vitillo, et al., 2014) and there are many examples of photos of relationships in these resources including in the videos, "I'm a Substitute Decision Maker…" and "Confirming Your Substitute Decision Maker in Ontario" (HPCO, n.d.-h) where intimate relationships play a central role. But again, there is no connection made between relationships and spirituality.

Aside from these general multimodal images of nature and of intimate relationships that have an unclear connection to spirituality, the one more seemingly obvious visual reference to an aspect of spirituality is found in the videos "Advance Care Planning in Ontario", "I'm a Substitute Decision Maker…" and "Confirming Your Substitute Decision Maker in Ontario" (HPCO, n.d.-h) that feature the same photo of a smiling young person wearing what looks like a hijab[195]—presumably a person of Muslim faith wearing a head covering with religious

[195] To provide some context to the presence of the *hijab* in the ACPO website I note that Rahman et al. (2016) describe the *hijab* as part of Islamic attire meaning "veil" in the Arabic language with various diverse and complex

significance that suggests an aspect of spirituality. The scene in the "Confirming Your Substitute Decision Maker in Ontario" video also includes a phrase imposed over top of the photo of the person that appears to be wearing a hijab: "Your SDM needs your help! Give them the information and confidence NOW" (2:08). And while the photo with words does not explicitly highlight spirituality in the decision-making process, it does subtly imply an acceptable level of comfort, integration, and naturalization of spirituality in the ACP process as demonstrated by the smiling engagement of the character with the apparent hijab, and the inclusion of words connected to their participation in the photo. The animated "5 Steps" video also includes a scene with a young person reading a book who is wearing what appears to be a hijab (HPCO, n.d.-h), while the other animated video, "A 5 Step Process for Future Planning", also includes a similar young person wearing what appears to be a hijab and sitting at a computer while a child plays in the same room (HPCO, n.d.-h). And while nothing is explicitly spoken about spirituality here, these images may suggest a subtle naturalization and normalcy of ACP alongside one's spiritual or cultural beliefs. I share this frame in the video I describe in the paragraph above in Figure 1.

Figure 1

Subtle Naturalization of Spirituality in ACPO Website with a Person Wearing a Hijab

meanings in different global and social contexts. Seeking meanings of the *hijab* from the perspective of Muslims in Canada, Litchmore and Safdar (2016) interviewed Muslim women in the Toronto area. Summarizing their findings, the authors suggest "women interviewed spoke of the *hijab* as being related to their religiosity, or a symbol of religious practice" (p. 203) and a commonality of participants in the study suggested "wearing the *hijab* made them more easily identifiable Muslim" (p. 204, italics theirs). I note this research to briefly outline the religious and potential spiritual symbol of the *hijab* intersecting with both religion and identity. But a fuller exploration of these symbols is outside the scope of this dissertation.

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

In addition to the inclusion of what appears to be people of Muslim faith represented in the four videos with the inclusion of a character wearing a hijab, the final multimodal references to spirituality that I observe are in the seventh video that is positioned on a different place on the website with the title "The Time is Now" that focuses on First Nations, Indigenous, and Métis participants (HPCO, n.d.-y). In observing potential hints of how spirituality may be situated in this video on the ACPO website I observe hints of an openness to spirituality in comparison to the other six videos positioned on the "Educational Videos" page. For example, "The Time is Now" video begins with the sounds of drums and chanting (0:54)[196] and continues with words from an Elder who shares their personal perspectives on ACP (0:45). Additionally, the opening frame of the video includes two people sitting on a fallen log in wooded nature area warmly smiling together and holding what appears to be grasses of some sort (0:41). I observe in these images what may be hints of a focus on nature as an important aspect of ACP,[197] and the presence of the grasses[198] as holding hints of spiritual significance as well. In all these examples I observe an integration of spirituality into the ACP conversation in a prominent way. Additionally, I observe that the involvement of an Elder sharing their personal wisdom in the

[196] In striving for cultural sensitivity, I lean into Indigenous research to offer possible meanings of multimodal observations in these resources. Focusing on traditional healing, the Indigenous voices in Waterfall et al. (2017) that include Dan Smoke and Mary Lou Smoke describe the spiritual significance of drumming suggesting "it reminds us of the heartbeat that we felt when we were in the wombs of our mothers, the drumbeat connects us to the heartbeat of Mother Earth" (p. 11). The Ojibway author, Richard Wagamese (2016). suggests a similar theme: "When the drum beats it resonates beyond your body. It becomes the heartbeat of Creation as it was meant to be" (p. 56).
[197] Again, seeking Indigenous voices to articulate possible meanings, I note the work of Waterfall et al. (2017) that include again Indigenous educators, Dan Smoke and Mary Lou Smoke, who suggest the importance of nature in suggesting that "the Creator of Life exists within all life forms, inclusive of the four elements of the earth, water, air, and fire, as well as rocks, trees, plants, animals, birds, and fish, as examples" (p. 5).
[198] I draw on Ojibway writer, Richard Wagamese (2016) once more who notes the significance of sage, cedar, sweet grass, and tobacco this way: "The sacred medicines. When you start your day with them, along with a prayer of gratitude, your energy becomes joined with the creative energy of the universe" (p. 154).

video suggests a potential communal value and invites hints of openness to wisdom sharing within a community. In addition to the video, I also observe hints of spiritual elements on both the poster and brochure focusing on First Nations, Indigenous, and Métis participants to the website (HPCO, n.d.-y). The poster includes the same nature photo situated in the video I referenced above along with a graphic of a circle divided into four sections of white, yellow, black, and red in what appears to be the traditional Medicine Wheel (HPCO, n.d.-y)[199] and an additional graphic with unknown significance with eight feathers in a circle.[200] Overall, I observe what seems to be a greater openness to spirituality in these First Nations, Indigenous, and Métis resources—and more, what I observe to be a prominence given to spirituality as evidenced by images mentioned above and music including drums and chanting that seem to hold spiritual significance for the First Nations, Indigenous, and Métis community as referenced above.

Returning to the mainstream ACPO website resources, multimodal aspects of spirituality seem absent in the character stories where no explicit or subtle visual references to aspects of spirituality exist. One of the photos of a character named Anaya appears to have a head covering of some sort (HPCO, n.d.-d) but the narrative description also references their bone cancer. Hence, it is unclear whether the head covering is cultural, religious—or related to the cancer therapy that is common with some therapies. Broadly speaking, the character stories and images that are included do not allude to spiritual aspects but are focused on values and medical

[199] The significance of the Medicine Wheel is described in the collection, *Indigenous Cultures and Mental Health Counselling* as "an ancient and widely used concept in Indigenous North American cultures that models health and wellness for multiple aspects of a person or community" (Stewart & Marshall, 2017, p. 84). Further, in reference to healing, Waterfall et al. (2017) draw on the perspective of White Bison, Inc. (2002) to describe the deep significance of the Medicine Wheel as: "Life within the Medicine Wheel understanding is conceptualized as being made up of four distinct areas corresponding to the four cardinal directions of east, south, west, and north; the four season of the year of spring, summer, autumn, and winter; the four stages of life from birth, youth, adulthood, and Elder hood, and the four components of self as emotional, mental, physical and spiritual" (p. 5).

[200] The theoretically focused research methodology I utilized in the present study did not allow for components like community engagement, but a second future study could reveal additional meanings in these ACP resources like the significance of this graphic. I will explore future recommendations like this in Chapter 5.

conditions—themes I will address in the section ahead on values after addressing discourses related to death. Other than the multimodal aspects I have named, no other obvious hints of spirituality were observed in my MCDA examination.

Having outlined findings related to the explicit and implicit presence of discourses related to spirituality on the ACPO website, I move now to my findings related to discourses connected to death that are found on the website—in alignment with my research questions, and the suggestion provided in Chapter 1 and 2 that death is interwoven tightly with spirituality.

4.3.2 Hints of Discourses Related to Death and Dying on the ACPO Website

Having outlined discourses related to spirituality in the previous section, I now outline my findings related to hints of discourses of death on the ACPO website. As noted in Chapter 1 there is an embeddedness of spirituality within themes of death and values necessitating exploration of all three together. I argue that a full approach to exploring discourses of spirituality on the ACPO website requires an examination of the interwoven aspects of death and values as well. I begin the examination of discourses related to death with a focus on explicit references to death and dying before moving to more implicit hints of discourse across the website.

Explicit References to Death and Dying. I begin this section focusing on my findings related to discourses of death and dying with a focus on explicit lexical references. My lexical examination begins with the finding that the word “death” is only mentioned in the text twice on the website—both in the “Resource Guide” that tends towards language within a medical-legal genre of writing as noted by references to hospital transfers and death (HPCO, n.d.-s, question 36, para. 3; HPCO, n.d.-b, question 16, para. 10). Meanwhile, the word “die “is included twice in the “Resource Guide” in the main body of the website—both as technical references to dying at

home (HPCO, n.d.-b, question 10, para. 4; HPCO, n.d.-s, question 37, para. 1). And "dying" occurs twice on the main body of the website, once in reference to "Medical Assistance in Dying" (HPCO, n.d.-f, question 25, para. 4), and once in the preamble to the section focusing on First Nations, Indigenous, and Métis resources with a reference to dying being "deeply personal" (HPCO, n.d.-y, section 2, para. 1). Finally, "died' is mentioned five times in the main body of the website, all in relation to historical deaths in the character stories. For example, in the story related to the character, Bob, the narrative suggests "Bob's wife died 6 years ago and he has 3 children" (HPCO, n.d.-e) while in Priya's story the text notes: "Her husband died many years ago, and she has three daughters" (HPCO, n.d.-n). Finally, in addition to these references on the main body of the website, a single oral reference to "death" also occurs in the First Nations, Indigenous, and Métis video "The Time is Now" (HPCO, n.d.-y) in reference to one's personal experience related to navigating legal documents until the time of a loved one's death.

Having outlined the explicit lexical references to death and dying on the ACPO website, I ask the question—what do these limited textual references to death and dying on the main body of the website suggest? Examining the list of references more closely, it would seem that content-producers are suggesting that historical references to one having "died" are acceptable to name explicitly as noted by the five references to historical death in the character stories. Additionally, it seems that naming death explicitly is acceptable within a medical or technical genre that suggests professional or legal aspects of health care—like terminology related to Medical Assistance in Dying (HPCO, n.d.-f, question 25, para. 4) or hospital transfers that involve the possibility of death (HPCO, n.d.-s, question 36, para. 3; HPCO, n.d.-b, question 16, para. 10). But other than these specific references to death and dying on the main body of the website, there seems to be limits to using explicit language as noted by the absence of these

terms in main sections of the website including the "Values Exercise" (HPCO, n.d.-u) and the "How Will My SDM(s) Make My Future Decisions" (HPCO, n.d.-k) section where this language is not used. The anomaly to this once again is in connection to the video "The Time is Now" that focuses on First Nations, Indigenous, and Métis participants, where there is an oral reference to death, as noted above, where a character being interviewed in the video outlines their personal experience of using a legal toolkit "up until the point of her death" (HPCO, n.d.-y, 4:40) in referencing the death of a loved one. The other connection to death for the First Nations, Indigenous, and Métis resources is in the preamble to the video where the text suggests, "Health, illness and dying are deeply personal" (HPCO, n.d.-y, section 2, para. 1). There seems to be an increased presence of cultural sensitivity[201] in this statement in the First Nations, Indigenous, and Métis resources with the acknowledgment of diversity regarding the theme of dying being "deeply personal" which is neither historical or technical, but rather, flowing from what seems to be more sensitive and authentic engagement with diversity regarding death. Having outlined explicit references to death, I now move to exploring more implicit references to death and dying.

Implicit Hints of Discourses Related to Death and Dying. Having outlined explicit references to death and dying across the ACPO website above, I now articulate my findings regarding the implicit hints to death and dying and other subtle hints of a possible discursive script. I begin with the phrase "end-of-life" that is referenced frequently across the website.

Implicit References to End-of-Life. In addition to the few explicit mentions of "death", "dying", and "died" mentioned above, there are numerous mentions of the more covert phrase

[201]I will utilize this term at different times in this chapter. Baba (2013), in their publication, "Cultural safety in First Nations, Inuit and Métis public health: Environmental scan of cultural competency and safety in education, training and health services" draws on work from the Aboriginal Nurses Association of Canada (ANAC) to outline "cultural sensitivity" as "recognizing the need to respect cultural differences" (pp. 7 – 8).

"end-of-life" throughout the ACPO website.[202] What might be the meaning potential of this phrase? Overall, the references to end-of-life on the website seem to suggest the physically oriented process of one's dying and the literal *end* of one's bodily life. Some examples of the physical focus of death in the ACP resources include a reference in the "Six Questions" section that asks how one would like to spend "the last days of your life" (HPCO, n.d.-q, section 3, question 6) while the "ACP Conversation Starters" section focuses on "living well until the end" (HPCO, n.d.-g, section 2, para. 1). A few additional lexical examples include an invitation to "Think about past medical care a family member or friend received during an illness or at the end-of-life. Were there things that could have been done better?" (HPCO, n.d.-t, section 2, box 5) or "If you were near the end-of-life, what would make this time meaningful?" (HPCO, n.d.-q, section 3, question 6). A final example of this physical and literal focus on one's last days includes the phrase, "Think about the care you might need if you have a critical illness or if near the end-of-life. What worries or fears come to mind?" (HPCO, n.d.-q, section 3, question 4). These examples seem to suggest an understanding of death that is physically oriented and immanent with a focus on the dying process with references to "things that could have been done" to make the process better, or actions that could have made the time of dying "more meaningful" as referenced above. And to answer this question above regarding the "worries or fears" that might arise, the content-producers seem to provide the reader with a list of answers that foreground some options they could consider, noting, "Some people worry about being in pain, struggling to breathe or being a burden on others" (HPCO, n.d.-q, section 3, question 4)—examples that seem to highlight physical aspects of the dying process. And in this same section, there is a revealing statement with a glimpse of a discursive script in response to these worries

[202] The search function on the ACPO website suggested 23 different references to the phrase "end-of-life". I will not outline them all on this page but share this to suggest they are used frequently.

that relate to physical aspects leading to death, and an invitation for readers to work with the clinical team, “To come up with a plan to try and avoid these situations or make them better for you” (HPCO, n.d.-q, section 3, question 4). There is no plan suggested here to address the spiritual or existential aspects of struggle or worry that one may confront with the end of one’s life. The meaning potential in all these examples seems to suggest a focus on the physical trajectory of death and immanent factors in those moments of dying, with little hint of alternative discourses regarding death inspiring value reflection or the notion of the afterlife, faithfulness to one’s beliefs, one’s sense of duty, or meaning in suffering.

In addition to physical references to the end-of-life as noted above, another implicit mention of death or dying includes medicalized references like the ones found in the section “When does a substitute decision-maker make decisions?” (HPCO, n.d.-x). This page includes bulleted examples of the types of decisions the SDM makes including decisions involving “starting or stopping medications” (bullet 2) and “starting or stopping life support” (bullet 4). Additionally, in the “Resource Guide” one can see this same medicalized approach in references to code status and “resuscitation procedures (if any) that the health care team would provide to a patient if the patient’s heart stopped beathing and/or the patient stopped breathing” (HPCO, n.d.-f, question 21, para 2). References to death in these examples appear to be obscured behind medicalization and procedures and focused on physical concerns rather than spiritual or existential ones as these themes are not addressed or presented.

Implicit Multimodal Hints of Death Discourses. Having observed lexical references to death and dying above, I turn now to multimodal references found on the ACPO website. Here I observe that the broader website, not including video content, does not include images suggesting death or dying, rather, I observe multimodal choices of images or graphics that may

allude to themes of life. One multimodal example may be the subtle choosing of the colour of green[203] throughout the design of the site—a colour that might suggest themes like life, hope, and unity (Kress & van Leeuwen, 2021). Additionally, when considering colour dimensions like hue and fluorescence,[204] it is noted that meaning potentials of green can in some circumstances suggest what is "natural and optimistic" (Ledin & Machin, 2020, p. 107) or a sense of "vitality and energy" (p. 106). In addition to possible meaning potentials that could be represented through the colour green, the faces of the six characters highlighted on the website include either happy or contented gazes on the camera—despite the themes of death and serious illness that are involved with many ACP conversations.[205] Pictures of the characters represented include Althea who is reflecting on values in the description while smiling brightly in the photo (HPCO, n.d.-c), as well as the character Bob who suggests life not being worth living without independence in the narrative description—all with a large smile on his face and a gaze directed to the viewer suggesting a sense of connection and engagement with the reader (HPCO, n.d.-e). These images suggest a pleasantness regarding ACP with a backgrounding of tensions or struggles related to the ACP process and the implicit theme of serious illness and death that is often present in this conversation. Returning to the six main videos on the website (HPCO, n.d.-h), there are other multimodal aspects that surface that create a pleasant tone alongside the thematic content that involves notions of death. The animated videos "Five Steps" and the "5 Step Process for Future

[203] Addressing colour in MCDA is a challenging notion because of the many dimensions involved. Kress and van Leeuwen (2021) summarize historic approaches to colour and make some broad suggestions of the meaning potential of colour, but the meaning of colour is contextual across genres and time periods. Ledin and Machin (2020) summarize the work of Gage (1999) who suggests the limitations of using language to describe colour in saying, "language itself has been used to label only a tiny fraction of the millions of colour sensations that most of us are able to see" (p. 88). And while undoubtedly a potentially significant factor, I acknowledge that a larger examination of colour as a multimodal resource is outside the scope of this dissertation. I give these brief examples as possibilities of meaning potentials but will not expand further.

[204] "Flourescence" is described by Ledin and Machin (2020) as "where colours appear to glow" (p. 106).

[205] The one outlier to the happy or contentedness in the images of the six characters is the image of a younger person "Anaya" (HPCO, n.d.-d) whose face appears to have more of a flat affect without obvious emotion of any kind.

Planning" for instance feature melodic whistling music and folksy guitar in the background throughout the videos that imply a playful mood amidst ACP processes that can relate to serious themes including mortality. In these animated videos there appears to be no reference to themes like death or dying that might be unsettling (HPCO, n.d.-h) but rather a lighthearted and playful tone created by music and cartoon animation.

In contrast to the two animation videos referenced above with their pleasant music and playful tone, several of the other mainstream videos, while not explicitly mentioning death or dying, have numerous images that do imply death including "The Advance Care Planning in Ontario" video that opens (0:05) with an image of a car wreck along with fast pulsing music that seems to heighten a mood of urgency (HPCO, n.d.-h). And while death or dying is not named, the image of the car crash connotes possible themes of death, dying, or mortality. Additionally, the flow of words over top of the image suggesting, "Who will speak for you…If you can't speak for yourself?" (0:06) suggests someone not being present to speak and make choices because of a serious accident—a phrase that hints at a very serious health situation. This combination of images and text that have metaphorical potential involving meanings related to death and mortality seem to visually engage the topic of death—and inspire a sense of emotion suggesting persuasion regarding a need to engage in ACP. See the image described above in Figure 2.

Figure 2

A Car Crash with a Fire-Fighter Invoking Mortality and Implicit Thoughts of Death

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

The same video featuring the car wreck noted in Figure 2 also includes a picture of a patient in the ICU with what appears to be a breathing machine of some sort and obvious life saving measures being given (0:22).[206] These images too have metaphorical potential suggesting medical emergency, uncertainty, and potential for one's death. The text overlaying this video invokes urgency, spelling out a message in bold, red lettered font in all capital letters "WHAT IF YOU CAN'T SPEAK FOR YOURSELF?" (0:52). The bold lettering could possibly suggest an added "weight" to an argument here that can "increase salience" (Ledin & Machin, 2020, p. 125). And returning to the vast possibility of meaning in colours, the choice of red in the lettering could potentially suggest emotional intensity (Ledin & Machin, 2018), or "emotional excitement and engagement" (Ledin & Machin, 2020, p. 100).[207] Also, the music underneath this scene sets a mood with an emotive, fast and pulsing tone that seems to heighten the sense of urgency. I observe the suggestion of mortality in this image in Figure 3 where the potential presence of death may be invoked with a patient facing serious illness with life-saving machines.

Figure 3

Life-Saving Machines Displayed in the Follow-up Frame After the Picture of a Car Crash

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

[206] See Figure 3 for the photo I am describing in the paragraph to follow.

[207] Again, I reiterate the meaning of colour is contextual and multidimensional as well as widely contested. Ledin and Machin (2020) suggest "artists, psychologists, philosophers and theologians have never really come up with anything that allows prediction of meaning" (p. 88). I offer here some general meaning potentials only as a larger discussion is outside the scope of this dissertation.

In addition to the image noted in Figure 3, the "I'm a Substitute Decision Maker…" (HPCO, n.d.-h) video features similar images of hospital beds along with visual references to loved ones engaged in what looks like concerning conversations with serious-looking medical professionals (0:08). The facial expressions on the faces of loved ones (0:08; 0:17) connote both intense emotion and concern. And while death is not spoken, the visual meaning potential in the conversations appears to reference high stakes conversations that may involve death. These images fused together with the mood inspired with pulsing music seems to suggest increased emotional intensity of a serious nature be it fear or anxiety. Yet, even with the suggestion of mortality and this level of intensity, I also observe a kind of resolution emerging with the introduction of ACP. In the video "Advance Care Planning in Ontario" (HPCO, n.d.-h), that features the car wreck referenced above in Figure 2, one can observe this noticeable shift in tone with the move from serious illness and possible death to the lexical reference that "ACP can help!" (0:38) along with a shift to a smiling conversation (0:57) and images of loved ones gathering to talk (1:10). There is not only a modality here that suggests a commitment to the efficacy of ACP to resolve these moments of intensity but I observe a sense of causality that connects the mortal challenges and intensity to active resolution through ACP.

I also note here my observation of some incongruence regarding how death is approached in the six main videos in comparison to the framing I see around the First Nations, Indigenous, and Métis resources. While none of the six main videos are framed with any lexical introduction regarding the theme of death in any way, the introduction to the First Nations, Indigenous, and Métis video includes an inviting paragraph with culturally sensitive language alongside the same photo I referenced above with two individuals sitting together in a forested area on a fallen log while engaging in conversation. The text beside this photo sensitively suggests, "Health, illness

and dying are deeply personal experiences. We recognize everyone will approach these differently. While ACP Ontario resources are intended for Ontarians, we continue to partner with organizations to produce culturally safe and diverse resources." (HPCO, n.d.-y, section 2, para. 1). Not only does the sensitive patient-centred language use the word "dying" here very explicitly but there is a tangible sensitivity regarding the diversity of views related to death and a suggestion of an institutional aspiration toward culturally safe practices regarding dying and decision-making that invite inclusion. There is a cultural sensitivity in this paragraph connected to the First Nations, Indigenous, and Métis video and acceptance of diversity around approaching death with a mindfulness that "everyone will approach these differently".

Another example of this kind of cultural sensitivity is found in the First Nations, Indigenous, and Métis resources that includes some words by an Elder in the "The Time is Now" video (HPCO, n.d.-y). The Elder describes ACP as providing a culturally sensitive way to "deal with your health care issues in a way that you would feel comfortable with culturally" (1:17). This intentional focus on one's comfort in a cultural sense echoes the importance of cultural sensitivity in this multimodal resource—an approach that seems very different from the rest of the site where cultural sensitivity is largely left unaddressed. These examples demonstrate a more sensitive and inclusive approach than resources found elsewhere on the website that seem to suggest what seems like cultural universality regarding topics involving death including the video "Five Steps" (HPCO, n.d.-h) that suggests a homogeneity regarding ACP with the phrase, "ADVANCE CARE PLANNING IS FOR EVERYONE" (1:44)[208] or text in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) that suggests "Your SDM

[208] I will address this phrase and possible questions around cultural sensitivity regarding diverse expressions of spirituality, death, and values later in this chapter.

needs your help! Give them the information and confidence NOW" (2:08).[209] This bold and capitalized statement might suggest that talking about topics related to death are appropriate for all groups—but this may potentially suggest a lack of sensitivity towards the topic of death considering the significant diversity of Canadians including 450 cultural and ethnic backgrounds along with 100 religions represented (Statistics Canada, 2022b) that I noted in Chapter 1.

While the introduction to the First Nations, Indigenous, and Métis section suggests ACPO, "continue to partner with organizations to produce culturally safe and diverse resources" (HPCO, n.d.-y, section 2, para. 1), this seems like an aspirational note for the ACPO to work toward in the future[210] rather than something fully operationalized in the present—with the notable exception being the sensitivity and inclusion found in the First Nations, Indigenous, and Métis resources. While there are translated postcards summarizing ACP principles in Chinese, Spanish, French, Italian, Punjabi, and Tagalog[211] languages, I observe little explicit culturally sensitive language in the introductory text or multimodally in the designs where they are positioned. The only introduction to the postcards, for example, is a matter-of-fact paragraph with little detail suggesting: "Below are postcards that provide brief explanations of ACP, identifying your SDM, information for your SDM and consent and capacity" (HPCO, n.d.-y, section 3, para. 1). This is in stark comparison to the sensitivity I observe being expressed in the preamble to the First Nations, Indigenous, and Métis resources that notes "Health, illness and dying are deeply personal experiences" (HPCO, n.d.-y, section 2, para. 1)—a phrase that demonstrates a desire for cultural safety that is sensitively articulated. Having examined implicit

[209] Additionally, this phrase "NOW" (2:08) in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) could also be construed as paternalistic, a theme I will address later this chapter.
[210] I will return to some observations of potential future recommendations for ACP resources in Chapter 5.
[211] I remind the reader here that an examination of these resources was outside the scope of my examination due to the language barrier they presented. I only address the preamble text that introduces these postcards.

multimodal hints of death discourses in the ACPO website, I now turn to another observation around death in my findings—the absence of struggles related to death in the ACP process.

Absence of Struggle Around the Topic of Death. In addition to implicit lexical and multimodal references to death explored above, there is another implicit hint I observed on the ACPO website regarding death discourses—the absence of struggle around the topic of death for the individual or the SDM. In the page, "When does a substitute decision-maker make decisions?" (HPCO, n.d.-x), there is a listing of some of the interventions that may be involved in one's decisions including potential surgery, transition to a long-term care setting, as well as "Starting or stopping medications" (bullet 2) and "starting or stopping life support" (bullet 4). But appearing to be absent in these references to decision-making is the notion of struggle and the possibility that these potential choices may influence aspects of death and dying—impacting both the individual and the SDM. Also noteworthy is in the addressing of worries and fears in the "Six Questions" section where there is the suggestion that, "Some people worry about being in pain, struggling to breathe or being a burden on others" (HPCO, n.d.-q, section 3, question 4). I observe the scope of struggle in this phrase to be quite narrow with struggle named in regard to one's breath but no mention of worries or fears that might flow from existential or spiritual struggle[212] as it relates to the end of one's life and potential for an afterlife or transcendent factors that might impact decision-making.[213]

[212] The work of Pargament and Exline (2022) focuses on spiritual struggles that can include "divine struggles", "interpersonal struggles", "moral struggles", and "struggles of ultimate meaning" (p. 10)—all aspects of struggle that are unnamed here. I circle back to existential struggles named by Yalom (2009a) who notes death anxiety for some includes being "staggered by the enormity of eternity" (p. 7) or the potential to "wrestle with the issue of death's inevitability" (p. 7). These kinds of struggles are not observed in the ACPO website.

[213] Noteworthy in the research by Jacobs et al. (2008) is that 66% of respondents suggested "very" or "somewhat" in regard to, "How important would your religious beliefs be in guiding decisions about your own medical care if you were critically injured?" (p. 733). This would suggest spiritual factors involved in potential struggles are indeed important in end-of-life conversations involving the potential of death.

In addition to the lack of acknowledging struggle regarding death and decision-making, there is also a lack of reference to the potential emotional struggles that surface with death. Despite the research suggesting the presence of feelings of guilt and tension around one's part in making medical decisions involving a loved one's death,[214] there is little mention of the emotional impact on decision-making on either the individual or the SDM. While the section "Some Tips on Working Through the Questions" (HPCO, n.d.-q) acknowledges briefly, "It can be very distressing for SDMs to make decisions" (bullet 4), the very next line moves the conversation back rather quickly to what seems like a simple cognitive task: "Your answers to these questions will give your SDM(s) helpful information" (bullet 4). The suggestion of having more knowledge seems to be the answer but the emotional impact of death is not explored for the participant. This is congruent with the research of Watson and Thomas (2018) I referenced in Chapter 2 who observe that one's own responses to death as a human tend to be missing in ACP resources. Instead, emotional aspects of death seem unacknowledged in the ACPO website with the character stories of "real people" participating in ACP processes appearing largely happy, contented, and unconflicted. There does not appear to be any struggle.

In addition to the lack of reference to struggles around death and decision-making, as well as the emotional aspects of these conversations, I reiterate the presumption of easiness in these processes that may involve the theme of death. Despite the SDM's potentially gut-wrenching choices involving a loved one and the possibility of influencing the dying process in the future, there seems to be an oversimplification presented that ignores some of the tensions in ACP that may lead to difficult future decisions. In the summary at the end of the animated video,

[214] I reference here the quote from an SDM who participated in a study I referenced in Chapter 2 by Wendler and Rid (2011) where an SDM suggested, "The thing I love most in my life I don't want to kill. That's the part that I agonized over a lot" (p. 343).

"5 Steps" (HPCO, n.d.-h) for instance, there is a video frame that suggests "THAT'S IT!" (2:33) in large bold letters and an exclamation mark that connotes both simplicity and emphasis. But the question arises—what about the difficult aspects of ACP that may intersect with death and relationships? I reference this frame of the video in Figure 4.

Figure 4

Video Frame Focusing on the Simplicity of ACP with the Message "THAT'S IT!"

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

Examining the "5 Steps" video noted in Figure 4 further (HPCO, n.d.-h), I suggest that in addition to the absence of struggle there is a naturalizing quality to this phrase "THAT'S IT!" (2:33) that may suggest oversimplification and not attending to the fullness of the human person or the presence of challenging themes like death in ACP. Referencing Balboni and Balboni's (2019) suggestion of a "conspiracy of silence" (p. 95), as noted in a Chapter 2, I reflect on a medical culture that distances itself from death. In this video I certainly observe hints of this avoidance of death including no references to emotional aspects of the ACP process or beliefs around death from various spiritual traditions that demonstrate diverse views.[215]

[215] I remind the reader of some of the spiritual practices regarding death I named in Chapter 2 including Buddhist practices of not being over sedated and maintaining responsiveness as one approaches death (Akileswaran et al., 2014), Chinese cultural suggestions that require one's stomach to be full for a peaceful death to occur (Yeo & Hikoyeda, 2000), and Muslim perspectives regarding suffering as a testing of faith (Akileswaran et al., 2014).

Finally, while the website seems to give additional opportunity to address struggles and some of these sensitive human themes in the section, “What else do I need to know about ACP?” (HPCO, n.d.-a), the section tends to move the conversation away from death in saying: “Advance Care Planning is not just about preparing for end-of-life. It is about planning for any health care needs you may have in the future” (section 2, bullet 2). And in a follow-up phrase in the same section it alludes to only a vague sense of tension suggesting, “If you are not ready to have a conversation about your values and wishes that’s ok. This website also gives you information to help you identify who would be your SDM(s)” (section 2, bullet 6). There is no acknowledgment about the reasons *why* one would not be ready to have these conversations—including the relational, spiritual, or emotional themes that might arise for participants. And rather than addressing some of these themes that may involve death, the content-producers opt to invite one to choose their SDM that is presumably an easier question to answer. I observe elements of the discursive script of avoiding these potentially heavier and messier topics like emotions and humanity—and even spirituality—that surface when death is in the room.

A final example of the absence of struggle on the website has a subtle implication for death being controllable. With an invitation for people to sign up for a monthly newsletter, the messaging on the page reads: “Take control of your health care journey. Sign up for our monthly newsletter.” (HPCO, n.d.-m). In addition to a reference to control of one’s health care that may or may not be possible, there is also a lexical connotation in this same message of the apparent ease of attaining this control with the message being linked to a simple sign-up to a newsletter. Here again there is a suggestion of causality as well with the simple link between taking control and signing up for the newsletter. But what is missing in this implicit suggestion of control is the many struggles involving ACP and the intertwined theme of death that may be out of one’s

control—including one's emotional responses to death, spiritual aspects, or one's potential choices to make difficult health care decisions amidst uncertainty that influence death.

In summarizing the hints of discourses related to death in the ACPO website named above, I observe a fragmented presentation of death and dying. References on the main body of the website largely suggest an avoidance of the topic—except in certain circumstances. First, death seems to be explicitly addressed in references to historical deaths like I observed in the character stories of loved ones who had died. Second, death is noted explicitly in functional medical-legal references like what I observed in the "Resource Guide". And finally, with several videos invoking a sense of urgency with emotions around serious illness and the presence of end-of-life scenarios and possible death, there seems to be an acceptance of death being present multimodally to serve the purpose of inspiring change and engaging participants in the ACP process with a promise of some resolution. But the outlier to these references is the significant contrast I observed to the referencing of death in the introduction to the First Nations, Indigenous, and Métis resources. The introductory preamble to the video especially suggests a level of sensitivity to the topic in regard to "dying" with the suggestion that "Health, illness and dying are deeply personal experiences. We recognize that everyone will approach these differently" (HPCO, n.d.-y, section 2, para. 1). There is a sensitivity to the uniqueness of one's beliefs around death that are not present in other parts of the website.

Having addressed the discourses related to spirituality in the first part of this chapter, and discourses related to death in this last section, I move now to the third interwoven aspect of spirituality that provided focus for my MCDA analysis—hints of discourses related to values found on the ACPO website.

4.3.3 Hints of Discourses Related to Values on the ACPO Website

Having highlighted findings from this MCDA examination related to what hints of discourses related to spirituality and death might be present on the ACPO website, I move now to the third interwoven aspect of this examination—discourses related to values. In this section I begin by outlining explicit references to values focusing on character stories as a starting place before outlining other explicit references to values within the main body of the website. I will then shift the conversation to implicit hints of values on the website before transitioning to Part 2 of the chapter focused on theme generation through reflexive TA. I begin next with explicit evidence of values in the character stories.

Explicit Reference to Values.

Explicit Hints of Discourses Related to Values in Character Stories. A central component of the larger ACPO website, as mentioned above, is the stories of six characters from different walks of life and who appear to be at various stages of their health care journey. The characters, named Althea, Bob, Tran, Priya, Jacob, and Anaya, are all introduced on the first page of the webpage (HPCO, n.d.-j) with a brief outline of their health condition with their stories extending to pages throughout the website. The character stories appear to connect the theoretical concept of values to personal narratives—presumably fictive case studies chosen by content-producers as no reference to names are provided. It is important to highlight the narrative genre in these stories that invite a sense of emotion and humanity which presents a contrast to the medical-legal focus in the "Resource Guide" that includes more technical language relating to medicine and law. Upon examination, what is central to these stories is the theme of values. The first character story involves a 72-year-old healthy black woman named Althea. In summarizing her approach to values, the website suggests:

> The most important values to Althea are her dignity and being able to interact with people. She worries about losing her dignity if she is hooked up to machines and she needs total care. She can't imagine not being able to speak and share moments with her sisters (HPCO, n.d.-c, para. 4).

Using the MCDA tools of inquiry, I observe several hints of discourse regarding values here in this paragraph. First, of course, is the explicit and obvious reference to the values of dignity and interacting with people being named so clearly. But more, to highlight these values, there are evocative examples provided for emphasis including a potential overlexicalization in naming both being "hooked up to machines" and needing "total care"—hints of the over-persuasion regarding one's dependence with the potential use of metaphors for emphasis and to increase impact. I observe that "total" is used as an adjective before "care" that may invoke emotions of fear, while these stark images are juxtaposed just a few words later in Althea being unable to "share moments with her sisters" that seems to increase the emotion with a connection to sisterly connection. What is the discourse here involving values? I observe a commitment here in the authors of this story, or a glimpse of a high modality[216] regarding values of dignity and family.

Adding to the explicit lexical articulation of values of dignity and family in this story that intersects with images of "total care" are the visual elements of Althea's gaze that include a bright smile and eye contact directed at the viewer which invites relationship, empathy, and connection (HPCO, n.d.-c). Together, the multimodal layers of the lexical description and the visual photo of Althea smiling brightly suggest an impression of a happy person who has named values clearly—and presumably easily—with seemingly no hint of anxiety or feeling unsettled

[216] Again, modality within MCDA refers to the author's level of commitment towards what they are suggesting with a high modality referring to a high level of commitment (Machin & Mayr, 2023).

about ACP. And more, her smiling face is cropped against a white backdrop with no other context or background that could foreground any other context. There is no reference to the possibility of a larger untold story here, or any other context—just the simplicity of values named and a smiling individual.

Further to values, a second character story I will highlight focuses on a different value that seems to be foregrounded in the ACP resources—that of independence. In this character story, a 76-year-old white man named "Bob" with heart disease is featured (HPCO, n.d.-e). Again, there is an explicit naming of the character's values and the vivid use of imagery to connect the story to a family member like in the previous story: "For Bob, 'life isn't worth living unless I have my independence'. When Bob thinks of losing his independence, he pictures his brother Jim in the intensive care unit and how he never fully recovered. Jim needed help with everything" (HPCO, n.d.-a, para. 5). The value of independence is named explicitly in this story, suggesting for Bob, as noted in the paragraph quoted above, "life isn't worth living" without it—a strong statement suggesting death is preferable to being dependent. Again, I observe hints of overlexicalization in this story with references in this same paragraph to a brother who "never fully recovered" and "needed help with everything". Additionally, these emotional references invite a larger conversation involving ICU, family involvement, and other factors that are not elaborated upon. Further, there is a clear emphasis on personal agency in the focus narrowed to the individual and with it a potential glimpse of a discursive script through the presence of structural opposition, once again, where Bob is portrayed as potentially distancing himself from his brother's own decisions. There is a potential opposition presented here of "good" versus "bad" that may possibly suggest independence as being "good" and his brother's story of dependence as being "bad". And multimodally, the picture is of a smiling face with a gaze

directed clearly at the viewer that invites connection and emotional response to this situation. Not unlike the character Althea who I highlighted earlier (HPCO, n.d.-c) there is no sign of anxiety to their naming of values or the prioritization process, but rather, a visual suggestion of happiness. And again, with the white background without any other background to images, there is no context to the smiling face—only the story of values presented in the text. Additionally, I observe no allusion to value conflict or possible tensions regarding the ACP process.

In regard to the other four character stories that reference values, I elaborate only briefly on them here to provide a picture of the larger landscape of values painted in these stories. One character story features a 15-year-old youth facing cancer that is connected with the value of peer relationships and enjoyment: "What is most important to Anaya right now is being able to hang out with her friends and watch movies" (HPCO, n.d.-w, section 2, box 6). Another character story involves a 48-year-old woman named Tran with a breast cancer diagnosis that highlights family as a key value (HPCO, n.d.-v). Additionally, another story highlights a 9-year-old boy named Jacob with a brain injury who *"*rarely smiles anymore*"* (HPCO, n.d.-l) suggesting a value of happiness. And finally, the sixth character relates to an 84-year-old woman named Priya who has advanced dementia. The focus on this story is the family considering her values as well as quality of life (HPCO, n.d.-n). In assessing the discursive script of these six stories together, there are obvious hints of specific values that are being foregrounded for viewers of the ACPO website including dignity, independence, enjoyment of life, happiness, family, and quality of life. What is also evident is that these values all seem focused on physical or in-the-moment aspects of life, rather than values that may extend into spiritual domains—including value themes like suffering, duty, faithfulness to one's beliefs, or ultimate meaning. These missing components related to values will surface in my examination at various times in

the rest of this chapter. Having outlined explicit reference to values in the character stories, I now move to examine the "Values Exercise" that explores values in a central place on the website.

Explicit Hints of Discourses of Values in the "Values Exercise". In addition to the character stories providing a glimpse of the discursive script regarding values, another area where I focus my findings is in the "Values Exercise" (HPCO, n.d.-u)—the same section I explored earlier in this chapter where I applied a spiritual lens to the reference to "spiritual beliefs" and "spirituality". Here I examine the same portion of text with a lens to discourses relating specifically to values. This section suggests in its preamble that "The following exercise encourages you to think about common values" (HPCO, n.d.-u, bullet 1). And despite listing the importance of both cultural *and* personal values in the introductory paragraph to begin this section, the list of options provided for reflection is framed as offering a "brief list of personal values" (section 2, para. 1) with a notable absence of the cultural aspect of these values. The result is a list of personal values that are chosen to be emphasized and the absence of cultural values that may intersect with aspects of one's spirituality or religion. Of note in this section referenced above is also the lexical suggestion of using the word "common" in describing these values, inviting presuppositional questions like—who might be defining them as common? And which group are they common for? From a multimodal perspective, the design includes an unalphabetized list of values that begins with dignity and independence, the same two values I observed as being highlighted prominently in the character stories above. This is important because the content-producers have the power to potentially prioritize values they see as most important at the top of the list. And with the same two values of dignity and independence named here and in the character stories, this may suggest not only a potential overlexicalization in emphasizing these particular values, but it also could be named as a kind of recontextualization

of value reflection for participants where an order of values is implied for the reader to follow that may actually be different from their own beliefs. And what other values are foregrounded in this list? As noted above in the section addressing the presence of spirituality in this list, after leading with references to dignity and independence on top, the list continues with other values chosen by the content-producers including, in order: “wellness”, “clear-mindedness”, “Family”, “Hard work/dedication”, “Strength”, “Spirituality”, “Not being a burden” and “Relationships”. As noted above, while named as a value along with other values on this list, spirituality does not seem like a priority in terms of values and is given little context or elaboration despite the seriousness of the ACP conversation that may involve the high stakes of death.

Another hint of discourse in this list of values, as noted above in my findings related to spirituality, is the graphic space provided in this same “Values Exercise” section that provides room in the design to enter one’s personal thoughts regarding values (HPCO, n.d.-u). After providing one “other” box (box 1) along with space to describe “what your most important values mean to you” (box 2) the reader is presented with some specific options for consideration chosen by the content-producer. And what values are chosen as needing more reflection? The content-producers choose to foreground two direct questions related to dignity, two focused on independence, followed by one focused on family. The dignity-focused questions include, “What does having dignity mean to you?” (box 3) and “What comes to mind when you think of losing your dignity?” (box 4) while the independence-focused questions include, “What does independence mean to you?” (box 5) and “What comes to mind when you think about being dependent on others?” (box 6). The last question relates to family: “If spending time with family is important, what is it about spending time with family that makes it so important?” (box 7). The content of the questions and design choices seem to reveal additional hints of a discursive script

with specific values that are foregrounded as demonstrated by these additional opportunities for focused consideration. What is missing is opportunity to reflect more deeply on values related to one's ultimate beliefs that arise with conversations involving illness and death including, once again, values intersecting with faithfulness to religious beliefs, duty, suffering, the value of human life, or setting an example for future generations to name a few—values that may arise from one's spiritual tradition or belief system.

Another notable part of this same page is the ease of value reflection being presented. This theme is not unlike my suggestion earlier in this chapter regarding the ease and lack of complication regarding aspects of death and decision-making. In this section, positioned in the introductory bullets to the "Values Exercise" (HPCO, n.d.-u), the content-producers ask the question: "Which one is most important to you?" (bullet 2). This question seems to suggest a more binary choice of values that possibly minimizes the complexity of value discernment and the presence of value conflict and potentially ignores the challenges implicit in value prioritization that can often surface tensions regarding health care decisions. But there appears to be no struggle presented here. Additionally, the graphic presents tick boxes given in the exercise seems to suggest an easy toggle of one's value choices with the question, "Which are the most important to you?" (section 3, para. 1). As referenced in the section around death, there is no indication as to the stakes involved in these decisions, the potential conflict, or how one might prioritize their values. The assumption seems to be that one can know and simply tick the boxes and fill out the form. Having provided my findings around values in character stories and the main "Values Exercise" section, I now outline my observation of there being little elaboration regarding the meaning of values on the broader website.

Little Elaboration Regarding an Understanding of Values. While explicit attention to values is featured in the character stories and "Values Exercise" (HPCO, n.d.-u), there is little explanation given to what values actually are and how they might relate to decisions and prioritization. The "Values Exercise" simply moves the conversation into a list of examples of values while the character stories focus on the suggested value itself with some short examples. Other parts of the website demonstrate a similar lack of elaboration of the meaning of values. In the "Resource Guide" that focuses on the SDM (HPCO, n.d.-s), for instance, there are 44 separate questions and answers, but no questions related to the definition of a value. Rather, there is an assumption of knowledge of values and a suggestion for the SDM to "step in the shoes" (HPCO, n.d.-s, question 1, para. 3) of a patient to consider their values and beliefs. Despite lengthy documents in the resource guide that spell out medical-legal aspects like hierarchies of consent (HPCO, n.d.-s questions 1 – 7), and the referencing of relevant legislative Acts in the guide with significant detail (HPCO, n.d.-s), values are not spelled out or adequately addressed. The closest the content-producers get to an articulation of values is within a "Resource Guide" question and the asking of, "What are ACP 'wishes'?" (HPCO, n.d.-b, question 10). While the question is regarding wishes, the 11-paragraph description of "wishes" diverges briefly in one paragraph to reference values as noted in this paragraph:

> Wishes may also be expressed to the SDM to consider the person's values and beliefs held by that person when capable, when considering care options and treatments. The values and beliefs may be from a particular faith or religion or may be opinions of that person about the value of life and how life should be lived. Values and beliefs usually affect how a person sets priorities in their life are [sic] the measures that the person uses

> to determine if their life is being lived in the way they want to live it (HPCO, n.d.-b, question 10, para. 6).

Examining this paragraph regarding wishes more closely, it is reminiscent of the treatment of "spiritual beliefs" outlined above with its peripheral, vague, and unfocused mention of values as it relates to spirituality. Here the content-producers appear to digress briefly from the topic of wishes to the origins of values that includes spiritual aspects of faith and religion. But this sentence addressing faith and religion seems to be rather suddenly introduced in the text and appears tangential in its reference to spiritual themes relating to values rather than a strategically focused point—again, inserted into the conversation with vagueness and without elaboration. The brief and vague insertion of values related to faith and religion in this sentence presents a sharp contrast to other mentions of values in the rest of the "Resource Guide" where the focus tends to be more on the medical-legal aspects. Again, there is little clarity of meaning—and even a prominent typo in the last sentence in the above reference that potentially suggests some unresolved wordsmithing or an unfinished tangential topic that was not completed. But in contrast to the lexical crispness in the "Resource Guide" with frequent examples given for medical-legal clarity, this reference to values and faith seems, in my opinion, vague and unfocused. Regardless of the awkwardness, this reference is the closest the ACPO website comes to offering a full definition of values.

Additionally, in glimpsing this one-sentence description of values in the "Resource Guide" (HPCO, n.d.-o), one must wonder why separate headings or questions related to values are not appearing? Is there a hint of discourse here in what is chosen to be presented? In the preamble to the whole guide, it suggests, "The questions included in the Resource Guide are common questions that are frequently asked by the general public and health care providers"

(HPCO, n.d.-o). Considering this focus is to be on what is "common" in the over 100 questions and answers offered in the "Resource Guide", I wonder—what is potentially being suggested here with not a single direct heading for values or the spiritual aspects of one's values? With conflict regarding spirituality intersecting with values being a clear theme arising in the literature at end-of-life (Bandini et al., 2017), I wonder—why it is not considered a "common" enough theme for a collection of questions and answers focusing on what people consider to be most important?[217] Additionally, this suggests some recontextualization may be happening regarding how one is to engage in ACP and what topics of inquiry might be presented as being preferable to content-producers, and which ones are best left on the periphery or absent altogether—namely the spiritual aspects of values. Having provided my findings regarding explicit hints of discourses related to values in focusing on the character stories, the "Values Exercise" and the "Resource Guide", I now move to outlining my findings related to implicit references to values, beginning with the connection or possible conflation of values with wishes and beliefs.

Implicit References to Values and Hints of Discourses.

Implicit References that Possibly Conflate Values with Wishes and Beliefs. As noted in the above section where a question in the "Resource Guide" focusing on wishes evolved into a discussion on values, there is a frequent connection, and possible conflation, between values with wishes and beliefs. While the character stories and "Values Exercise" are explicit in highlighting one's values, in observing resources broadly across the website, the trio of words—values, beliefs, and wishes—seem to be often grouped together that suggests some confusion.[218]

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[217] I surface once again the work by Jacobs et al. (2008) who note 66% of participants answered "very" or "somewhat" in relation to the question: "How important would your religious beliefs be in guiding decisions about your own medical care if you were critically injured?" (p. 733). This would suggest to me that a "common" factor involving value-centered decision-making is the spiritual notion of religion.

[218] I note that all three words are important to ACP more broadly due largely to the connection to legislation. I review here that the *Health Care Consent Act of Ontario, 1996* suggests that consent for treatment on behalf of one who is incapable follows the path of: 1) following applicable wishes the individual expressed while capable; and 2)

Examples include an invitation in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) that suggests, "Don't wait until a crisis happens. Talk to them today about your wishes, values and beliefs" (2:10) or the question related to choosing one's SDM in the "Who is my SDM" (HPCO, n.d.-z) section with the question raised under the heading, "Other things you might want to consider…", that includes the question: "Can I talk with this person(s) about my wishes, values and beliefs?" (section 3, bullet 1). Additionally, there is a suggestion in the "I'm a Substitute Decision Maker…" video (HPCO, n.d.-h) for participants to "Make sure you understand the wishes, values and beliefs of your family member or friend" (0:48). Multimodally, I observe this same grouping in the "5 Step" video (HPCO, n.d.-h) as well that invites one to think about their values, beliefs and wishes with an animated photo that invites one to think "About what's important to you –about your values, beliefs and wishes" (1:10). One can see this in the example provided in Figure 5 regarding the connection between values, beliefs, and wishes in this video that could potentially seem to conflate the terms in a video.

Figure 5

Connection of Values, Beliefs, and Wishes in the "5 Step Video"

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

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if there are no wishes, then a decision is made based on the individual's best interests where one's values and beliefs are taken into account along with factors related to benefits and potential harms. Here the terms wishes and also values and beliefs seem unique and serve specific purposes in the Act.

Whether or not the three terms of values, beliefs, and wishes are interconnected, or unique, there is potential in this image to group them all together—or even conflate them. Regardless, it is ambiguous in this image exactly how they are unique. I observe the terms are often grouped together without explanation which can lead to less precision in following the legislation noted above in the *Health Care Consent Act of Ontario, 1996* that suggests processes that depend on the SDM's knowledge of one's wishes, before turning to values and beliefs if no wishes are known or expressed. Why does this matter? As mentioned above in Chapter 2, there is a proposition implicit in wishes that suggests a more instrumental and objective "expression of desire" (Black, 1979, p. 1436) while belief is rooted in a "proof addressed to the judgment" (p. 141). And while wishes and beliefs are more propositional, values can be more challenging, potentially more subjective, and less easy to define with broad notions like being life's "yardsticks" (Rokeach, 1969, pp. 550 - 551) that one might move towards.[219] Regardless, the three terms—beliefs, values, and wishes—are not clearly differentiated or elaborated upon, leaving the reader to wonder about their meaning. In addition to the connection and potential conflation of values, beliefs, and wishes, I turn now to two other observations I make regarding values in examining the image in Figure 5 and other multimodal references on the ACPO website—the portrayal of ease and pleasantness of value reflection, and the cognitive and process-oriented approach presented with the invitation to "think" as part of the five-step process. I start with hints provided of the easy and pleasantness of reflection.

[219] It can be debated from a theological and philosophical lens regarding whether values are indeed less subjective. I reference Lonergan's work here that relates to values in their suggestion that, "Objectivity is the fruit of authentic subjectivity" (Lonergan, 1979, p. 292, as cited in Gregson, 1988, p. 27). This relates to Lonergan's (1972/2017) suggestion of values holding "some scale of preference" (p. 32) that is discerned subjectively. This has implications for value reflection in ACP that I will address in Chapter 5. Byrne (2016) echoes this work in moving beyond values being "merely matters of subjective opinion" (p. 7) with the thinking rooted in Lonergan and the suggestion that "values, especially ethical values, can be known objectively" (p. 7). I return to this theological thinking in Chapter 5.

Implicit Suggestions of the Pleasantness and Ease of Value Reflection. In addition to the ease of value reflection observed in the "Values Exercise" with tick boxes for simple selection, similar perspectives are offered in some of the ACPO videos. Multimodally, the "Five Steps" animated video (HPCO, n.d.-h) includes cartoon drawings that appear on a whiteboard with a graphic human hand playfully wiping away each scene on the board before new themes arise (0:23). The ease of ACP may be suggested by whistling and folksy music creating an atmosphere of pleasantness. With this cartoon-like design, the video presents a five-step model focusing on the words "identify", "learn", "think", "talk", and "include".[220] Additionally, there is a suggestion of simplicity in the final words of the video: "So just remember the 5 steps!" (2:18). The image in Figure 6 is an excerpt from the "Five Steps" video I am referencing that portrays the boldness of the message, "IT'S JUST 5 STEPS…" (0:17) in a playful way. In this there is a pleasantness to the process. Once again, as noted above, little difficulty or conflict is presented.

Figure 6

Video Frame Outlining the Simplicity of "It's just 5 steps"

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

[220] I note here that the other animated video created by ACPO, "A 5 Step Process for Future Planning (HPCO, n.d.-h), includes a slightly different version of the five steps that includes "think", "talk", "learn", "plan" and "share". While the videos have no date of publication it would appear that stylistically this version is older and that there was an evolution in the five steps in content and order. Moreover, the broader website includes the five steps of "identify", "learn", "think", "talk" and "include" that are in the "Five Steps" video. Additional analysis of this evolution of change regarding the steps would be purely speculative and outside the scope of this dissertation.

In addition to the reference to easiness with the phrase, "IT'S JUST 5 STEPS" (0:17) in the "5 Steps Video (HPCO, n.d.-h), as noted in Figure 6, other videos also portray an emphasis of the ACP process that includes values to be simple. In the video entitled, "I'm a Substitute Decision Maker" (HPCO, n.d.-h), there is a textual emphasis on "TALK!" (0:47) with a suggestion to "Make sure you understand the wishes, values and beliefs of your family member or friend" (0:48). And the photos that correspond with the suggestion to "TALK" in this video include people talking to each other and appearing happy giving the suggestion of pleasantness. There is potentially an oversimplification of value reflection and ACP that may avoid relational complexity or messiness in the understanding of values, and the real relational challenges to values that might emerge in talking. While simplicity in processes may be beneficial for ease of use, one's discernment around ACP is potentially incomplete.[221] Having outlined the ease and pleasantness of value reflection presented above, I now observe another hint of discourse related values—the cognitive emphasis of ACP and focus on processes procedures.

Implicit Cognitive and Process-Oriented Value Reflection. In addition to the potential for oversimplification of the process and apparent easiness of the ACP process, as well as the suggestion of a generalized pleasantness related to value reflection that seems to avoid the challenges, there is also a cognitive and process-oriented aspect to decision-making I observed related to values and reflection on the ACPO website. Not only is there frequent reference to "thinking" in the five steps (HPCO, n.d.-w), but in the "5 Step" video (HPCO, n.d.-h) I outlined in Figure 5 that seemed conflate values, beliefs, and wishes, this frame also emphasizes the task of thinking "About what's important to you – about your values, beliefs and wishes" (1:10).

[221] A balance is needed in resources where there is increased accessibility and also engagement in the complexity of value reflection that includes human challenges and ultimate themes. I return to this in Chapter 5 in my conclusion.

Additional multimodal examples include the subtle image of a lightbulb over a character's head in the "Confirming Your Substitute Decision Maker in Ontario" (HPCO, n.d.-h) video, suggesting the thinking process related to one's SDM (1:56). The "Value Exercise" (HPCO, n.d.-u) too suggests a more cognitive approach with the invitation to "think about common values" (section 2, bullet 1). But what may be missing from this is engagement on values is the role of feelings.[222] Mindful of the work referenced in Chapter 2 from Nullens (2017) that "Values are like ideas of orientation, not primarily known cognitively, but intuitively and emotionally" (p. 41), I wonder whether the cognitive focus of thinking on the ACPO website may decrease deeper engagement in value reflection as other ways of knowing like emotion and intuition are not included. This is important because some spiritualities may be rooted in ways of knowing that are outside the cognitive domain.[223] Excluding opportunities for value reflection based on other ways of knowing may lead to decisions lacking the fullness of one's deepest beliefs and values that are needed in high stakes decisions that may involve death. In addition to the cognitive orientation regarding values, I also observe a process-oriented approach that seems overly focused on a simplified task processes through tools like diagrams and flow charts. In the section relating to, "How will my values be used to make my healthcare decisions?" (HPCO, n.d.-k) for example, a diagram is given to summarize the SDM's role in *thinking* about values and the application to a decision. The diagram in Figure 7 simplifies the process in a diagram with values and goals meeting the right information that ends up with a tidy decision with arrows noting the

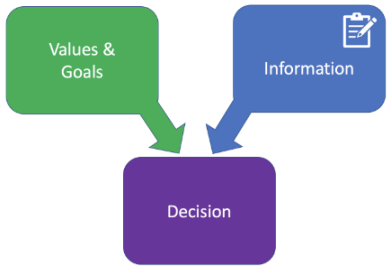
[222] I return to the suggestion by Lonergan that "feelings respond to values" (1972/2017, p. 32) and Byrne (2016) whose work that is grounded in Lonergan's thinkings suggests aspiring to "what is deepest and best within us" (p. 16) that is guided by conscience which involves far more than just a cognitive activity. I will offer additional theological reflection around these aspects in Chapter 5.

[223] I will return to this theme of embracing diverse ways of knowing in Chapter 5 when I discuss possible recommendations for increasing patient-centered approaches to ACP resources.

destination. Using multimodal tools of inquiry to analyze this diagram, one could suggest an oversimplification of the process through the diagram, potentially hiding complexities.

Figure 7

Graphic Outlining the Simplification of the Process That Leads to a Decision



Note. From *How do SDMs make decisions?, by HPCO, n.d.,* https://advancecareplanningontario.ca/substitue-decision-makers/how-do-sdms-make-decisions. Copyright 2024 by HPCO.

Adding to the reflection above, I observe that what is backgrounded in this diagram in Figure 7, once again, is any hint of challenge or struggle. The instrumental diagram presents a process around values and decision-making that appears smooth and unproblematic. There are small indications of acknowledging distress or conflict but they are largely left without further elaboration. An example is in the "Six Questions" (HPCO, n.d.-q) section, as noted above, where it notes, "It can be very distressing for SDMs to make decisions" (section 2, bullet 4). And while this section does acknowledge the challenge, the second half of this sentence suggests, "Your answers to these questions will give your SDM(s) helpful information" (section 2, bullet 4), potentially indicating to the participant that the process of questions provided by ACP should solve the distressing challenges. Again, considering the literature that alludes to the difficulty in making choices with few knowing what they would have wanted (Sibbald & Chidwick, 2010), and the dynamic of changing one's mind about what they might want (Torke et al., 2008), and

the potential for conflict with family (Bandini et al., 2017)—the simplicity presented in making choices with a reflection diagram like this that offers a simple procedure seems incomplete. Again, what is absent is the acknowledgement of the potentially emotional decisions involving death of a loved one and the potential for differing views and conflict. The reality is that many of these conversations are not linear, but rather, involve complex human and relational aspects that intersect with one's spirituality. Having outlined the implicit cognitive and procedural aspects of discourse related to values, I now offer additional findings related to the medical-legal focus.

Implicit Medical-Legal Focus on Wishes Not Values. While values, beliefs, and wishes may be conflated in the broader website, or at least connected together, as noted above, when it comes down to legal matters and decisions, I observe that the medical-legal focus of the website privileges wishes and not values. In the "Resource Guide" (HPCO, n.d.-o) for example, a section that contains a significant amount of textual information, 13 of the questions have "wishes" in the title giving a sense of the medical-legal privileging of this word for ACP. None of the titles include values. With wishes suggesting a propositional "expression of desire" (Black, 1979, p. 141), as noted in Chapter 2, there is a privileging of these seemingly more objective aspects of decisions that the medical-legal perspective prefers, rather than the apparent subjectiveness of values.[224] Multimodally, the medical-legal lens is also prominently displayed. In Figure 8 I share one example of a photo used in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) that frames the conversation legally with an image of a courtroom with a prominent wooden gavel, what appears to be a large legal book of some sort, and a gold scale (0:15). Machin and Mayr (2023) would suggest images like this as being a strong indicator of

[224] I suggest again here that I will return to the theological aspects of subjectivity regarding values in Chapter 5 with a return to the work of Lonergan (1972/2017) to suggest the importance of layers of values and spirituality.

"visual modality" (p. 293) that sends a strongly articulated message of the power of the legal system. This image from the video, as posted in Figure 8, has unmistakable connotations of power and medical-legal authority with symbols foregrounded so prominently.

Figure 8

Legal Symbols Featured in Video Outlining Medical-Legal Authority

Note. From *Educational Videos, by HPCO, n.d.,* https://advancecareplanningontario.ca/resources/educational-videos. Copyright 2024 by HPCO.

And while this photo with the gavel in Figure 8 is contextually a part of videos related to ACP more broadly, the image contributes to the overall framing of values and the entire process within a medical-legal context where spirituality is situated. Additionally, this medical-legal perspective may bring a sense of paternalism that hovers over the website and peaks out more prominently at different times. With paternalsim being noted as when "a health care professional acts as a parent with all of its negative and positive connotations" (Purtilo & Doherty, 2011, p. 88) there is a sense that the medical community knows best.[225] Additionally, in the "Advance Care Planning in Ontario Video" (HPCO, n.d.-h) there is also a hint of paternalism in a frame

[225] I note here that Pellegrino and Thomasma (1988) caution against medical paternalism because it "can fail to distinguish contexts and their role in medical and ethical decision making" (p. 23) and suggest "Perhaps the biggest failure in medical paternalism is its assumption that medical values or the medical good is the highest good, with an absolute quality that overrides other values" (p. 23). I return to this theme in addressing implications of a paternalistic and legal focus in Chapter 5.

that showcases a physician's note pad, gold pen and a stethescope (0:30) —all potential symbols of the power of the field of medicine. Machin and Mayr (2023) would suggest the symbols are chosen in relation to their "persuasive function" (p. 242) which in this case could suggest medical authority along with paternalism. The suggestion I observe in the phrase utilized alongside these images in the same video, "Your doctor will need to turn to someone else to make decisions for you" (0:30), includes this same power and authority. And while not related directly to spirituality, one can see the larger website environment that creates a tone that can open or close conversations regarding values with the suggestion of influence and power of a physician. Another example of possible paternalism is the repetition of the phrase, "You should be" (0:33) that is utilized three times in succession in a frame from the video, "I'm a Substitute Decision Maker" (HPCO, n.d.-h). With pulsing music playing in the background to the video the text and the words "You should" appear alongside the doctor's stethoscope faintly in the background once more and what appears be a pen and their written documentation in the background (0:33). With the previous frame showing a doctor looking down toward a patient in what appears to be the ICU with a ventilator (0:21), the three references to "should" on the single frame (0:30) emphasize what seems to be a paternalistic suggestion that one "should" have confidence in speaking up, be "willing and able" to make decisions, and finally, ability to "interpret and honour" one's wishes—all phrases shown in this same frame (0:30). While these suggestions may be legal requirements, the paternal language here suggests a medical-legal authority that multimodally frames a broader discourse across themes on the website that may reverberate more broadly—including in regard to their relatedness to values and spirituality. The message being sent might be the physician knows best rather than the focus being on the good of

the patient[226] and leading with what is most important to them. Having outlined the medical-legal focus informing the presence of values and the potential for paternalism, I close this section by observing an alternative view of values I see as an outlier on the website.

Implicit Alternative Perspectives Regarding Values. Having outlined both explicit and implicit references to values on the website, it is important to note glimpses of an alternative discourse I observe regarding values on the periphery of the website. While the discursive script in the six videos (HPCO, n.d.-h) I have been highlighting would suggest a universal participation in value reflection with messages like "ADVANCE CARE PLANNING IS FOR EVERYONE" (1:46), as noted in the "Five Steps" video (HPCO, n.d.-h), I observe that in a longer seven-minute video, "The Time is Now" (HPCO, n.d.-y), that focuses on Indigenous, First Nations, and Métis participants, I observe a culturally sensitive message being very different—and something that may provide valuable insight into further development on the ACPO website.[227] There is a lexical message at the beginning of the video that suggests, "Some of the topics discussed in this video are very personal and sensitive in nature. We acknowledge that there may be cultural teachings, values and beliefs which make having these conversations difficult or not culturally appropriate" (0:12). In this introduction to the video I observe a clear philosophical difference to the other videos on the website. This video invites sensitivity to the topic of ACP at the outset and suggests a discursive script that is open to diverse expressions of spirituality and values and acknowledges the sensitivity required in ACP reflection in order to respect the personal nature of these values conversations. As noted earlier in this chapter when addressing cultural sensitivity

[226]As alluded to at several points of my dissertation, Pellegrino and Thomasma (1988) suggest the good of the patient leads with a focus on the ultimate beliefs of the patient rather than the suggestion by medical culture that the physical aspects are most important. I return to this in Chapter 5 when addressing implications of privileging certain values in ACP resources and the potential exclusion of the diverse values held by Ontarians

[227] I will offer recommendations regarding spiritual and cultural inclusivity in Chapter 5 but offer this suggestion here to frame the alternative discourse I observe in Indigenous, First Nations, and Métis resources that may provide insight for inclusion of different perspectives in future development of spiritually integrated ACP resources.

around the topic of death, the rest of the video too invites inclusivity around values with reference an Elder who suggests the importance of helping loved ones in ACP "in a way that you would feel comfortable with culturally" (1:17). This kind of sensitivity and respect for diversity I observe to be present with greater focus in these Indigenous, First Nations, and Métis resources.

Additionally, the other aspect of an alternative discourse regarding values that I see implicit in the video, "The Time is Now" (HPCO, n.d.-y), is there seems to be a greater emphasis on values of personal connection and relationships in decision-making. Not only are benefits of ACP named in this video that include the explicit suggestion that ACP "helps avoid conflict" (1:25) that suggests a relational focus, but this same value of relationship seems to be demonstrated by a character in the video referencing their wish for a loved one to "teach me, teach me anything that you think is going to be important" (5:16). There is a personal and authentic quality in this testimony that seems to honour values around the depth of relationships and the connectedness between decisions and to relationships—something I do not observe to be present in the rest of the website. In summary, the small collection of Indigenous, First Nations and Métis resources seem to be an outlier on the larger ACPO website in their values and approach to cultural sensitivity, inclusion, and relational depth—perspectives regarding values that may provide some insight to the future development of ACPO.

Having outlined the findings of Part 1 that focused on the MCDA examination that I carried out with the tools of inquiry presented in Chapter 3, I now move to the next section of this chapter that is related to Part 2 of my examination that involves the coding and generation of themes related to discursive themes. In the next part of this chapter I will outline Level A and Level B of the findings related to my research questions: what discourses related to spirituality, death, and values might be both present or absent in website? And secondly, what bioethical

values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death and values? I start this next section by introducing the coding and theme generation process.

4.4. Part 2: Coding and Theme Generation

Having outlined the findings of Part 1 of my MCDA examination of the ACPO website using the tools of inquiry presented in Chapter 3, I move on now to Part 2 of this analysis focused on coding and the generation of themes using Braun and Clarke's (2022) reflexive TA. I begin with my Level A findings focusing on what discourses—the "broader frameworks of interpretation" (Machin and Mayr (2023, p. 26) —related to spirituality, death, and values might be present on the website, followed by Level B's focus on what bioethical values, principles, assumptions, and ideologies—"an overall world view that reflects the interests of the powerful in society" (Machin & Mayr, 2023, p. 37) —that might be embedded within these discourses of spirituality, death, and values?[228] I start this next section by outlining the discursive findings that are rooted in the six phases of the reflexive TA process, beginning with the familiarization phase.

4.4.1 Level A Findings: Discursive Themes

In Part 2 of this analysis of the ACPO website, I used Braun and Clarke's (2022) coding and theme generation process—reflexive TA—that I outlined at length in Chapter 3. I outline briefly the process I followed in the paragraphs below before outlining the final discourses that I observed. I began Phase 1 of the coding process with the first step of "Familiarizing yourself with the data" (p. 56) where I read through the new dataset of findings that emerged from the MCDA examination using the tools of inquiry. After immersing myself in the website and

[228]To refresh the reader in regard to the understandings I am using for these terms, I have inserted these definitions of discourse and ideology once more that are drawn from Machin and Mayr (2023).

viewing it adequately, I engaged in Phase 2's focus on generating codes where I used sticky notes to place a code label on elements of the MCDA dataset that surfaced for me. These code labels were meant to reveal something "potentially relevant" (p. 52) or interesting with an initial label of what the discursive element might mean—and not meant to be a final label, but rather, an initial impression. The code labels I utilized would eventually lead to the final discursive themes I outline later in this chapter. I liberally assigned code labels to discursive examples I observed across the website in the MCDA analysis carried out in Part 1 that included over 300 separate code labels as initial impressions. I also aligned the code labels to a number system that I created allowing me to easily connect the code labels with the website parts should I need to return to them later for reference and to increase organization.

Following the process of Phase 1 where I focused on familiarizing myself with the data, and Phase 2 that included my own generation of initial codes through assigning code labels liberally across the dataset, I moved to Phase 3 of the reflexive TA process that focused on observing themes within the code labels assigned. At this stage I used a physical paper and scissor approach to searching for themes as outlined by Braun and Clarke (2022)—a traditional method that many researchers still utilize. I cut up the over 300 code labels into paper slips and began to organize them into meaningful patterns.

Out of the larger collection of these preliminary code labels I began to cluster them into groups. Again, with paper strips, I organized the themes into groupings and came up with 24 initial prototype discursive themes—mindful the themes continued to be in development. The 24 initial discursive themes I observed in Phase 3 of this process are included in Table 6 and organized alphabetically.

Table 6

Phase 3 Initial Discursive Themes Observed on the ACPO Website

1. A selection of values are privileged but this doesn't include spirituality
2. Authority of medicine and legal perspectives are most important to ACP
3. Concreteness of wishes is emphasized with its many examples; while values remain vague
4. Control of life is possible
5. Cultural elements are largely unimportant to ACP
6. Dignity is a value frequently named but also left undefined
7. Hope is ambiguously connected to a vague reference to miracles
8. Indigenous approaches to ACP include cultural safety and increased relatedness
9. Lack of complexity to ACP but much simplicity
10. Morality is not a factor in ACP
11. One's origins are vaguely mentioned, but unimportant to value reflection
12. Paradox of chaos and order
13. Personal values are appropriate for reflection, but cultural/religious values are unimportant
14. Promise of easy, uncomplicated, and conflict free discernment
15. Quality of life holds a place of reverence in ACP but with a sense of vagueness
16. Reflection, feeling or intuition is not a legitimate option in value reflection
17. Religious organizations, communities, or groups are not included
18. Spirituality is limited, vague, and awkward
19. The horizon of values is truncated to medical understandings
20. There is awkwardness in addressing spiritual themes like hope and miracles
21. Thinking and cognitive approaches are privileged
22. Value reflection follows a simple linear and procedural process
23. Values are treated as commodities that are easily ranked and traded
24. What is "common" to ACP content producers is what is "common" to them

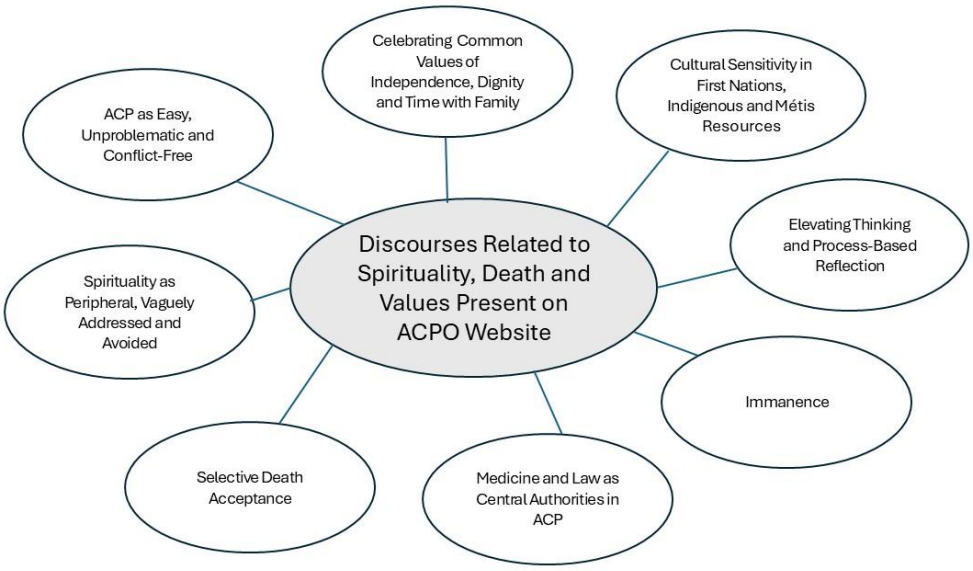
While Phase 3 included the grouping of over 300 initial code labels into the 24 initial discursive themes displayed in Table 6, this collection of themes was still too large and needing further thematic refinement. In Phase 4, I took these initial 24 themes and reviewed them again for thematic content with the goal of refining them further. In this phase, I also went back to the dataset from the MCDA analysis in Part 1 to explore the original assignment of codes to ensure alignment, as well as lining up the coding process against my research questions once more to increase my coding focus. In going back to the dataset of the website pages once again, I

engaged in what Terry and Hayfield (2021) call “pressure testing” (p. 56) the themes to see if they held up to the data while following their suggestion of “holding on to your prototypes only lightly is essential” (p. 56). At this point I analyzed for duplication in the themes and assessed which themes could potentially be tangential to the research questions I was seeking to answer. I repeat my research questions here for convenience. My main question was, how is spirituality situated in ACP resources found on the ACPO website? My research sub-questions include: 1) what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website?; 2) what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death and values?; and 3) what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization? As I have noted previously, the first sub-question was the focus of Layer A of this coding section, the second sub-question focused on Layer B of coding that will be outlined later in this chapter, and the third sub-question I will answer in my discussion in Chapter 5.

Returning to the work of Phase 4, I utilized reflective questions inspired by Terry and Hayfield (2021) to narrow the themes including factors around what might be included in the discursive theme, having concrete examples to affirm the finding, and whether the themes I named were too broad, too narrow, or too simplistic. After narrowing the themes in Phase 4 down to eight to ten themes, I began crafting enduring titles and explanations in Phase 5 with initial definitions and examples before finishing with the following eight discourses in final written form below with descriptions in the section ahead to complete Phase 6. I present the final eight discourses related to spirituality, death and values on the ACPO website in the graphic in Table 7 followed by more detailed descriptions of the eight discourses in the section to follow.

Table 7

Phase 5 Discourses Related to Spirituality, Death, and Values Present on ACPO Website



Having outlined the process in developing the discourses related to spirituality, death, and values that I observed within the ACPO website, I will now outline the eight[229] discursive themes and provide a description of what is meant by each along with providing a few brief examples.[230]

Eight Discourses Related to Spirituality, Death, and Values on the ACPO Website.

ACP as Being Easy, Unproblematic, and Conflict-Free. The first discourse I will outline is my observation of the presence of a discourse on the website that suggests the ACP process as being easy, unproblematic, and conflict free.[231] Examples of the easiness of the process is

[229] I note here as well that while there is thematic overlap in some of the content of these discourses, I observe that each one has distinct qualities deserving of a separate category. This kind of discernment and potential for overlap is common to the approach I have taken in reflexive TA.
[230] I have arranged the eight themes presented in alphabetical order as to not privilege any above another.
[231]This apparent ease is in sharp contrast to the complexity of factors regarding informed consent and decision-making that I broadly referenced in Chapter 2 that includes religious and cultural differences (Zhang, 2021); the healthcare bureaucracy (Stanton-Jean et al., 2014); challenges facing the SDM about not knowing what a loved one

suggested in the videos that note references like “IT’S JUST 5 STEPS” (0:19) in the “Five Steps” video (HPCO, n.d.-h), or another reference in the video entitled “A 5 Step Process for Future Planning” (HPCO, n.d.-h) that offers the simple message: “So just remember the 5 steps” (2:22). Further, diagrams and graphics note a simplicity to the task including an oversimplified diagram noted in Figure 7 that suggests bringing one’s values and goals together with information to create a decision that appears quite simple (HPCO, n.d.-k). The tick-box graphics in the “Values Exercise” (HPCO, n.d.-u) also suggest a sense of ease in value prioritization with simple selections rather than a more complex discernment of deeper spiritual values that may involve discernment and prioritization. Additionally, more than just the ease of value reflection being presented and the apparent simplicity, I also see evidence of ACP being unproblematic. I see this in the portrayal of largely happy and pleasant characters in the stories (HPCO, n.d.-e; HPCO, n.d.-c) and videos that animate a lighthearted and straightforward process (HPCO, n.d.-h) that lacks acknowledgement of real-world problems. Some possible real-world challenges that may intersect with the ACP process, as I mentioned in Chapter 2, include the clinical complexity of health care and the many elements of consent (Beauchamp & Childress, 2019); the potential for psychological dynamics emerging in patient and health care relationships (Tran, 2023); language barriers to the process (Stanton-Jean et al., 2014); or the challenges of making a decision for another and the burden of decision-making (Wendler & Rid, 2011) to name only a few. In contrast to these real-world challenges, the character stories on the ACPO website feature smiling faces alongside stories of value reflection that imply an unproblematic process and absence of conflict (HPCO, n.d.-c; HPCO, n.d.-e) with few outliers. Additionally, the easygoing folksy music in the two animated videos, (HPCO, n.d.-h) “Five Steps”, and “A 5 Step Process

would want (Sibbald & Chidwick, 2010); and the shift of individual wishes that can happen over time (Torke et al., 2008).

for Future Planning", also suggests a pleasant and unproblematic tone alongside the serious topic at hand that may include themes of serious illness and death. Conflict or problems related to the potential messiness of value reflection, possible family conflict, spiritual or existential concerns, struggles regarding death, or the potential for heaviness of these conversations seem largely absent.[232] Rather, there is a larger discourse regarding value reflection and ACP processes as being easy, unproblematic, and conflict-free—a discourse with implications for spirituality considering research suggesting potential conflict at end-of-life.[233]

Celebrating Common Values of Independence, Dignity, and Time with Family. A second discourse that I observed on the website is a discourse of celebrating "common" values of independence, dignity, and time with family. The term "common" is especially important here in this framework of interpretation presented by content-producers. A reference to "common" in the "Values Exercise" for instance invites participants to "think about common values" (HPCO, n.d.-u, bullet 1) that seems to suggest an understanding of "common" values being linked to those of content-producers and not necessarily that of diverse patients from various spiritualities. Returning to the work of Machin and Mayr (2023), there is a naturalizing of the content-producers' perspective of what is "common" in this section, including my observation of an ongoing focus on specific values of independence, dignity, and family. I observe the privileging of these "common" values both lexically through the character stories (HPCO, n.d.-e; HPCO, n.d.-c) and also in the "Values Exercise" (HPCO, n.d.-u) with implicit suggestions made through subtle design features. Not only are the first two values in the "Values Exercise" listed non-

[232] I note here once more that the outlier to this perspective on ACP processes being easy, unproblematic, and conflict free is again the First Nations, Indigenous, and Métis resources that I observe to embrace a sensitivity, authenticity and relational honesty.

[233]Again, Bandini et al. (2017) note in their research that 25% of conflict at end-of-life is related to religion while Sibbald and Chidwick (2010) note the presence of religion in cases involving clinicians and SDMs in cases brought to the Consent and Capacity Board.

alphabetically as dignity and independence, but the open text boxes also elevate these values together with family as being the only three values from the longer list that participants are invited to elaborate upon from their own experience. The privileging of these "common" values is also notable in the character stories, as mentioned above, that seem to celebrate the values of independence, dignity, and family with characters voicing these values with clarity in their stories—including Bob's section focusing on independence (HPCO, n.d.-e), Althea's story centering on dignity (HPCO, n.d.-c) and Tran inviting family as the most important value (HPCO, n.d.-v). And as noted above, the smile of the characters in each image, together with their gaze directed towards the viewer, seems to suggest a sense of connection around these themes and a naturalization of what might be "common" to this broad group of people. Overall, I observe a discursive script that celebrates these values the content-producers choose to highlight more centrally—values of independence, dignity, and time with family. All the while, other values that may be important to diverse groups of patients that may intersect with one's spirituality and belief system, are not provided the same opportunity for inclusion or reflection.

Cultural Sensitivity in First Nations, Indigenous, and Métis Resources. A third discourse I observed in the ACPO website is an alternative discourse of sorts, as I observe it to be present only in a small section of the website—a discourse of cultural sensitivity observed in First Nations, Indigenous, and Métis resources. In surveying the entire ACPO website, I observe the First Nations, Indigenous, and Métis resources to be clearly different in their approach, featuring an increased focus on cultural sensitivity, an inclusiveness to diverse perspectives, as well as a greater openness to spirituality. For example, at the beginning of the "The Time is Now" (HPCO, n.d.-y) video, as I have referenced previously in this chapter, it sensitively suggests, "Some topics discussed in this video are very personal and sensitive in nature. We

acknowledge that there may be cultural teachings, values and beliefs which make having these conversations difficult or not culturally appropriate" (0:11). This intentional suggestion that ACP conversations may in fact be challenging or not culturally inappropriate[234] appears in stark contrast to the mainstream ACP reference in the "Five Steps" video (HPCO, n.d.-h) that includes an image featuring a diverse group of animated characters standing together alongside lettering that says, "ADVANCE CARE PLANNING IS FOR EVERYONE" (1:43). There is a culturally sensitive suggestion in the First Nations, Indigenous, and Métis resources that suggests ACP conversations may not actually be culturally appropriate. And more, the preamble to this video on the ACP website language that would suggest these conversations involving dying are "deeply personal" (HPCO, n.d.-y). This kind of language is also unique to the First Nations, Indigenous, and Métis resources. Additionally, this same video also includes words from an Elder who references the importance of sensitivity in engaging in health care decisions "in a away that you would feel comfortable with culturally" (1:17). There is a unique cultural sensitivity in these resources seemingly absent from the larger ACP site. Additionally, included with the noticeable presence of cultural sensitivity is also an openness to integrating spirituailty that aligns with this spirit of inclusivity. Examples of this spiritual integration include an Elder providing personal perspective and the inclusion of drumming and chanting at the beginning and the end of the video provide hints of an openness to spirituality being a central part of ACP (HPCO, n.d.-y). There is a modelling of cultural sensitivity regarding the topic of death in these First Nations, Indigenous, and Métis resources and an openness to spirituality that I do not

[234] This welcoming of different views and sensitivity to how ACP conversations may be difficult or even inappropriate exemplifies the suggestion by Goodchild (2021) who invites inclusion of different perspectives with an "invitation to sit in a circle with us, in the sacred space of non-interference in between epistemologies" (p. 99). I will return to this theme in the discussion in Chapter 5 including implications of cultural sensitivity.

observe elsewhere on the website—an approach that may provide insight and inspiration for additional development for ACP resources in the future.[235]

Elevating Thinking and Process-Based Reflection. Fourthly, I observe a discourse that elevates thinking and process-based reflection that extends to how one interacts with spirituality, values, and death. Thinking-oriented activities include engagement that is focused cognitively. Obvious examples of the privilege given to thinking-oriented processes include the prominence of "thinking" in the five step ACP process (HPCO, n.d.-w) as well as the highlighting of the word "THINK" (1:01) in resources like the "5 Steps" video (HPCO, n.d.-h). But more subtly than naming the presence of this thinking orientation in the five steps, there is an overall privilege given to thinking related engagement across the website. A prime example is the "Resource Guide" (HPCO, n.d.-o) that contains lengthy legal descriptions and theoretical content outlining over 100 questions and answers linked to nuances of consent, the role of the SDM, and ACP. Engagement includes complex concepts like the hierarchy of one's SDM (HPCO, n.d.-s; HPCO, n.d.-f) as well as weighing capacity questions (HPCO, n.d.-b) and other questions involving legislation. In contrast to other modes of knowledge gathering in many traditions where people may draw upon other ways of knowing including feeling, intuition, or emotion in their decision-making and value prioritization, I observe a leaning towards thinking-oriented engagement on the website with lengthy written materials and process-oriented tools across the website. This observation of the thinking-oriented discourses is important because it privileges a particular way of knowing and may exclude other ways of knowing that may be outside of the

[235] I will address future recommendations in Chapter 5 and will include aspects of this discourse as an example of cultural sensitivity.

cognitive domain. Additionally, the resources may exclude those who are at different stages of life or those who are cognitively challenged (Liégeois, 2021).

And more than lexically, there are numerous multimodal symbols throughout the website featuring different thinking-oriented elements. Subtle examples include a visual reference in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) containing an image of someone with a graphic lightbulb above their head that suggests the centrality of the thinking process (1:54) and also in the "Five Steps" video where a frame in the video shows a character sitting at a computer with a large shelf of books as part of the ACP process (0:55) that seems to suggest reasoning and study with regards to exploring the topic of ACP (HPCO, n.d.-h). In contrast to non-cognitive ways to engage these themes of death and value prioritization through the inclusion of feelings, intuition, community, or emotion that may be present in many spiritualities and belief systems, there is a framework presented on the website that seems to privilege a discourse related to thinking without mention of other ways of discerning values.[236]

Immanence. The fifth discourse I observe relates to the presence of immanence that underpins understandings of spirituality, death, and meaning on the ACPO website. This framework of interpretation related to immanence is reflected philosophically in the work of Taylor (2007) and their concept of an "immanent frame" that reflects an order to the world that is natural and "understood on its own, without reference to interventions from outside" (p. 543). From a health care perspective, Balboni and Balboni (2019) suggest a kind of spirituality of immanence with "a fundamental centering on bodily health, cure and physical comfort" (p. 221) or "focus on the body" (p. 221). I observe these immanent notions on the ACPO website with a

[236] I note here that theology becomes a potential avenue here to expand reflection of values beyond the cognitive domain. As noted in Chapter 2, Lonergan's (1972/2017) work in particular speaks to how feelings relate to values and reflection. I return to this theological perspective in recommendations in Chapter 5.

focus on the natural, bodily, and physical aspects of care without reference to the transcendent aspect to ACP processes that may be important to many spiritualities. Having outlined what is meant by a discourse of immanence, I now offer a few examples of this discourse from the APCO website. This discourse of immanence that focuses almost entirely on bodily and physical aspects of health can be observed at numerous places on the website including conversations around death and one's possible fears. Content-producers in these sections provide immanent examples of worries related to physical pain, breathing problems, or being a burden (HPCO, n.d.-q, section 3, question 4) rather than offer examples of transcendent worries that may include existential worries regarding an afterlife, faithfulness to one's religion, the meaning in suffering, or duty to one's spiritual beliefs that stretch beyond one's physical life. Additionally, there is an invitation elsewhere to come up with a plan to avoid physical suffering (HPCO, n.d.-q, section 3, question 4)—a suggestion that, once again, does not allude to the possible transcendent meaning found in suffering that is found in some belief systems. The focus on immanence related to death includes an invitation to think about one's previous medical experiences and reflect on what could have been done differently—an invitation that implies the bodily aspects of care (HPCO, n.d.-t, section 2, box 5). Hints of this discourse of immanence are also found on the values listed in the "Values Exercise" (HPCO, n.d.-u) that privilege physically-oriented perspectives of human life including values of independence, dignity, clear-mindedness, and strength—very similar to the character stories that focus on physical aspects noted above including Bob not wanting others to bath or dress him, or Althea not wanting to be hooked up to machines (HPCO, n.d.-c)—both examples of immanent aspects of life. And while family is named as a value, it is referenced regarding immanent time with family that suggests an in-the-moment presence (HPCO, n.d.-c; HPCO, n.d.-t) rather than spiritual notions like legacy or ancestral connections

beyond the physical that may be important to some spiritual traditions. And finally, spirituality, while vaguely elaborated upon, includes this same leaning towards the physical with a vague focus leaning towards understandings related to wellness and quality of life with the suggestion of the spiritual notion of meaning being tied to one's enjoyment of life and "things" that make one's life good (HPCO, n.d.-q, section 3, question 3). It is this centering on the in-the-moment physical health, bodily care, and comfort that suggests this discourse of immanence underpinning the overlapping domains of spirituality, death, and values across the website, rather than an openness to transcendence that may be important to many spiritualities.

Medicine and Law as Central Authorities in ACP. Sixth, I observe a discourse revolving around medicine and law as central authorities in ACP that provides a framework for interpretation for the larger conversation around spirituality, death, and values. With the focus of ACP being that of health care,[237] there is a central medical focus that underpins the whole website, and with it, frequent references to medicine having a layer of authority. Multimodally, the videos portray this authoritative medical aspect strongly like the video, "I'm a Substitute Decision Maker…" (HPCO, n.d.-h) that features physicians prominently as authorities in one's medical decisions with language like "You should" (0:34) that suggests, once again, an authority with images that include a gold pen with a stethoscope in the background that could represent symbols of medical power. Together with medical authority, there is also an aspect of law that is also present and powerful with numerous references to legislation and legal systems—especially in the "Resource Guide" that even acknowledges the support of a law firm (HPCO, n.d.-o). Not only does the guide seem like an authoritative resource that includes over 100 legally oriented questions and answers that outline various interpretations that help individuals align with the

[237] While there is a power of attorney for finance, this aspect is beyond the scope of my thesis focused on healthcare.

nuances of legislation, but multimodal examples of legal aspects of medicine are observed across the website that symbolically suggest this kind of authority. For example, the video, "Confirming Your Substitute Decision Maker in Ontario" (HPCO, n.d.-h) begins with imagery of a medical scenario where the opening frames show what appears to be a vulnerable patient with a loved one looking upward towards the physician with an angle of the photo suggesting one being higher than another in terms of power (0:17). A legal reference happens in the next frame where the attention turns to a photo of a court room (0:20) and then follows next with diagrams related to a hierarchy of SDMs that contains strong legal language (0:28).[238] Further relating to these kinds of health care challenges, another video, "Advance Care Planning in Ontario" (HPCO, n.d.-h), notes with an exclamation mark that "ACP can help!" (0:36), suggesting medicine can solve this conundrum. Adding to the medical-legal power of this video is the question which ends the video regarding ACP: "Who should do this?" (1:32). And the answer is "Every adult!" (1:32) that suggests a solution with an exclamation mark—punctuation that could be seen as paternalistic as some spiritualities may have issues with reflection around death as noted above.[239] Overall, the presence of medicine and law as authorities in ACP seems unmistakable.

Selective Death Acceptance. The seventh discourse I observed in my analysis suggests what I am calling selective death acceptance. While I certainly observe an overall framework of interpretation related to avoidance of death across the website, there is also a limited aspect of acceptance regarding death in certain selected situations where explicit references to death seem

[238] I offer one example of this strong legal language from the "Resource Guide" referencing understandings of the SDM, court orders, and the *Consent and Capacity Board*. The description suggests "'Next of Kin' is not a term used in the *Health Care Consent Act, 1996* and does not appear in the hierarchy list. However, it also suggests that all the "automatic" SDMs that may act without the patient having appointed them, or without getting authority to act as SDM through a court order from the Consent and Capacity Board, are all what is commonly thought of as 'next of kin'" (HPCO, n.d.-s, question 4, para. 5). It is this kind of legal description that is prevalent in the resource guide.

[239] I mentioned some traditions who do not name death in Chapter 2 including the work of Yeo and Hikoyeda (2000) whose research suggest a "cultural barrier against talking about death" (p. 108) in Chinese Americans. This is just one example I provide here of traditions that may not be comfortable engaging with the topic of death.

acceptable. I begin by outlining the death avoidance I observe on the website. As noted in Chapter 2, the suggestion of death denial and death repression (Balboni & Balboni, 2019) is well-established in the literature as noted by Northcott and Wilson (2022) and Kübler-Ross (1969/2003). Overall, this death avoidance is observed as the broader framework of the ACPO website with frequent language of end-of-life (HPCO, n.d.-s; HPCO, n.d.-a), one's last days (HPCO, n.d.-a) or "living well to the end" (HPCO, n.d.-g) instead of mentioning death explicitly. Additional masked references to death include suggestions of an SDM starting or stopping life medications or life support (HPCO, n.d.-x)—references that again do not spell out death explicitly. While the overall framework suggests death denial, in my examination of the ACPO website more broadly, I did observe selective pockets of acceptability of death that I have noted as a discourse of "selective death acceptance". I observed death to be acceptable to name in relation to historical deaths, technical references to medical-legal aspects related to death, references related to culturally sensitive approaches to the topic of dying in First Nations, Indigenous, or Métis resources, and also references to death that are utilized for persuasion. Examples of naming historic death are found in the character stories with references like "Bob's wife died 6 years ago" (HPCO, n.d.-e), while acceptability in naming death in medical-legal references include Medical Assistance in Dying (HPCO, n.d.-f) or a resident's wish to die at home (HPCO, n.d.-q). Hints of sensitivity in addressing death explicitly in relation to the First Nations, Indigenous, and Métis include the reference to the personal nature of "dying" that is mentioned in the preamble to the video "The Time is Now" (HPCO, n.d.-y, section 2, para. 1). A final place where an explicit portrayal of death is observed is in the multimodal images that openly imply death through images—but seemingly only in service to persuade the viewer to engage in ACP processes. These persuasive references to death I observed in the video "Advance

Care Planning in Ontario" (HPCO, n.d.-h) include photos of an ICU room, a car accident, and the emergency room—all with emotive music along with the end goal of inspiring ACP involvement as in the example of words "ACP can help!" (0:36). While death is not explicitly named, it seems to serve as a means of persuasion or to inspire one to engage in ACP. Hence, while a larger death denying framework exists, I observe an overall discourse of selective death acceptance in certain situations that include historical references, medical-legal aspects, sensitivity in First Nations, Indigenous, and Métis references, and functional uses to persuade.

Spirituality as Being Peripheral, Vaguely Addressed, and Avoided. Finally, the eighth discourse I observed is a discourse of spirituality being peripheral, vaguely addressed, and largely avoided.[240] This finding is rooted in my observation of the words "spirituality" or "spiritual" being explicitly mentioned only three times across the entire website (HPCO, n.d.-u; HPCO, n.d.-t). It is peripheral in that spirituality is indeed included in some form on the website, but its presence seems on the outskirts of discussion, not well defined, and lacking integration as a prominent part of the ACP process. An example would be the "Values Exercise" mentioned above (HPCO, n.d.-u) where both references to "spiritual beliefs" and "spirituality" are buried in a longer list of options and not given central graphic space for additional reflection. In the list of "personal values" in this same section, dignity and independence are given prominence in both their positioning on the list of check boxes, and also in the free text boxes that invite specific reflection on these values—but not spirituality. Spirituality seems positioned on the periphery of this conversation suggesting it is not central in ACP or to the prioritization of one's values.

[240] I note again here that this discourse I am naming is an observation of the larger website. As I have noted frequently in this examination, the outlier to this finding is the First Nations, Indigenous, and Métis resources where I observe an openness to spirituality as noted in the discourse I observed above with my finding of *Cultural Sensitivity in First Nations, Indigenous, and Métis Resources.*

Not only do I observe spirituality to be on the periphery of the conversation, I also observe a vagueness regarding spirituality's meaning when the topic does surface. In observing possible implicit meanings on the website, it seems that spirituality is loosely connected to meaning and quality of life in one part (HPCO, n.d.-q), as included as a value among other values like "hard work" and "strength" in another section (HPCO, n.d.-u), or used elsewhere as a functional comfort measure to be used at end-of-life (HPCO, n.d.-q). Additional examples of the vagueness of its meaning on the website include the abrupt and possible tangential inclusion of the spiritual notion of "hope"[241] in connection to miracles without elaboration or examples, as well as the loose connection to how "spiritual beliefs" may "affect us deeply" (HPCO, n.d.-u). While these references invite a level of depth regarding spirituality, there is no additional elaboration or description provided, leaving these references rather empty in terms of possible meanings. This kind of vagueness regarding descriptions related to spiritual themes is in stark contrast to the precision and crispness I note in the content-producers' articulation of technical medical-legal notions like "wishes" in the "Resource Guide" (HPCO, n.d.-o). Despite being named a few times, and vaguely referenced in other times, there is a discursive sense that spirituality is potentially being avoided when looking at the broader website. Examples include the absence of references in the six main videos or in any of the main character stories that serve as central features of the website. Overall, I see a generalized closedness in this discourse with spirituality being peripheral, vaguely addressed, and largely avoided—again, with the exception of the First Nations, Indigenous, and Métis resources where there is an openness to integrating spirituality in connection with cultural sensitivity as noted above.

[241] The reference to "hope" I am referring to is found in the "Six Questions" section (HPCO, n.d.-q) where hope is referenced as being important but the reference notes: "it is possible to be hopeful and believe in miracles and at the same time think about, talk about and prepare for the future" (question 2, bullet 4).

Having outlined the Part 2 findings of this analysis with Level A's focus on the eight discourses I observed related to spirituality, death, and values in the ACPO website, I now present my findings in my analysis in Level B of my examination with a focus on the assumptions, values, principles, and ideologies emerging from the eight discourses named above.

4.4.2 Level B Findings: Analysis of Ideological Assumptions, Values, and Principles

Having outlined the Level A findings of this examination that focused on coding and theme generation related to discourses of spirituality, death, and values connected to my first research sub-question,[242] I now present the findings related to assumptions, values, principles, and ideologies present in Level B of my examination that relate to my second research sub-question.[243] In this part I examine the eight discourses I observed in Level A on a deeper level with analysis focusing on the embedded ideological assumptions, values, and principles that may be present. But before outlining my findings, it is important to say a few words about terminology. Drawing on Machin and Mayr's (2023) suggestion of ideology being "an overall world view that reflects the interests of the powerful of society" (p. 37), these observations intersect with this notion of power—and in this case, the potential interests of content-producers rooted in bioethics. I have intentionally included four overlapping terms—values, principles, assumptions, and ideologies—to explore this research question to ensure a fullness of analysis.[244]

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[242] For review, I offer my first research sub-question I addressed here: what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website? I remind the reader that the focus on absent discourses will be addressed in Chapter 5.

[243]For convenience, I offer the reader a review of my second research sub-question: what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death and values?

[244] I am aware of the overlapping meanings of these terms. "Values", as noted above by Sagiv and Schwartz (2023), includes the notion of guiding principles, while "principles" as defined by the Oxford English Dictionary (Oxford University Press, 2002) means "a primary assumption forming the basis of a chain of reasoning" (a1387), while "assumption" being "The taking of anything for granted as the basis of argument or action" (1656). My approach to these overlapping words is an ideological one and rooted in Machin and Mayr's (2023) definition of ideology as being "an overall world view that reflects the interests of the powerful of society" (p. 37). For the sake of brevity, in the sections to come I will often refer more broadly to these overlapping terms as "ideological assumptions".

Before outlining the reflexive TA process I utilized in Level B, I pause to say a brief word regarding the inductive versus deductive nature of this approach that I referenced in Chapter 3. My approach to Level B of this analysis is inductive in that I was not analyzing data or discourses from an explicit theoretical codebook related to these ideological assumptions and values. Rather, these ideological themes arose inductively from my own observations from the reflexive TA process that I will outline below. But as noted in Chapter 3, I was also mindful during my examination of my own existing theoretical knowledge and the general theoretical background regarding bioethics that I presented in Chapter 2 that certainly underpins my own examination. It is important to name that my inductive analysis of the discourse also holds my own preconceived understandings and theoretical perspectives in what Braun and Clarke (2022) suggest as something that is "unavoidable" (p. 211). I undertook this inductive analysis, mindful of the theoretical background I brought to my examination. Some self-reflexive observations will be offered at the close of this chapter and in Appendix B acknowledging my own biases.

Having provided some clarity regarding the inductive nature of this next part of the analysis, I begin by briefly outlining the process used here in Level B of my examination focusing on ideological assumptions. Following the same six-phase reflexive TA process used in Level A focused on discourses, I began Phase 1 by refamiliarizing myself with the data. In this phase I began by reviewing the eight discourses arising in Level A along with the website more broadly—but this time reflecting on possible ideological assumptions that may be present. In Phase 2 I liberally placed code labels on the eight discourses presented above with a focus on what might be potentially relevant ideologically—again my process included the use of paper labels with scissors. Like the process focused on discourses in Level A, I next took the code labels from Phase 2 and began to group them into clusters in Phase 3 with hopes of finding larger

ideological themes across all the discourses. Using paper and scissors, I grouped codes into clusters with shared meanings based on ideological assumptions. Below I offer the 16 initial themes I observed in Phase 3 of this analysis that I arrange in Table 8 alphabetically.

Table 8

Phase 3 Clusters of Values, Assumptions, Principles, and Ideologies

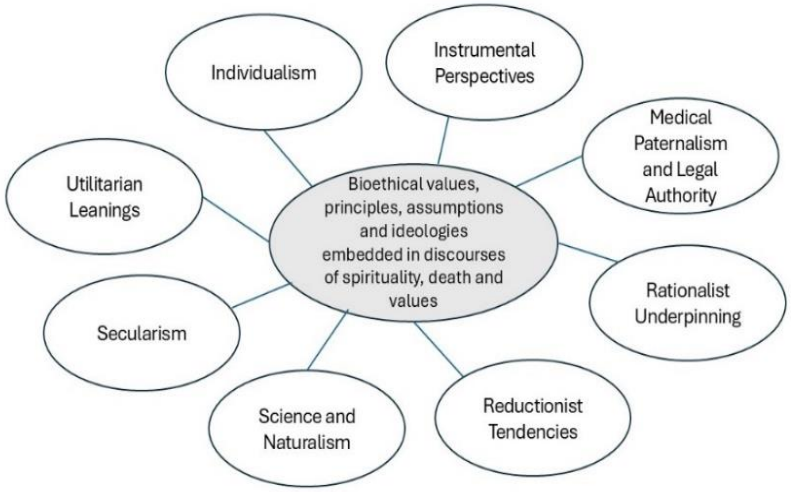
1. Certainty, controlling, actionable
2. Conflict avoidant
3. Cultural safety in Indigenous resources, harmony, peace, humility
4. Existentialism, secularism, humanism
5. Immanent, compartmentalization, reductionism, simplistic, detached
6. Individualism, self-determination, autonomy
7. Instrumentalism, functionalism, pragmatism
8. Law and legalism, technical, professionalism, expert, manualism, bureaucratic, euro-centric
9. Materialism, naturalism, physicalism
10. Medicalism, paternalism, authoritative
11. Pleasure principles, utilitarianism, pain avoidance, hedonism
12. Rationalism, secularization, objectivism, scientism, empiricism, exclusive humanism
13. Reductionism, mechanistic, medicalization, commodification, unidimensional
14. Sensationalism, consumerism, positive perspectives, customer-service orientation, business sense, fantastic approaches
15. Task oriented, process driven, technical
16. Tokenism, isolationism,

Next, I took these "prototype themes" (Terry & Hayfield, 2021, p. 46) that I observed in Phase 3 and reviewed them in Phase 4—this time with a focus on refinement and a lens to thematic conciseness and coherence. With themes having similar meanings, I narrowed the clusters down even further in this phase. Further, in Phase 4, I not only re-analyzed the eight discourses in Layer A to solidify themes, but I also returned to the broader MCDA data once more to confirm evidence across the dataset and to narrow the findings into eight clusters. Finally, in Phase 5 I reviewed the clusters and theoretically analyzed each one for conciseness and meaning, before crafting the final names of eight thematic clusters related to ideological

assumptions along with descriptions of each theme.[245] The iterative process resulted in the final eight themes that were written up in Phase 6 with full descriptions and examples. I outline the final ideological assumptions I observed in Table 9 and descriptions of all eight clusters ahead.

Table 9

Bioethical Values, Principles, Assumptions, and Ideologies Embedded in Discourses



Having outlined the clusters of ideological assumptions and values in the diagram above, I now move to describing the clusters with a brief description of what is meant by each ideological assumption along with examples of findings from the discourses and dataset.[246] I have organized the ideological assumptions in alphabetical order and begin with the finding of individualism.

[245] I note that these are broad themes I observed across the entire website that do also include some outliers that I will mention in the paragraphs to follow—including the unique attention paid to cultural sensitivity I observed in First Nations, Indigenous, and Métis resources.

[246] Here it is important to note that a more expansive treatment of these ideological assumptions is not possible within the confines of this dissertation. Rather than a detailed theoretical treatment of these assumptions, my intention is to provide enough theoretical background information to adequately link the concept to the ACPO website discourses. Some additional reflection will be included in Chapter 5 when focusing on implications.

Ideological Assumptions Embedded in Discourses of Spirituality, Death, and Values.

Individualism. The first potential ideological assumption I observed in discourses noted above is the underlying bioethical assumption of individualism. Again, before I make the link to discourses, I will briefly articulate what I mean by individualism and some of the dialogue within bioethics around this notion. Individualism is defined by the Oxford English Dictionary as "The habit of being independent and self reliant; behaviour characterized by pursuit of one's own goals without reference to others; free and independent individual action or thought" (Oxford University Press, 2002). And while the field of bioethics is rooted in legal notions of personal autonomy and informed consent as noted in Chapter 2, I also note that, philosophically, this focus on individualism has been contested with suggestions of bioethics ignoring the web of relationships that exist (Collier & Haliburton, 2021) or lacking integration of the cultural aspects of community that are not necessarily included in autonomy (Colenda & Blazer, 2022). Additionally, Sommerville (2000) describes an "intense individualism" (p. 6) found in medicine and a rejection of the community with an observation that, "we give preeminence to the values of personal autonomy and self-determination" (p. 7) which can disconnect one from the larger community. Hence, there appears to be an overall bioethical assumption of individualism related to these foundational bioethical themes of autonomy and informed consent. It is this overall understanding of individualism that I am referring to in this section. Having outlined a general meaning of individualism that I am utilizing in this section, I now outline hints of this ideological assumption based on evidence from the discourses observed above.

In terms of evidence of individualism from the eight discourses named above, I return to the overall bioethical focus underpinning the website that is based upon notions of consent and autonomy. The focus on the individual on the APC website is unmistakable in the discourses I

observed above—especially linked to the discourse of medicine and law being central authorities in ACP. In the guidance provided in places like the "Resource Guide" (HPCO, n.d.-o), for instance, there is a clear underpinning of one's implicit individual rights and personal choices. Additionally, I observe processes on the website like the "Values Exercise" (HPCO, n.d.-u) that have an emphasis on one choosing one's own personal values with the focus clearly on "you" that I observe to be mentioned 12 times on this single page suggesting the individual rather than the communal aspect of choices as being the focus. While I certainly observe aspects of community in these pages with family and friends in the pictures and videos (HPCO, n.d.-g; HPCO, n.d.-h; HPCO, n.d.-t) and "talking" being one of the five steps that implies relationship (HPCO, n.d.-w), I see a distinct positioning of value discernment and ACP proceses that focuses on a path of the individual on a journey as noted in the "thinking" focus I observed the discourse related to thinking and process-based activities (HPCO, n.d.-t; HPCO, n.d.-w; HPCO, n.d.-h). Additionally, I observe obvious links here to instrumentalism, that I will address later in this section, and the suggestion of both self-mastery and individual action in the suggestion of one taking control of one's health (HPCO, n.d.-m). Another discourse that suggests this assumption of individualism is the celebration of values of independence and dignity (HPCO, n.d.-c; HPCO, n.d.-e; HPCO, n.d.-u). These personal values that celebrate individuality are noted in stories referencing individual preferences related to care like indepedence to dress or bath oneself (HPCO, n.d.-q) or losing one's dignity (HPCO, n.d.-c) or to walk or swallow (HPCO, n.d.-l). Finally, I observe individualism to surface in the discourse around the ease and unproblematic nature of the ACP process. I observe a simplicity of the individual on this journey to be able to make choices from a tick-box list of options (HPCO, n.d.-u) or, as referenced previously, the reference to "THAT'S IT" (2:33) in the "Five Steps" video (HPCO, n.d.-a). While an individual

facing decisions can easily make their choice as an indivdiual, what is not suggested is that many cultures make decisions as a family, or involving a faith community, or through wisdom offered by elders.[247] The reflections and priorities I observe on the ACPO website are rooted in assumptions of indivdiualism.

Instrumental Perspectives. Another ideological assumption I observe on the ACP website is the finding of what I am calling "Instrumental Perspectives". In advance of outlining examples from the eight discourses observed above, I take a minute to outline briefly what I mean by "instrumental" as an ideological assumption of the content-producers. Tied closely to utilitarian perspectives common to bioethics and its consequentialist focus on outcomes, the instrumentalist perspective in health care assumes a focus on means and ends where "calculation begins with the identification of a need and terminates when that need has been met" (Sedgwick, 2013, p. 209). The patient's goal here, not unlike the goal of utilitarianism, is "exclusively to be a seeker after satisfactions" (p. 216). But more than just meeting a need or achieving an end, there is a practical, useful, methodological, and transactional focus on "the most direct, and apparently most efficient, means to the achievement of that end" (p. 209). In clarifying instrumentalism, Sedgwick compares the patient facing illness to a consumer looking for a reliable and efficient solution to their problem with "the calculation that best ensures the individual's illness is vanquished or controlled so that daily life can be resumed" (p. 211). Linked to this efficiency in achieving an end through instrumentalism, Mirowsky et al. (1996) also suggest notions like mastery and efficacy when exploring instrumentalism and "belief in individual agency" (p. 322) where "people control their own lives" (p. 322). Assumptions and values of this overall

[247] While I suggest an overall ideological assumption across the overall website as a broader sense of individualism, I note again the outlier being the very different approach I observed in the First Nations, Indigenous, and Métis resources that integrates an Elder within the community—an approach I observe as being an excellent example of the potential for relational and communal integration. I will echo this thinking again in Chapter 5.

worldview include calculation, control, efficacy, and solutions—principles that underpin the website as noted in the examples given below. This brief theoretical outline provides an overarching understanding of how I see instrumentalism.

Having outlined an ideological understanding of instrumentalism, I now offer some examples of where I observed this ideological assumption in the eight discourses named above. One of the discourses related to this commitment to an assumption of instrumentalism is observed in the discourse of selective death acceptance where one can see instrumental approaches. In this discourse, I observe the ACPO website asking participants to review previous experiences with death to look for improvements to death processes that suggests a pursuit of efficiencies. Additionally, the reference to end-of-life ceremonies, music, and sacred readings tends to suggest a practical and task-oriented approach to achieving the desired end goal (HPCO, n.d.-q). Further, on the page on the website inviting the taking control (HPCO, n.d.-m) of their health care journey, there is a suggestion of self-mastery and controlling circumstances. One can also see aspects of this transactional approach in the discourse related to value reflection being easy, unproblematic, and conflict-free including a reference to the tick-box value exercises that suggest calculation and directness in making decisions (HPCO, n.d.-u) and diagrams that outline an easy and functional path to decision-making (HPCO, n.d.-k). Additionally, there are references once again to “IT’S JUST 5 STEPS” (0:17) and “THAT’S IT!” (2:33) in the “Five Steps” video (HPCO, n.d.-h). Both of these references suggest the achievement of an end with a level of efficiency and control. I observe aspects to this instrumental ideological perspective that are interwoven throughout the website as evidenced by these discourses that outline this practical and methodological approach to ACP.

Medical Paternalism and Legal Authority. Further, in my continued exploration of the ideological assumptions embedded in discourses I observed on the ACP website, I also see the bioethical assumption of medical paternalism and legal authority that suggests significant power inherent in these resources created by content-producers to influence one's future health care decisions and privilege certain approaches. Again, in advance of articulating how this connects to discourses named earlier, I offer a brief background of what is meant by medical paternalism and the notion of legal authority. I begin with the legal aspect. More than just the field of medicine and bioethics, Sommerville (2000) notes that "We have become legalistic societies" where "Law provides the bottom line" (p. 11). As mentioned in Chapter 2, the emergence of the medical-legal in ACP emerges from informed consent that requires the authorization of the medical intervention (Beauchamp & Childress, 2019). The medical-legal influence in ACP emerges from landmark cases in both the US and Canada that involved both medicine and law. These cases shaped approaches to informed consent and culminated in legislation like the *Health Care Consent Act of Ontario, 1996* and the *Substitute Decisions Act, 1992*. These legal underpinnings suggest an authority that is implicit in the larger ACP conversation that intersects with medicine. This additional dynamic relates to the paternalism that flows from this authority exercised by law and medicine. Brody and Macdonald (2013) articulate this by suggesting, "A core belief of medical ethics was what we now label 'paternalism'—the view that the physician knows best" (P. 134).[248] Pellegrino and Thomasma (1988) also note the challenge of paternalism—whether strong paternalism that overrides the patient but more so the weak paternalism where "action is taken in the best interests of a patient" (p. 7). This paternalism

[248] This links to the work of Katz (1984) who addressed dynamics of silence and the distance of the physician suggesting a paternalism—a silence that is noted in the ACPO website in regard to different aspects of spirituality. In the case of the ACPO website, the limited inclusion and peripheral positioning of spirituality may suggest to individuals that it is potentially of lesser importance.

suggests that what may be the good of the patient, as expressed by the patient's own values and preferences, may be secondary to the good of what the medical field suggests. I observe in the discourses named above the potential influence of the dynamics of paternalism found in the leanings of value assumptions across the website in privileging certain views. I outline some examples below.

Having provided context to what I mean in terms of the medical paternalistic assumptions and legal authority in the eight discourses I observed on the ACP website, I offer several examples. I return to the example from the discourse related to celebrating common values of independence, dignity and time with family. There seems to be a paternalistic underpinning in the privileging of certain values in the "Values Exercise" (HPCO, n.d.-u) and character stories (HPCO, n.d.-e; HPCO, n.d.-c). In these resources there seems to be a subtle yet clear message of the field of medicine's assumptions of what values should be privileged, including the two values I observed to be highlighted most consistently and most prominently: dignity and independence. Further, the overall silence, vagueness, and peripheral attention to spirituality link to the work by Katz (1984) who suggests that silence too sends a subtle paternalistic message too of what is accepted—in this case, the possible suggestion that spirituality and other human struggles appear to be kept to the background and periphery of ACP resources. One can also see a glimpse of paternalism in strong messages like the multiple references to "You should" (0:33) in the "I'm a Substitute Decisions Maker" video (HPCO, n.d.-h) where three times there is this suggestion with the underlying photo beneath the text of a physician's stethoscope and legal pad underneath. With these images of medical and legal power, the theme of authority enters the conversation more prominently. Other notable images suggesting assumptions of paternalism and authority include the courtroom and gavel in "Confirming Your Substitute Decision Maker

in Ontario" video (HPCO, n.d.-h), where in my opinion, these legal symbols send a strong message of authority. Additionally, the frequent reference to the *Health Care Consent Act, 1996* (HPCO, n.d.-s) and my observation of a disproportionate attention given to legal aspects in the "Resource Guide" send a strong message of the medical-legal assumptions and principles that underpin ACP. The disproportionate focus on more propositional aspects like wishes (HPCO, n.d.-o) as opposed to less-definable concepts like values and spirituality also suggest a bias towards this ideological assumption of paternalism. And while the importance of helping guide individuals in abiding by laws and legislation is a necessary standard, it is insufficient in making personal health care decisions potentially involving death. Together, text and image in the discourses above suggest an ideological assumption of medical paternalism and a strong sense of legal authority that frames the ACPO website.

Rationalist Underpinning. Next in this exploration of possible bioethical ideological assumptions that are embedded in the ACP website, I note a tendency towards a perspective with a rationalist underpinning. Again, before outlining the connection to the eight discourses I observed on the website, I provide a brief outline of what I mean by a rationalist underpinning. The term rationalism stems from the Enlightenment that was characterized by "the emergence of individual reason" (Livingston, 2006, p. 6) and an autonomous philosophical shift focused on "the duty of not entertaining any belief that is not warranted by rational evidence" (p. 7). Dupré (2004) articulates this spirit of rationalism as being where "the human mind is the sole source of truth and hence must reject faith as a possible source of truth" (p. 7).[249] Moving the conversation

[249]It is worth noting that Dupré (2004) outlines two understandings of rationalism that emerged in the Enlightenment, one suggesting "the primacy of a priori concepts in the process of knowledge" (p. 7) that opposed empirical emphasis on experience; and secondly, a broader rationalist designation of the Enlightenment that includes "philosophical empiricists as well as rationalists" (p. 7) linked by the human mind and "a method of thinking" (p. 7). It is this second understanding that I offer in this thesis but further philosophical reflection around these theoretical concepts is outside the scope of this dissertation.

to health care, Somerville (2006) outlines the strong role of reason in bioethics focusing on a strict "logical, cognitive mentation" (p. 29) while Murray (1997) describes a core understanding of contemporary bioethics "as a set of propositions expressed as sentences" (p. 5). Hawkins (1997) too describes "the overriding assumption" (p. 153) of many in the field of ethics that "decision-making should involve only the rational or logical faculties of mind" (p. 153). Having outlined what I mean by rationalist underpinnings in bioethics, I turn to evidence of this ideological assumption in the eight discourses I observed on the ACPO website.

In terms of discourses on the website that suggest this rationalist ideological framework, I observe cognitive assumptions arising in many areas of the website including the discourse around immanent understandings of spirituality, death, and meaning. I observe a rationalist focus in regard to aspects of human life and an absence of outlining ways of knowing that include a sense of mystery.[250] This is expressed in the discourse I named above suggesting spirituality as being treated peripherally and vaguely, if not avoided almost completely. Examples of this include the lack of elaboration of spiritual aspects in the "Values Exercise" (HPCO, n.d.-u) where references to "spiritual beliefs" and the factors that may "affect us deeply" are only addressed vaguely. In contrast, more propositionally based factors are given fuller treatment on the website including lengthy functional descriptions in the "Resource Guide" regarding more logic-based topics like consent as well as clinician involvement or the nuances of wishes in ACP (HPCO, n.d.-o). I observe this same dynamic in the "FAQ" section that includes several specific questions given to the topic of wishes that includes longer elaboration—but less propositional questions like those related to spirituality are absent (HCPO, n.d.-i). Additionally, prominent

[250] Again, Sommerville (2000) notes an "intolerance to mystery" (p. 5) in medicine. I will pick up on this theme of mystery in Chapter 5 in my discussion of absent discourses as well as in my recommendations.

multimodal symbols also suggest this rationalist ideology including a lightbulb over one's head in the "Confirming Your Substitute Decision Maker in Ontario" video (HPCO, n.d.-h) and the focus on "Thinking" in the five-step process (HPCO, n.d.-w) as opposed to other ways of knowing that may include one's intuition, emotions, or spiritual aspects important to the person. I also observe rationalist leanings in the discourse related to selective death acceptance where mystery around death is largely avoided,[251] and only rational aspects of a physical death are outlined including historical references and technical medical-legal references, as well as interventions at the literal time at the end of one's physical life (HPCO, n.d.-q). But absent is reference to non-physical beliefs of an afterlife, or the impact of the high stakes of death on one's decisions that may be considered outside of a rational underpinning. Rather, what is communicated, from my perspective, is a focus on physical factors that privilege a rational understanding (HPCO, n.d.-q). Overall, this rationalist ideological underpinning is widespread and overlaps with the next bioethical ideological assumption observed, reductionist tendencies.

Reductionist Tendencies. Continuing in my examination of the potential embedded bioethical ideological assumptions found in discourses on the ACP website, I turn now to reductionist tendencies that suggest another underlying worldview of content-producers. Again, before making a connection to the eight discourses found on the ACPO website with examples, I offer a brief outline of what I mean by reductionist. Sommerville (2000) describes a view of pure science rooted in genetic reductionism where, "What it means to be human and the meaning of human life are seen and explained only in terms of scientific constructs" (p; 17). Sulmasy (2006) describes reductionistic approaches as a soulless reality of medicine with patients becoming

[251] I suggest here as I have in other sections the exception being the approach taken in regard to First Nations, Indigenous, and Métis Resources where there is acknowledgment of the "deeply personal" (HPCO, n.d.-y) nature of death and the importance of sensitivity.

"scientific specimens rather than human beings" (p. xii). Hence, reductionism is prefaced on naturalistic tendencies to "reduce the patient to a collection of precise molecular sequences" (Greene et al., 2017, p. 2493) and the attempt to "try to assemble these atomized pieces into meaningful wholes" (p. 2493). With the reduction of the complexity of the human person to the atomized physical domain, criticism has emerged from social sciences suggesting the results of reductionism as being "the loss of the person as an individual in a knowledge system that privileges the atomization of the body" (p. 2495). Balboni and Balboni (2019) outline the results of reductionism in medicine as that which "abandon mystery and dehumanize the patient" (p. 182). This perspective of reductionism presents another aspect of the worldview of the powerful that frames this website.

Having provided an outline of what I mean by reductionist tendencies, I now offer evidence of reductionist ideological assumptions found in the eight discourses noted above, beginning with the discourse of value reflection appearing easy, unproblematic, and conflict-free. In this discourse, I observe the content-producers' reduction of the complexity of the human person down to five simple steps (HPCO, n.d.-w). But absent in the five simple steps are the deeper complexities of human relationships and possible diversity of spiritual views that may intersect with ACP processes. Also, the discourse I named regarding the celebrating of common values of independence, dignity, and family (HPCO, n.d.-c; HPCO, n.d.-e; HPCO, n.d.-u) further narrows the ACP process into the physical domain as noted in the focus of character stories being on physical aspects of care rather than the whole person. Further, the discourse related to the authority of medicine and law also suggests a selection of questions and answers in the "Resource Guide" that privileges a view that reduces decisions to medical aspects of ACP rather than larger holistic, complex, social, and human ones (HPCO, n.d.-o). Finally, I observe an

expression of reductionism regarding spirituality most prominently in my observation that the spiritual aspect of one's life is isolated and not integrated, including the "Values Exercise" where spirituality seems peripheral and reduced to one value among a longer list of parts that is not elaborated upon holistically (HPCO, n.d.-u). In this, the relationship to power is especially pronounced in the privileging of certain values other than spirituality in this list, and also the brief and vague articulation of spiritual beliefs I have noted frequently. I also observe this reductionism in some of the ACO diagrams that reduce the complexity of human decision-making down to simplified steps (HPCO, n.d.-k). Overall, this reductionistic ideological assumption suggests a worldview influenced by content-producers that seems to reduce participants in ACP to sequences and smaller parts without a strongly holistic perspective.

Science and Naturalism. Additionally, in my exploration of possible ideological assumptions on the website, I address the bioethical value of science and naturalism as emerging in discourses. But in advance of articulating my findings across the ACPO website, I present a brief description of what I mean by science and naturalism. Also rooted in Enlightenment thinking, like rationalism, is the link between the natural and reasonable with the assumption that "what is reasonable in human affairs is what is natural" (Livingston, 2006, p. 8) and the suggestion that "Nature reflects not only great rational simplicity but also order and regularity" (p. 8). Extended to philosophy, Ferry (2011) outlines a view where, "Any philosophy therefore takes as its starting point the natural science which reveal the structure of the universe" (p. 14). In a similar vein in health care, Sommerville (2000) suggests pure science underpins the field medicine where "What it means to be human and the meaning of human life are seen and explained only in terms of scientific constructs" (p. 17). Overall, the principles of science and

naturalism are embedded in this website as it relates to the foundations of medicine that are central to bioethics. I will now provide examples related to discourses I observed on the website.

Having outlined the meaning I am suggesting by ideological assumptions of science and naturalism, I offer some evidence from discourses I observed on the website. In terms of hints of discourses revealing this link to science and naturalism, certainly the discourse related to immanent understandings of spirituality, values, and death provides a link with its focus on physical experiences and the leaning towards wellbeing and quality of life that can be measured by physical ability rather than the vague connection to spirituality that is offered (HPCO, n.d.-t). The discourse of selective death acceptance I observed would also suggest this assumption of naturalism where death is framed as the literal end of one's physical life with little additional consideration of possible other beliefs. Examples of this include the naturalistic leaning towards historic references of a physical death (HPCO, n.d.-e; HPCO, n.d.-n) and technical references to death (HPCO, n.d.-o) with the perspective of death being objective and naturalistic rather than something that includes an element of mystery.[252] This overlaps with the discourse I observed above that elevates thinking and process-based reflection as well as a stepped approach (HPCO, n.d.-w) where one rationally processes ACP decisions largely based on physical consequences rather than on holistic factors that may include elements of mystery noted in many spiritualities and other ways of knowing outside of science. Finally, another discourse where this ideological assumption of science and naturalism is observed prominently is the discourse related to spirituality being peripheral, vague, and largely avoided. The awkward and vague addressing of hope in relation to miracles I noted above (HPCO, n.d.-q), the peripheral outlining of spiritual

[252] I return to the statistic offered by Bibby (2017) that in in 2015, 66% of Canadians believed in life after death. This would be a strong example of a belief that is outside of naturalistic tendencies—a belief of many Canadians.

beliefs and spirituality in the "Values Exercise" (HPCO, n.d.-u), and a focus on meaning that appears physically oriented to wellness (HPCO, n.d.-q), all suggest to me a hesitancy to include the non-scientific aspects of spirituality I see as being core to this ideological assumption.

Secularism. Continuing on in my examination of potential ideological assumptions found on the ACP website, I move the conversation to the bioethical assumption of secularism. But before I connect secularism to discourses named above, I offer a few words of clarity regarding what is meant by secularism in bioethics. Fox and Swazey (2010) note the secularist orientation as "the dominant framework of bioethics" (p. 279) while Berger (2015) observes modern medicine with the following: "A single overwhelmingly secular discourse dominates the proceedings" (411). But what is meant by secular? Zuckerman and Shook (2017) suggest many aspects to the secular including agnosticism, atheism, modernism, naturalism and rationalism that surface in the literature. They suggest several views of secularism with a basic understanding of the secular involving "personal and social matters concerning the mundane temporal world and one's daily life" (p. 10). But more, they argue that ethical secularism suggests, "scientific explanations for human morality…and promotions of kinds of ethical systems having only naturalistic bases and secular aims, such as human excellence and happiness" (p. 12). In contrast, they note that educational secularism suggests, "advocacy of the widespread availably of primary and secondary education that is not infused with religious indoctrination or denominational proselytizing" (p. 12).[253] Hence, the secular understanding in

[253] These two definitions of secular—the first focusing on "scientific explanations" and the second cautioning *against* "religious indoctrination" mirror the work of Taylor (2007) that is summarized by Smith (2014) where the word secular is understood three ways: first, the mundane, earthy and temporal; second, the secular as being non-religious; and thirdly, where "a society is secular insofar as religious belief or belief in God is understood to be one option among others, and thus contestable" (p. 21). I will explore this in Chapter 5 where I offer discussion on implications of secular assumptions in ACP resources.

bioethics includes a nuanced understanding of both a focus on the mundane, temporal and natural scientific aspects, as well as a focus on non-religious aspects.

Having outlined an understanding of the secular, I now offer evidence of the secular ideological assumption with its implicit values in the discourses I observed. First, I observe this secular assumption in the discourse of spirituality, values, and death as being peripheral, vaguely addressed, and largely avoided. Having outlined the lack of elaboration regarding "spiritual beliefs" and also "spirituality" in the "Values Exercise" (HPCO, n.d.-u), I observe a secular ideology present that seems to hesitate to elaborate on spiritual matters. I also observe a secular tension on the addressing of hope and miracles (HPCO, n.d.-q) as noted in the above section where I observe an undercurrent of discomfort and awkwardness in the addressing of this spiritual theme in a largely secular website. Additionally, while the medical-legal perspective is clearly articulated with lengthy prose around technical themes like consent and wishes (HPCO, n.d.-o), references to spirituality are only vaguely addressed as noted in my reflection around the vagueness of articulating "spiritual belief".[254] Also absent are more traditional notions of morality that would possibly suggest a religious connection. Rather, there is a focus on values related to the mundane and temporal aspects of the world as noted in discourses celebrating certain secular values they frame as "common". In the "Values Exercise" (HPCO, n.d.-u) and character stories (HPCO, n.d.-e; HPCO, n.d.-c), for example, there is a privileging of temporal and mundane values like independence, dignity and family rather than ultimate values and spiritual perspectives that would be considered non-secular. The immanent discourse, as noted above, also addresses the secular domain, with the observation of there being little opportunity

[254] I note here again the outlier to this is the inclusion of spirituality I observed in the First Nations, Indigenous, and Métis resources that may provide an example for ACP content-producers regarding how openness to spirituality and cultural sensitivity can be demonstrated. I return to the theme of this positioning of spirituality in ACP in Chapter 5.

for exploration of transcendent aspects of belief like the afterlife. Overall, the values of a secular ideology underpin several discourses at play in the ACPO website.

Utilitarian Leanings. Finally, in examining potential ideological assumptions embedded in the ACP website, the last one I observe here is what I am calling "utilitarian leanings". Before making a connection to discourses found on the ACPO website, I offer a brief outline of the bioethical world view of utilitarianism that influences this website. Beauchamp and Childress (2019) suggest that utilitarian thinking, and the principle of utility, as being "deep and abiding" (p. 391) in bioethical circles making it align almost naturally with these ACPO resources I have examined. In summarizing the 18th century work of influential philosopher Jeremy Bentham, Chukwuneke and Ezenwugo (2022) note this utilitarian lens where humans are "under two sovereign masters" of pleasure and pain (p. 20). Hence, the utility of an action is gauged by the suggestion that "The ethical person will act to increase the amount of pleasure or utility in the world and decrease the amount of pain" (p. 20). This approach focuses on what a moral decision accomplishes and privileges "consequences to the exclusion of everything else" (Häyry, 2007, p. 57). In terms of what makes a good consequence, Häyry summarizes a simple calculus in medicine where, "Physical health and psychological well being are good, whereas illness and suffering are bad" (p. 58). For patients this simply means, "well-being should be maximized and their illness and suffering should be minimized" (p. 58) or to put more directly, "Health and well-being are promoted, illness and suffering are removed" (Häyry, p. 60). Ideologically, the utilitarian ideological assumption suggests an underpinning I observe to be extended across the website as I note with examples in the next paragraph.

Extending this understanding of utilitarianism to my examination of the ACPO website, this underpinning is evident in several of the eight discourses I presented above. The discourse of

immanence, for instance, highlights assumptions of care related to consequences to bodily health and comfort as noted in examples in the character stories focused on the physical consequences of serious illness like total care (HPCO, n.d.-c) or examples of one's independence in not needing help with physical aspects of life (HPCO, n.d.-e). I also observe elements related to the utilitarian assumption of removing suffering in language in the discourse related to death avoidance where the focus is on care at the literal end of one's life (HPCO, n.d.-q) and one living with a sense of wellness to the end (HPCO, n.d.-g), rather than spiritual or cultural elements that might embrace suffering in connection to one's belief systems. I also observe utilitarian perspectives in the discourses related to independence, dignity, and time with family that suggest an embrace of pleasure, and avoidance of suffering in the form of dependence and indignity (HPCO, n.d.-c; HPCO, n.d.-e). Additionally, principles of utilitarianism can be observed in the medical-legal discourse focused on outcomes and promises of resolution that come with one's participation in ACP (HPCO, n.d.-m; HPCO, n.d.-h). The discourse of ACP being easy, unproblematic, and conflict-free also suggests principles of comfort and well-being (HPCO, n.d.-h) where suffering has been backgrounded—a theme with possible meaning important to many spiritualities. Overall, I observe there is an assumption underpinning the website grounded in utilitarian ideology suggesting principles focusing on pursuing comfort and wellness and distancing one's self from suffering, pain, and the mention of death.

Having outlined the findings I observed in Level B related to my second research question and the exploration of embedded ideological assumptions found in the eight discourses I observed on the ACPO website, I conclude this chapter by addressing my own assumptions, values, and biases that framed my research with a section on self-reflexive findings.

4.5. Self-Reflexive Findings

Having outlined my findings related to the MCDA analysis of Part 1, as well as findings focused on Layer A and Layer B of my reflexive thematic analysis in Part 2, I now close this chapter by focusing on self-reflexivity and provide some commentary regarding findings related to my own biases and assumptions during the research process. This process aligns with the importance of self-reflexivity to the methodological approach I outlined in Chapter 3 with a rootedness in subjectivity inherent in both MCDA and also reflexive TA. Having outlined the ACPO website examination findings in the sections above, I will now address findings with regards to my own self-reflexivity that will include some initial reflection regarding my discernment process regarding the format, positioning, and location of my self-reflexive journalling. I then provide a rationale for my self-reflexive journal summary to be available for the reader to engage further in Appendix B.

Navigating the "Swamp" of Self-Reflexivity in this ACP Examination. In Chapter 1, I outlined my own positionality as a researcher, and in Chapter 3 I outlined the importance of self-reflexivity, referencing the work Wodak and Meyer (2016) who encourage the researcher to "attempt to make their own positionings and interests explicit" (p. 4) as well as the work of Braun and Clarke (2022) who suggest engaging in self-reflexivity by keeping a journal. Aligning with the methodological approach I provided in Chapter 3, I kept a reflexive journal throughout the examination of the APCO website with a diversity of entries. But a question emerged in the later stages of the writing process of this dissertation—specifically *how* and *where* should I locate this personal collection of subjective reflexive expressions? Rooted in my aspiration towards transparency and self-reflexivity, I provide a brief glimpse of my deliberation regarding

this question below before inviting the reader to access the "Thematic Summary of Self-Reflexive Journal Entries" that I have inserted into Appendix B at the end of this dissertation.

Returning to the question regarding *how* and *where* self-reflexivity should be positioned in one's manuscript, I observe considerable debate in academic circles. Finlay (2002) likened the process of negotiating self-reflexivity to "Negotiating the swamp" (p. 209) and included a warning to researchers: "When it comes to practice, the process of engaging in reflexivity is perilous, full of muddy ambiguity and multiple trails" (p. 212). Olmos-Vega et al. (2023) suggest a similar notion focused on scholars in health care who "are often lost in a fog of uncertainty when it comes to understanding what reflexivity is and how to use it" (p. 242). In terms of templates, Olmos-Vega et al. suggest that "there is no one way to practice reflexivity" (p. 248) while Trainor and Bundon (2021) suggest there are few examples to follow in the literature. Adding to the challenge of including self-reflexivity in research is the potential pitfalls related to reflexivity articulated by Finlay (2002) who offers a caution regarding, "researchers getting lost in endless narcissistic personal emoting or interminable deconstructions of deconstructions where all meaning is lost" (p. 226). In reflecting further on this self-reflexive crossroads, I asked myself some questions—how do I meaningfully integrate my self-reflexivity journal entries into my manuscript? And more, how can I present these expressions in a way that is meaningful in the context of my research while minimizing the potential for narcissistic personal emoting as Finlay warns? In finding my path forward, I have leaned into the work of Finlay who offers some overarching guidance for researchers that focuses on encouraging empowerment and thoughtful choices in finding one's "preferred route through the swamp" (p. 213). Articulating this individualized and empowered approach to self-reflexivity in research, Finlay suggests:

> It is the task of the researcher, based on their research aims, values and the logic of the methodology involved, to decide how best to exploit the reflexive potential of their research. Each researcher will choose their path—a perilous path, one which will inevitably involve navigating both pleasures and hazards of the marshy swamp (p. 227).

It is in this spirit of empowerment and faithfulness to the methodology I have chosen, that I step into the "swamp" of my self-reflexivity that for me includes a collection of 26 self-reflexive journal entries I wrote during my examination of the ACPO website. I outline in the paragraphs below the path I will take to integrate my self-reflexive entries into my thesis to offer the best potential for insight, focusing on examining the situatedness of spirituality on the ACPO website.

Summarizing Journal Entries and Locating them in the Appendix. Having addressed some of the themes impacting self-reflexivity above, I turn my attention to my application of these theoretical aspects through my integration of self-reflexivity through the 26 journal entries I wrote during my examination of the ACPO website. I will now outline my rationale for offering a thematic summary of the 26 journal entries related to my ACPO research instead of raw journal data in its entirety, as well as my decision to locate this thematic summary in Appendix B as opposed to the body of this chapter.

Considering the length of the self-reflexive journal entries I wrote, the diversity of style observed from entry to entry, and also the tangential and sometimes unfocused nature of some of the journal entries involving thematic territory outside the focus of this thesis, I decided the best path to exploiting the reflexive potential of the entries was to summarize the self-reflexive journal entries in a separate document I have called "Thematic Summary of Self-Reflexive Journal Entries". This enabled me to reflect on overarching themes across my research. Further, in creating a focused thematic summary, my work aligned with the suggestion of Olmos-Vega et

al. (2023) who suggested placing one's focus on those themes that proved to be "most impactful in the research process" (p. 247). The most impactful aspects of my research would best be captured by an overarching summary. Additionally, in taking a thematic approach that focused on impactful themes across the spectrum of journal entries, it also helped ensure meaningful and relevant reflection and a greater likelihood of minimizing tangential expressions or those expressions bordering on peripheral emoting or narcissism that Finlay (2002) suggests. Additionally, my approach in summarizing themes across the journal entries enabled an additional layer of reflexivity in analyzing overarching themes with additional reflections emerging across all journal entries.

In addition to the decision to thematically summarize my journal entries, another challenge emerged in regard to discerning *where* I would put this thematic summary of journal entries within this manuscript. After discerning possible locations, including within the body of this chapter, I decided that the best location to situate this thematic summary was in the Appendix—due in part to the length of the self-reflexive summary, but more so, in attempt to heed the warning of Finlay (2002) in not allowing these self-expressions to become a distraction or possible narcissistic focus of the dissertation. By placing the self-reflexive summary in the Appendix I not only provided easy access to this additional layer of perspective for the reader to access at any point, but I also maintained the integrity of the chapter focused on MCDA findings within the ACPO website and the themes generated through reflexive TA. In positioning the "Thematic Summary of Self-Reflexive Journal Entries" in the Appendix I could balance meaningful inclusion of my self-reflexive thoughts in an accessible location, while safeguarding the focus of this chapter on the findings related to my engagement of the MCDA tools of inquiry and the process of reflexive TA. Hence, the reader can access my "Thematic Summary of Self-

Reflexive Journal Entries" in Appendix B. Having outlined my approach to self-reflexivity in this last section of the chapter, I close Chapter 4 by offering a conclusion.

4.6 Conclusion

In this chapter I began with an introduction before outlining the findings of my examination. Beginning with Part 1 of my MCDA findings and the explicit references to spirituality and the spiritual on the ACPO website, I then moved the conversation to implicit hints of discourses related to spirituality and the spiritual before outlining multimodal aspects. After exploring discourses related to spirituality, I detailed findings related to discourses connected to death, beginning with explicit references to death followed by implicit references. I then outlined discourses related to values on the website beginning once again with the explicit and then moving to implicit findings using the MCDA tools of inquiry. In Part 2 I addressed two layers of thematic analysis, beginning with findings in Layer A from my discursive analysis that revealed eight discourses related to spirituality, death, and values. This was followed by Layer B of Part 2 where my findings revealed eight ideological assumptions embedded in the discourses from Layer B. I closed this chapter with a focus on self-reflexivity and my own biases and assumptions along with the suggestion of their availability in Appendix B. I move now to Chapter 5 and a discussion of my findings, a review of my research questions, some recommendations, and finally some conclusions to finish this dissertation.

Chapter 5

Discussion

5.1 Introduction to Chapter 5

In Chapter 4 I outlined the findings of my study. After offering an overview of the ACPO website components that were examined with MCDA tools of inquiry, I summarized my findings. I began with Part 1 of my research that focused on my MCDA findings that included hints of discourses related to spirituality, death, and values on the ACPO website, and I then provided my findings related to Part 2 of my research focusing on coding and theme generation. In this section I outlined my findings with two levels of analysis that I took with the reflexive TA approach I utilized with its six-phase process. In Level A of this process, I summarized my observation of eight distinct discourses related to spirituality, death, and values that I observed to be present on the ACPO website. In Level B, I outlined eight bioethical ideological assumptions that I observed to be embedded in the eight discourses—again utilizing the six-phase reflexive TA approach for examination. I closed the chapter with my findings related to self-reflexivity.

Having provided the findings related to my research questions in Chapter 4, I now offer some discussion of these findings in Chapter 5. In this chapter I will circle back to my research questions once more for greater reflection. In addition to briefly reviewing my findings from Chapter 4, I will extend the discussion to the absent discourses I have observed before shifting the focus to the potential implications of both discursive and ideological findings that I have identified. While the previous chapter examined specific findings that I observed in my critical exploration of the ACPO website content through MCDA and reflexive TA processes, in this section I extend reflection around themes that may be absent and the potential implications of

this for ACP. I will then offer some recommendations that I see arising from this examination, suggest some limitations of this thesis, and then offer some potential directions for future research. I begin the chapter by returning to my research questions once more.

5.2 Returning to my Research Questions

In the discussion to follow I return to my research questions that have been addressed at points throughout this dissertation. Having already provided some reflection around my research questions in Chapter 4, in this chapter, I seek to review some of my previous responses while also providing some additional discussion. For convenience, I review here once more my main research question—how is spirituality situated in ACP resources found on the ACPO website? And my research sub-questions include: what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website? What bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death, and values? And finally, what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to openness or closedness to spirituality in individual value reflection and prioritization? I begin with reflection related to my sub-questions focusing on discourses and ideological assumptions before closing this section focusing on my main question regarding spirituality's situatedness in ACP resources.

5.2.1 Presence and Absence of Discourses Related to Spirituality, Death, and Values

My first sub-question asked: what discourses related to spirituality, death, and values might be both present or absent in ACP resources found on the ACPO website? In the MCDA examination outlined in Chapter 4, I articulated eight discourses that I observed to be present across the ACPO website. I begin this section by listing those eight discourses. I will then take time to explore the second aspect of this sub-question focusing my discussion on my

identification of the potential discourses related to spirituality, death and values which may be *absent* in the ACPO website. While in Chapter 4 I observed discourses directly from my examination of the ACPO website itself, here I identify possible absent discourses based on my own theoretical knowledge and experience more broadly. Before exploring absent discourses, I review the eight discourses I observed to be present as noted in Chapter 4.

Discourses Related to Spirituality, Death, and Values Observed to be Present. As noted in Chapter 4, I observed eight discourses through my MCDA examination of the ACPO website that utilized reflexive TA to generate these discursive themes. Having elaborated on these themes at greater length in Chapter 4, I list them here without additional reflection as previous description was adequately provided earlier. Listed alphabetically, they include: 1) a discourse of ACP as being easy, unproblematic, and conflict-free; 2) a discourse of celebrating common values of independence, dignity, and time with family; 3) a discourse of cultural sensitivity I observed in the First Nations, Indigenous, and Métis resources; 4) a discourse of elevating thinking and process-based reflection; 5) a discourse of immanence; 6) a discourse of medicine and law as central authorities in ACP processes; 7) a discourse of selective death acceptance; and 8) a discourse of spirituality as peripheral, vaguely addressed, and largely avoided. Having listed these eight discourses that were elaborated upon in greater depth in Chapter 4, I move to absent discourses I have identified related to spirituality, death, and values.

Absent Discourses Related to Spirituality, Death, and Values. Having focused the MCDA examination I articulated in Chapter 4 on the discourses I observed to be present on the website, I now offer some discussion regarding the second part of my first research sub-question: what discourses related to spirituality, death, and values might be *absent* in ACP resources found on the ACPO website? In this section I have identified eight discourses I have observed to be

absent on the website. While some thematic overlap certainly exists in these absent discourses, I have also discerned distinct qualities in each of these absent discourses that I discuss below. The absent discourses I have identified include: 1) absent discourses of transcendence; 2) absent discourses involving deeper layers of value reflection, discernment, and prioritization; 3) absent discourses related to moral struggles related to ACP; 4) absent discourses embracing the mystery of death; 5) absent discourses that welcome other ways of knowing; 6) absent discourses that situate spirituality as being central, fully addressed, and integrated; 7) absent discourses that include a broader cultural sensitivity; and 8) an absence of discourses including authorities outside of medicine and law. I begin my discussion regarding absent discourses with my identification of an absence of discourses related to transcendence.

Absence of Discourses of Transcendence. In contrast to my observation of the presence of a discourse of immanence on the ACPO website that I highlighted in Chapter 4, what I observe to be notably absent from the website is a discourse including transcendence. Transcendence, as noted by Pargament (2007) in Chapter 2, is "something that goes beyond our everyday lives and beyond our usual understanding" (p. 39). Examples of transcendent discourses include narratives in Abrahamic faiths of Christian, Muslim, and Jewish traditions where a larger transcendent or cosmic story is central to one's spirituality focused beyond one's life (Balboni & Balboni, 2019). Beyond Abrahamic traditions, another example of a transcendent spiritual tradition includes Hinduism with a transcendent focus on reincarnation, and karma as "a combination of cosmic and moral cause and effect that can cross lifetimes and includes lessons learned for spiritual growth" (Chaturvedi & Simha, 2014, p. 55). And more than just organized religion being absent in these transcendent discourses, I also do not observe transcendent discourses related to atheist expressions of transcendence like those noted by Ferry's (2002)

transcendental humanism described as being "in the hearts of human beings" (p. 143). Rather, I observe in the ACPO website an overall absence of transcendence as evidenced by the lack of elaboration regarding potentially transcendent aspects like one's spiritual beliefs (HPCO, n.d.-u), the limited menu of values provided for reflection that lean towards immanence (HPCO, n.d.-u), and the focus on bodily and physical aspects of death that do not invite transcendent beliefs to conversations around death that may include themes like the afterlife, meaning in suffering, or faithfulness and duty. Rather, I observe discourses on the ACPO website being reminiscent of what Taylor (2007) suggests as a closedness of thinking and "the naturalistic rejection of the transcendent" (p. 548). This absence is important to note because this aspect of spirituality may be important to many participants utilizing the ACPO website who are making high stakes decisions involving the theme of death that should invite the deepest reflection that aligns with their understanding of spirituality. And for many, a transcendent perspective provides that deepest reflection, aligning with the thinking of Stanworth (2006) who suggests, "The spiritual is our furthest interpretive horizon" (p. 28). Without openness to transcendent beliefs in reflective tools and resources individuals may be unable to utilize the full potential of their spiritual resources to make decisions rooted in this furthest horizon.

Absence of Deeper Layers of Value Reflection, Discernment, and Prioritization. Linked directly to my observation of the absence of discourses related to the transcendent, I also observe an absence of discourses related to a deeper value reflection, discernment, and prioritization. In contrast to the discourse I observed where ACP processes are portrayed as being easy, unproblematic, and conflict-free, I observe an absent discourse involving deeper layers of reflection. This depth of value reflection and personal discernment aligns with Byrne's (2016) suggestion of one's conscience being one's guide in an ethics of discernment and a focus on

paying “attention to that something extra—what is deepest and best within us—and about learning to act ever more consistently in fidelity with what is deepest and best” (p. 16). But I do not observe a discourse of depth in value reflection, discernment, and prioritization on the ACPO website. Rather, what I observe is an approach with simplified exercises and tick boxes (HPCO, n.d.-u) with little opportunity for deeper reflection on this “deepest and best within” (p. 16)—but rather what might be easiest. Absent are discourses that invite deeper layers of discernment of values with “some scale of preference” as Lonergan (1972/2017, p. 32) suggests that invites reflection on what Frankl (1946/2019) suggests as the meaning-centred task of seeking fulfilment where life is “directed toward the value-potentialities of each individual human person” (p. 9). With the task-oriented focus of value reflection on the ACPO website I observe discourses involving a deeper level of engagement to be absent. This intersects with an absence in the ACPO website of the deepest layers of ultimate values as noted by Pellegrino and Thomasma (1988) in their four-fold approach to patient good with the highest level of good being ultimate good as “the reference standard for all decisions” (p. 77) that serves to “justify and define the nature and aim of moral choices” (p. 77). Drawing on Taylor (2007), I observe an absence of depth and “fullness” (p. 5) in the ACP resources and an absence of reflection on the “fuller, richer, deeper” (p. 5) aspects of life that intersects with how “we orient ourselves morally or spiritually” (p. 6). I do not observe discourses of transcendent depth and fullness on the ACPO website. Rather, I observe a discourse of immanence and a closedness to opportunity for deeper value reflection and prioritization. In this I join with the question raised by Thomas (2018) regarding how to get to “the deeper significance” (p. 14) in ACP. I observe an overall closedness here to a fuller and deeper reflection that potentially limits the depth of reflection in these

conversations that involve serious themes of serious illness and death. And connected to this absent discourse of depth is an absent discourse of moral struggle. I make this connection next.

Absence of Discourses Related to Moral Struggles. Connected to the section above that suggests an absent discourse on the ACPO website relating to transcendence, and also deeper layers of value reflection, discernment, and prioritization, I now address another absence I observe—an absent discourse related to moral struggles. In contrast to my finding of a discourse of ACP processes as being easy, unproblematic, and conflict-free, a possible discourse that is absent includes the addressing of moral issues and potential spiritual-moral struggles. Morality is not mentioned on the website. What does this absence suggest? I appreciate the example provided by Williams (2012) who notes decision-making processes are not like the contemporary suggestion where people face choices, "with a series of clear alternatives, as if we were standing in front of the supermarket shelf" (p. 3). But rather, they suggest there is an aspect of complexity in decisions that inspires self-discovery and discernment involving "moral depth" (p. 8) where decisions involve "struggle and reflection" (p. 8). The word "moral" is one that sticks out here for me in decision-making. It invites the question—is making a moral decision important for many participants in ACP? The diversity of spiritual beliefs and the varieties of conviction present in each perspective would suggest morality does matter to many participants. But morality is not a word that appears on the ACPO website suggesting to me that it is not an important theme for content-producers. This absence does not accept the reality that for many spiritualities, one's moral and spiritual life are connected. Pargament and Exline (2022) note the phenomenon of "moral struggle" as a spiritual struggle involving "tension, conflicts, and strains around the incongruity between one's own values or moral standards and one's own actions" (p.

243).[255] From a Catholic perspective, morality is centrally located with moral decisions being rooted in a process involving deliberation, judgment, and choice (Cataldo, 2009) and an interwoven connection between one's moral decisions and one's spirituality. As Gula (2000) suggests: "the moral decision to refuse treatment or to undergo treatment cannot be separated from one's spirituality, from one's deepest longing for what makes life ultimately meaningful" (p. 19). But for whatever reason, discourses involving morality are not included on the ACPO website. Despite the potential moral weight of decision-making in withdrawing or withholding life support, conversations around feeding tubes, or even DNR status—there is no mention of moral struggle in discourses on the website despite the resonance of morality in many spiritualities. I reference again the work of Taylor (1989) who grounds their work in the notion of one's strong evaluations rooted in one's "deepest moral responses" (p. 8) and an orientation to "moral space" (p. 48) where finding this deeper moral orientation is "complex and many-tiered" (p. 29). But with no acknowledgment of morality or moral struggle in ACPO resources, there is a closedness presented to some spiritualities where moral integrity and expectations are extremely important to decision-making. By not providing opportunities for moral engagement, there may be decisions made that are incomplete and where moral integrity is left unconsidered.

Absence of Discourses Embracing the Mystery of Death. Linked with the absence of transcendence, depth of reflection, and prioritization, as well as moral struggles in discourses, I also observe an absence of discourses embracing the mystery of death. This links again to Sommerville's (2000) observation of a shift in culture from "the mystery of death into the

[255] I note here as well that Pargament and Exline (2022) suggest moral struggle is common, referencing a survey by Exline, Pargament, and Grubbs (2014) with upwards of 18,000 adults that suggest 57.5% having felt "some level of moral struggles, such as wrestling with attempts to follow their moral principles and feeling guilty about not living up to their moral standards" (p. 242). While not a Canadian study, and not related specifically to the field of bioethics, this research could suggest the notion of morality is still an important one for people.

problem of death" (p. 13) to be solved. In the absence of this mystery and the focus on a solely physical understanding of death there is a lack of acknowledgement that many spiritualities embrace the notion of a spiritual mystery beyond physical death. Northcott and Wilson (2022) observe discourses around death that include spiritual and religious orientations. Examples of this orientation include the Catholic tradition that suggests "the human soul continues to exist because it is a spiritual being" (Moraczewski, 2009, p. 4) or the potential for joy or suffering for Muslims in the afterlife based on one's deeds (Al-Shahri, 2014). But it is not only institutional spiritual traditions that embrace a fullness of death, Frankl (1946/2019) suggests an embracing of death in a way that leans into transcendent aspects of meaning and a sense of destiny, suggesting, "death itself is what makes life meaningful" (p. 74) and that "The way he dies, insofar as it is really *his* death, is an integral part of his life; it rounds that life out to a meaningful totality" (p. 46, italics theirs). There is an expansiveness of death that is absent in discourses on the ACPO website that focus on physical aspects of death like how one would like to spend their last days (HPCO, n.d.-q). Absent are discourses related to life beyond death where spiritualities may connect meaning with suffering and pain, or with faithfulness in the dying process and a sense of hope for an afterlife. There is a discourse absent on the ACPO website that does not seem to account for the 66% of Canadians who believe in life after death (Bibby, 2017) and how this belief might intersect with how one makes health care decisions. This absent discourse in embracing death is important because there is a large and potentially sacred aspect of one's life that is not being considered in one's decisions. Aside from messaging in the First Nations, Indigenous, and Métis resources that suggest an openness to diverse perspectives on death, I observe a closedness in the broader website to the domain of death and mystery that may limit one's fullest value reflection. For the good of the patient, one's decisions involving the high

stakes of death require opportunity to discern how death may be integrated for decisions to be made that preserve one's integrity and where people feel a true sense of alignment with their ultimate values that are connected to their unique understanding of spirituality.

Absence of Discourses Welcoming Other Ways of Knowing. Connected to my observations of absent discourses related to transcendence, deeper layers of value reflection, the absence of morality, and also the lack of embracing the mystery of death, I also observe an absence of discourses that welcome other ways of knowing. In contrast to my finding on the ACPO website of a discourse that elevates thinking and process-based reflection, there is an absence of discourses focusing on other ways of knowing. One example is how one might know and discern their values in ACP. The website offers largely cognitive processes with the invitation to "think about what is important to you" (HPCO, n.d.-t). And while thinking and even talking with friends and family is listed on the website and demonstrated in images, there is no explicit invitation for other ways of knowing one's values including the discernment of one's feelings. I connect this absent discourse to the work of Conn (1988) who describes value reflection being inspired by Lonergan's thinking: "Values, after all, are not purely rational, abstract realities; they are rooted in our feelings at the depths of our psyche, and share the limits as well as the strengths of those feelings" (p. 42). This returns to Lonergan's suggestion that "feelings respond to values" (Lonergan, 1972/2017, p. 32) which requires a different kind of discernment that moves beyond the solely rational and cognitive tick-boxes, and the instrumental exercises offered by ACPO (HPCO, n.d.-u), to the potential other ways of knowing involving feelings. Similarly, Nullens (2017), inspired by Scheler, describes other ways of knowing by suggesting, "moral intuitions come from the heart and have a unique epistemic authority" (p. 33). But this invitation to other ways of knowing is not present in discourses I observe on the ACPO

website. This invites the question that I will return to later in this chapter—can ACP processes move beyond simply these thinking oriented discourses? Aside from First Nations, Indigenous, and Métis resources, what is absent on the website is opportunity for reflection that integrates other ways of knowing like intuition, emotion, somatic experiences, or feeling. With the goal of the fullest process of ACP possible that aligns with the patient's good, I am suggesting that the closedness to other ways of knowing has potential to limit opportunity for some spiritualities to engage more fully in ACP processes. Rather, seeking to include diverse ways of knowing can potentially open these ACPO resources to deeper engagement and more sensitivity beyond the privileged cognitive domain in bioethical circles that suggests closedness rather than openness.

Absent Discourses of Spirituality as Being Central, Fully Addressed, and Integrated. In contrast to my finding on the ACPO website of a discourse of spirituality as being peripheral, vaguely addressed, and largely avoided, I see discourses absent where spirituality is centrally located, fully addressed in all its complexity and diversity, and integrated into ACP. Beginning with its lack of centrality, a discourse I observe to be absent includes placing spirituality in a place of prominence—thinking congruent both with Frankl's (1946/2019) suggestion that the spiritual must lead the way in their logotherapy, and also the work of Pellegrino and Thomasma (1988) who prioritize the ultimate spiritual dimension in the pursuit of the good of the patient. Without a central location in discourses, the peripheral situatedness of spirituality may limit reflection in decision-making and could also potentially send a message of spirituality's lack of importance to the decision-making process.

And more than a discourse of spirituality's centrality in ACP processes being absent, I also observe an absent element of spirituality being more fully addressed. In my analysis of the ACPO website I observed an ongoing tendency to vagueness and a pattern of limited elaboration

in regard to approaching spirituality (HPCO, n.d.-u; HPCO, n.d.-q; HPCO, n.d.-t). Considering the complexity of the notion of spirituality that I noted in Chapter 1 and 2, and the multiple dimensions of spirituality that are consistently named by researchers (Oman, 2013; Pargament, 2007; Jastrzębski, 2023), what I observe to be absent from discourses on the ACPO website is any kind of acknowledgement regarding this complexity and multidimensionality. As noted in the short three-sentence paragraph addressing spiritual beliefs (HPCO, n.d.-u) that I alluded to frequently in Chapter 4, there is a consistent vagueness and what appears to be an avoidance of larger elaboration of spirituality. I observe a discourse being presented in ACPO resources that assumes an agreed upon, and an almost unidimensional expression of spirituality—an approach that comes with a risk of presenting a limited view of the complexity of spirituality (Oman, 2013) that may impact the inclusion of diverse understandings of spirituality in decision-making processes. Rather, the absent discourse is one that fully acknowledges and takes into consideration the diversity of spiritual expression that may include aspects of 450 cultural and ethnic backgrounds in Canada (Statistics Canada, 2022b) along with the many others of diverse spiritualities included in polls suggesting 20% of Canadians being "Spiritual but not religious" (Ipsos, 2017, p. 7). The diversity of spirituality needs to be acknowledged and articulated.

Finally, in addition to the absence of discourses where spirituality is centrally located, and more fully elaborated upon, another absent discourse is that of spiritual integration in decision-making processes. Sulmasy (2006) boldly suggests that "Spirituality is integral to health care practice" (p. 166) while Pargament's (2007) work suggests a similar integral view where, "Spirituality is not divorced from the psychological, social, and physical dimensions of life...The power of spirituality lies in the that fact that it is fully embedded in the fabric of life" (p. 21). I do not observe a discourse of spirituality being embedded or integrated on the ACPO website.

Rather, its peripheral situatedness and lack of elaboration suggests a separate location on the outskirts of ACP processes that seems separate from decision-making. But as Gula (2000) suggests, “Spirituality and ethics cannot remain two separate spheres” (p. 19). There is an imperative in some spiritualities where one’s spirituality must be integrated into the decision-making process. Overall, once again, aside from spirituality being more integrated in the First Nations, Indigenous, and Métis resources, I do not observe spirituality to be centrally located, fully addressed, or integrated in discourses but positioned peripherally and vaguely addressed.

Absence of Discourses of Broader Cultural Sensitivity. Another absent discourse on the ACPO website I observed is a sense of broader cultural sensitivity. I begin this section by reviewing the introduction provided to the First Nations, Indigenous, and Métis resources on the ACPO website. The language includes the following preamble: “Health, illness and dying are deeply personal experiences. We recognize that everyone will approach these differently. While ACP Ontario resources are intended for all Ontarians, we continue to partner with organizations to produce culturally safe and diverse resources” (HCPO, n.d.-y). In this preamble I see visible evidence of inclusion and sensitivity—an approach I applaud for its attentiveness to diversity. At the same time, I observe this statement to be in many ways an aspirational statement that has yet to come fully to fruition across the broader website. On the broader website, aside from the First Nations, Indigenous, and Métis resources, I observe that this aspiration to cultural sensitivity is a discourse that is largely absent. Considering the 450 cultural and ethnic groups in Canada, as noted above (Statistics Canada, 2022b), there is unmistakable diversity present in our society. But I do not observe this kind of cultural sensitivity and attention to diversity in discourses on the ACPO website. With messaging like the section on the “Five Steps” video that clearly suggests, “Advance Care Planning is for Everyone” (HPCO, n.d.-h, 1:44), there is little cultural

sensitivity or differentiation. In stark contrast, the video "The Time is Now" focusing on First Nations, Indigenous, and Métis participants suggests that ACP processes and conversations may be "difficult or not culturally appropriate" (HPCO, n.d.-y, 0:20)—suggesting an attunement to cultural sensitivity not evident to me in other parts of the website. Even in the preamble to the seven translated ACP postcards that provide some additional languages to offer ACP resources, I observe a lack of cultural sensitivity in the phrase that introduces the resources: "Below are postcards that provide brief explanations of ACP, identifying your SDM, information for your SDM and consent and capacity" (HPCO, n.d.-y). Unlike the introduction to the First Nations, Indigenous, and Métis resources that suggest an acknowledgement of diversity, there is a lexical brevity and absence of additional language of inclusivity in this phrase that seems closed to cultural sensitivity and the nuances of one's beliefs. I appreciate the goals of the Pan-Canadian Framework launched in 2020 (Canadian Hospice Palliative Care Association, 2020) with a ten-year plan to address many aspects of ACP including underserved communities and to "support culturally diverse forms of ACP" (p. 25), but I see absent discourses regarding this sensitivity in the ACPO resources—with the exception of the cultural sensitivity I see in First Nations, Indigenous, and Métis resources. This cultural sensitivity is important because often cultural discourses intersect with spirituality, death, and values, as noted in Chapter 2, where I explored cultural discourses of death including the example of Chinese Americans where there exists a "cultural barrier against talking about death" (Yeo & Hikoyeda, 2000, p. 108) that could suggest bad luck. Cultural aspects intersecting with religion may include moral aspects intertwined with spirituality that ACPO content-producers need to be aware of to ensure the fullest and most sensitive ACP experience. A closedness to cultural sensitivity may impact openness to spirituality that could lead to not inviting the fullness of one's beliefs into discernment processes.

Absence of Authorities Outside of Medicine and Law. A final discourse that I observed to be absent on the ACPO website is the absence of discourses that include authorities outside of medicine and law. Sommerville (2000) suggests in bioethics and contemporary society that "Law provides the bottom line" (p. 11) and this is evident on the ACPO website that expands generously on medical-legal aspects in its resources (HPCO, n.d.-o) while providing strong multimodal symbols of the medical-legal authority underpinning ACP (HPCO, n.d.-h). And while Sommerville (2000) suggests a shift in the locus of authority in society that has "moved from religion and the clergy to the legislatures and politicians and now to the courts and judges" (p. 12), I am suggesting this may not be true for some in society whose decisions may be made based on their own diverse sense of authority rooted in their own beliefs. In some traditions, for example, there is an aspect of discernment that comes from one's conscience that serves as an authority for living (Byrne, 2016). This dovetails with reflection I noted in Chapter 2 where Nullens (2017) draws on Scheler to suggest, "moral intuitions come from the heart and have a unique epistemic authority" (p. 33). The authority mentioned here seems to suggest a perspective that is nuanced and deeper than just legal expectations. And while it is absolutely essential to follow legislative requirements, I would also suggest legal requirements only frame part of decision-making processes. One's personal authority, or even one's alignment with an institutional authority, may be important to individuals. The Catholic tradition for instance suggests a philosophy of natural moral law using reasoning with moral principles that "represents a commonsense approach to ethics" (Furton, 2009b, p. 39) that have been passed along through the centuries. There is a personal and traditional aspect in this belief system. Other wisdom-oriented traditions look to historic moral exemplars for authority including the suggestion of narrative examples of spiritual leaders found in sacred texts that help humans in

their moral responses by "emulating them or imitating them" (Kidd, 2018, p. 386). If the focus is of ACP is truly seeking patient-centredness and an ultimate focus on the good of the patient as Pellegrino and Thomasma (1988) suggest, there is a need to acknowledge the varying perspective on authority that may be important to an individual making future decisions. A discourse that includes alternative authorities involved in one's moral decision-making is absent on the ACPO website, and with it I observe a closedness to including potential authorities—including spiritual leaders—that may be vital to reflection.

Having provided both a review of the eight discourses I observed to be present on the ACPO website, and then an outline above of some of the discourses I identified as being absent on the website, I now return to my second research sub-question related to the bioethical values, principles, assumptions, and ideologies that I observed to be embedded within these eight discourses I identified. I begin by reviewing the ideological assumptions I observed in Chapter 4.

5.2.2 Ideological Assumptions Embedded in Discourses on ACPO Website

Having reviewed the eight discourses I observed relating to the interwoven aspects of spirituality, death, and values on the ACPO website, as well as my identification of absent discourses, I now list my findings related to my second research sub-question: what bioethical values, principles, assumptions, and ideologies might be embedded within these discourses of spirituality, death, and values? I list my findings of the eight ideological assumptions outlined in Chapter 4 below before moving the discussion to the implications I observe regarding these findings that is the focus of my third sub-question.

In terms of bioethical assumptions, principles, values, and ideologies I observed to be embedded in the eight discourses found on the site, I briefly list them here without elaboration as I have articulated them in greater depth in Chapter 4. The eight embedded ideological

assumptions I observed included: 1) individualism; 2) instrumental perspectives; 3) medical paternalism and legal authority; 4) a rationalist underpinning; 5) reductionist tendencies; 6) science and naturalism; 7) secularism; and 8) utilitarian leanings. Having listed these eight findings related to the bioethical values, principles, assumptions, and ideologies that I observed to be embedded in the eight discourses relating to spirituality, death, and values that I identified in Chapter 4, I now address my third research sub-question: what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization?

5.2.3 Implications of Discourses and Ideological Assumptions

After outlining my observations regarding the presence and absence of discourses related to spirituality, death, and values on the ACPO website above, I then reviewed the eight ideological assumptions that I observed to be embedded within the present discourses. I turn my attention now to the implications of both the discourses, and also the ideological assumptions I observed. Having now addressed my first two sub-questions in the sections above, I shift my focus to my third sub-question in this discussion: what are the potential implications of these discourses, values, principles, assumptions, and ideologies in regard to an openness or closedness to spirituality in individual value reflection and prioritization? In focusing on implications in this section, I will break this third sub-question into two parts. In the first part I focus on the potential implications of discourses being both present and absent on the website. In the second part in the next section, I focus on potential implications of the ideological assumptions I observed to be embedded in discourses. I begin with implications of the presence and absence of discourses.

Implications of Discourses Observed to be Present and Absent. I begin this section focusing on the potential implications of the discourses I identified as being both present and

absent on the ACPO website. For greater clarity I have grouped discursive themes presented above in clusters. By arranging both present discourses and absent discourses in groups I seek to both avoid duplication while also attempting to deepen integrative discussion of overlapping themes. The eight discursive groupings I will utilize to reflect on implications in this section include the following: 1) the potential implications of the presence of immanent discourses and absence of the transcendent; 2) possible implications of privileging certain values and limiting deeper layers of value reflection; 3) potential implications of thinking oriented discourses and the absence of other ways of knowing; 4) potential implications of spirituality as being peripheral, vague, and avoided rather than central and integrated; 5) possible implications of cultural sensitivity in Indigenous resources and absent more broadly; 6) possible implications of ACP presented as easy and unproblematic while complexities are absent; 7) potential implications of selective death acceptance and absence of embracing the mystery of death; and 8) potential implications of medicine and law as central authorities and the absence of additional sources of authority. I begin with implications of immanent discourses and the absence of the transcendent.

Implications of Immanent Discourses and Absence of the Transcendent. What are the implications of a discourse of immanence that I have observed on the ACPO website? Immanence, as noted above, implies an overall focus on the physical aspects of medicine. And with the strong focus on bodily health as summarized by the term immanence (Balboni & Balboni, 2019), there is an absence of discourses of transcendence that are central to many understandings of spirituality. By privileging an immanent focus on the everyday physical and bodily aspects of life, spiritual traditions that are transcendently focused are potentially excluded from ACPO tools of reflection. Balboni and Balboni (2019) summarize this perspective in medicine as functioning with a spirituality of immanence that marginalizes Abrahamic traditions

that hold a transcendent story. They go as far as to say that medicine with its immanent focus "monopolizes the structures of medicine" (p. 198). Taylor (2007) describes a similar notion in their description of "the eclipse of the transcendent" (p. 307). And the implications that may be present in this privileging of the immanent with regard to value reflection include a potential closedness to transcendence. If processes provided by ACP reflection are immanently focused, and transcendent considerations are not, value reflection may remain in the physical realm that potentially limits a larger sense of ultimate meaning. I return here to Taylor's (1989) assessment of the modern climate that I referenced in Chapter 1 where they suggest, "the dissipation of our sense of the cosmos as a meaningful order, has allegedly destroyed the horizons in which people previously lived their spiritual lives" (p. 17). Hence, there is a similar modernist leaning I see present in the immanent focus of the ACPO resources that might exclude these larger horizons. The effect in ACP is reminiscent of Taylor's (2007) suggestion that the immanent frame can "slough off the transcendent" (p. 543). Indeed, I observe the potential for ACPO resources to be sloughing off the transcendent as observed by its lack of meaningful inclusion of transcendent aspects and the focus on immanent aspects of reflection. The potential implication is that reflection surrounding end-of-life themes may not include the fullness of one's spiritual horizons. And with the suggestion of Stanworth (2006) I referenced earlier, that "The spiritual is our furthest interpretive horizon" (p. 28), the risk in excluding transcendence in ACP is not providing access to this furthest horizon in one's decision-making. And the implications of immanence need not be only in theistic traditions. As Ferry (2002) suggests, "transcendental humanism posit values beyond life" (p. 137) and that "a radical transcendence" (p. 138) is utilized in framing meaning. Without opportunity for transcendent depth in ACP resources, many spiritual traditions—theistic and non-theistic—are potentially being short-changed in their

opportunities for value reflection. There is a potential incompleteness to their ACP processes that may not include the most important aspects to their life—their furthest interpretive horizon—that are needed for the fullest and deepest decisions involving serious illness and death.

Implications of Privileging Certain Values and Limiting Deeper Layers of Reflection.

Having addressed the implications of a discourse of immanence and an absence of transcendence, I move next to the implications of privileging certain common values and limiting discourses involving deeper layers of value reflection. Having outlined above my observation that the ACPO website celebrates common values of independence, dignity, and time with family, I suggest it may be unintentionally excluding other ultimate values deeply connected to one's spirituality. This is reminiscent of Pellegrino and Thomasma's (1988) caution of medical culture regarding paternalism and values with their suggestion that, "Perhaps the biggest failure of paternalism is its assumption that medical values or the medical good is the highest good, with an absolute quality that overrides other values" (p. 23). Hence, the danger in celebrating only certain values upheld by the bioethical community is that it exposes an aspect of potential paternalism regarding privileging values held by the medical community, rather than the diversity of values held by Ontarians. This privileging of values connects with another strong statement by Pellegrino and Thomasma who suggest there should be "No Automatic Ranking of Values" (p. 33). And while this statement relates to physicians privileging autonomy with conversations of informed consent, the principle may have implications in ACPO resources as well where there may be a similar mechanism at play. ACPO resources appear to be implicitly ranking values based on the bioethical importance placed on a narrow group of values including

dignity, independence and time with family.[256] But absent are other ultimate values that connect with one's spirituality that are important to many Ontarians. And while a physician is not explicitly presenting these values in ACP resources on a website like the one I examined, I would suggest that implied in the resources may be the potentially powerful presence of a larger field of medicine that is linked to the ACP content-producers that is suggesting these values rather than others that may be important to Ontarians.

Additionally, the presence of a discourse privileging certain values of dignity, independence, and time with family also means the neglect of other discourses focused on relationship—a layer that for many is deeper than just spending in-the-moment time with family but involving the impact of decision-making on the entire web of one's community. The tension regarding relationships is expressed by Liégeois (2021) who notes the importance of aspects of vulnerability, dependency, power dynamics and interdependence with the suggestion that "the human person is first and foremost connected" (p. 13). And how do these dynamics intersect with decision-making? Rather than just the suggestion of spending time with family there is an aspect of responsibility involved in value reflection and prioritization that intersects with relationships. From an ethics of care lens,[257] a process of decision-making might include a prioritization of values that takes into account one's community. With too much focus on a discourse on the individual, there is a risk of emphasizing the individual as a "self-contained

[256] I note here once more that the value of "time with family" in ACP resources does not appear to be referring to an ancestral perspective or how one fits in a larger transcendent narrative with family, but rather, a more immanently focused time with family and an in-the-moment presence. This is important because it keeps the values focus on immanent aspects rather than transcendent ones that may include aspects like legacy, afterlife, eternal destinations and relationships beyond the moment—aspects of relationships that are important to many spiritualities.

[257] There are many perspectives on ethics of care. I appreciate the approach by Liegeois (2021) who describes ethics of care this way:" If we take an ethical approach to a situation of care, we first of all see that it takes place within a relationship of care and that this relationship of care is part of a network of relationships. Within relationships of mutuality, the various partners in care relate to one another: care user, next of kin, care providers and other parties involved. Ethics happens within that network of relationships" (p. 10)

being, distinct and independent from others" (p. 20) that may eliminate focus on "mutual connectedness, commitment and dependence" (p. 20). Overall, I sense a closedness here to certain values that may limit the context and fullness of one's decision-making—including the lack of integration of communities and values outside of individually focused values.

Implications of Thinking Oriented Discourses and Absence of Other Ways of Knowing.

Related to discourses connected to immanence and transcendence, and the privileging of certain values, there are implications regarding a thinking-oriented discourse that excludes other ways of knowing. While I observed a discourse of a thinking orientation in ACPO resources above, an implication for individuals may include the absence of opportunity for participants to engage with other ways of knowing that may be important to them. Gula (2000) for instance refers to the challenge of engaging only the cognitive domain in discerning consequences and principles, suggesting, "Such reflection can be far removed from where our heart lies…Clearer indicators of the heart come through expressions of feelings, intuitions, and somatic reactions. Ethics has for too long, neglected these prereflective [sic] sources as being reliable guides to moral truth" (p. 18). The implication of this focus on thinking alone is that the cognitive domain may not connect to deeper levels of one's moral orientation that may require other ways of knowing to access. As noted above, Nullens (2017) suggests, "Values are like ideas of orientation, not primarily known cognitively, but intuitively and emotionally" (p. 41). If values are not primarily known cognitively, yet our resources privilege the cognitive domain, then I would ask what aspects of value reflection may be absent from ACP processes? What about emotions and intuition? What individual value knowledge may be excluded for many participants? Could the consequence of not welcoming other discourses that invite additional ways of knowing lead to an incomplete decision that does not connect to the deepest part of one's belief systems? With Murray (1997)

suggesting the possibility of narrative aspects, and Sommerville (2006) suggesting a variety of ways of knowing that include imagination, emotions, spiritual curiosity, and physical knowledge from our bodies, there are a lot of ways of knowing being neglected in making decisions involving serious themes like death. The implication for an openness or closedness regarding spirituality is an apparent closedness to including these important domains of engaging in value reflection. As noted several times in this dissertation, Lonergan notes that "feelings respond to values" (Lonergan, 1972/2017, p. 32), and if feelings are not meaningfully integrated into processes, than there may be an incomplete assessment of one's deepest values. Opportunity for deeper engagement of other ways of knowing including feelings is essential for a fullness of exploration of ACPO processes or one's reflection is potentially incomplete.

Implication of Spirituality as Peripheral, Vague, and Avoided Rather Than Integrated. Connected to the limited portrayal of values outside of a privileged few, and the absence of discourses related to other ways of knowing, I also observe a discourse of spirituality being peripheral, vague, and largely avoided—and with this, an absence of discourses of spirituality as being centrally present, fully addressed, and integrated in processes. What are the implications of these discourses where spirituality is on the periphery of decision-making processes, is vaguely addressed—or even avoided altogether? What message is being sent to participants in ACP? The implications from a patient perspective could be that the inclusion of one's unique spirituality in the ACP process may fall outside the tools given, suggesting engagement on these themes needs to be self-directed and self-initiated outside the resources offered. Additionally, the message may be sent from a system perspective that spirituality is not highly valued by Ontario health care institutions judging by the lack of prominence and integration given. And in this, individuals may feel a lack of safety in bringing forward spiritual beliefs. Statistics suggest 7% of Canadians

are talking to their health care practitioner about ACP (Canadian Hospice Palliative Care Association et al., 2021)—or numbers as high as 20% in a more recent study (Canadian Hospice Palliative Care Association et al., 2024). But when juxtaposed with another study suggesting that 66% of participants note the importance of religious beliefs in helping guide decisions if they were "critically injured" (Jacobs et al., 2008, p. 733), a question arises for me—is there safety felt by patients to share their spirituality in tools like those on the ACPO website that were developed by healthcare providers? It is established that spirituality is important in serious illness. A systematic review from Balboni et al. (2022) suggests several key global findings regarding spirituality in serious illness and health. They suggest, "spirituality is important for most patients" (p. 188) and that "spiritual needs are infrequently addressed in medical care" (p. 188) and that "spirituality can play a role in medical decision-making" (p. 188). But what are the implications for Ontarians regarding a discourse in ACPO resources where spirituality is peripheral, vague, and even largely avoided? I would suggest this discourse contributes to a closedness regarding spirituality and a sense that spirituality may not be welcome in reflection. I would suggest the implications of limiting spirituality could also be perceived as disrespect to a person along with questions for some patients like—does medical culture accept my spirituality?

Rather, I wonder if medicine could apply a reverent curiosity to different ways of knowing with a goal to learning along with an intentional posture of openness to spirituality in order to "respect and serve them better" as Klein (2020, p. 35) suggests—and truly respect the uniqueness of one's sources of meaning. But without spirituality being welcome, there is potential for incomplete and thinner decisions. As Gula (2000) suggests, "our spirituality is the wellspring of moral living. Ethics without spirituality is rootless" (p. 17). Hence, the potential implication of a discourse of spirituality being peripheral, vague, and even avoided is the

potential of rootless decisions unconnected to the deepest part of one's life. Considering McPherson's (2015) suggestion I have noted previously that, "the spiritual life in the fullest sense connects up then with the ethical life" (p. 336) and the suggestion by Gula (2000) that "Spirituality and ethics cannot remain two separate spheres" (p. 19) there is an integration of spirituality that is central to decisions that risks being neglected.

Presence of Cultural Sensitivity in Indigenous Resources But Absent More Broadly.

Next, I explore the implications of what I observe to be the presence of cultural sensitivity in First Nations, Indigenous, and Métis resources, but the absence of discourses related to cultural sensitivity more broadly on the ACPO website. Above I have highlighted the extraordinary inclusion and cultural sensitivity in the resources related to First Nations, Indigenous, and Métis participants. This sensitivity includes a suggestion in the introductory paragraph to these resources that I referenced in Chapter 4 where it says: "Health, illness and dying are deeply personal experiences. We recognize everyone will approach these differently…we continue to partner with organizations to produce culturally safe and diverse resources" (HPCO, n.d.-y). I would suggest that the implications of the content-producers addressing cultural safety and diversity in regard to the experience of death in this section includes an increased sense of belonging and inclusion. Additionally, I observe a strong and thoughtful commitment to diversity regarding cultural sensitivity in First Nations, Indigenous, and Métis resources that would be evident to communities and participants. I consider here the work of Baba (2013), who draws on definitions from *The National Aboriginal Health Organization*. They suggest that cultural safety: "within an Indigenous context means that the educator/practitioner/professional, whether Indigenous or not, can communicate competently with a patient in that patient's social, political, linguistic, economic, and spiritual realm" (p. 4). The implication of this sensitivity on the ACPO

website is that the resources demonstrate the importance of paying attention to all these factors in communication—including the social, linguistic and spiritual. There is a respect here that pays attention to the multiple dimensions including the social and spiritual.

In contrast, from a non-Indigenous perspective, I observe an absence of this same advancement and progress towards cultural sensitivity and safety. As noted above, while suggesting that, "Advance Care Planning is for Everyone" (HPCO, n.d.-h, 1:44) in the "Five Steps" video and the contrasting suggestion in the "Time is Now Video" that suggests ACP conversations may be "difficult or not culturally appropriate" (HPCO, n.d.-y, 0:20), there is a conflicting message that I would suggest as a clash of discourses. One discourse that is demonstrating explicit progress towards cultural sensitivity and safety, and one discourse that is not as far on the journey of inclusion towards sensitivity and understanding. The consequence of this apparent lack of sensitivity to all individuals engaging in ACP processes is the potential for exclusion and a lack of safety for some cultures. Additionally, the risk is a collection of decision-making processes that fail to take into account the fullness of their culture that may limit engagement in decision-making. There is an underlying potential for closedness here regarding one's value reflection if one's culture—that may include aspects of spirituality—is not being actively welcomed. The potential result is an incomplete ACP discernment process leading to future decisions that may not be fully aligned with one's culture or personal integrity.

Implication of ACP Presented as Easy and Unproblematic with Complexities Absent. I move now to exploring the implications of another discourse I observed on the ACPO website that presents ACP as easy, unproblematic, and conflict-free—and with it, my observation of an absence of discourses acknowledging the multidimensional complexity of these processes involving high stakes decisions involving death. This discourse implies an absence of problems

and challenges regarding value reflection despite the challenges present in healthcare that I have observed widely throughout this thesis. Not only are individuals facing multi-morbidities and increased options in care, but additional factors in decision-making include potential for family conflict, sensitive conversations, cultural barriers, and difficulties broaching these topics (Thomas, 2018). Further, Farber and Farber (2014) note the presence of uncertainty for those engaging in future planning regarding a "medical event that will happen at an unknown time in the future under unknown circumstances" (p. 110). They note a difficulty in anticipating future events. Another factor is the relationships that impact one's circle of family and friends and the potential that they "may not agree with the decision being made by the patient" (p. 112). In addition to individual choices, there are additional difficulties related to making choices on behalf of another. I return to the research of Wendler and Rid (2011) who observe the burden on the SDM regarding many struggles including sorting out a loved one's preferences, logistics, communication, time pressures, conflict and uncertainty. Contrary to the suggestion of easiness and a lack of conflict in the ACPO resources, I observe there to be many challenges and problems arising both personally and relationally. Additionally, there is the possibility that one may bare the weight of medical decisions and feel "morally responsible for the life or death of a person on life support" (Collier & Haliburton, 2021, p. 347) that may be distressing. Inserting spirituality into the conversation, I return to the conflicts noted in research regarding the end-of-life including the finding of religion being a central point of conflict in 25% of cases (Bandini et al., 2017). The implications of this discourse of ACP being easy and unproblematic includes a false sense of the larger picture and the potential for only limited holistic engagement in the process. In suggesting a discourse of easiness and a lack of conflict, the ACPO content producers may be obscuring the harsh realities of contemporary decision-making in medicine at the end-of-

life and may be potentially diminishing autonomous decision-making rooted in both understanding and appreciating the fullness of a situation and its consequences both personally and interpersonally. For values to be reflected upon fully with the high stakes of death being present, there needs to be an honest appraisal of the full context and themes needing dialogue.

In terms of honesty, the consequences of a discourse of easiness and a lack of conflict intersects with the work of Chapple and Pettus (2014) who reflect on the how central truth telling is for palliative care. They suggest it is even an ethical premise, noting a kind of friendship with virtues at play where, "relief of suffering, and meaning-making, depends on increasingly transparent communication among all parties…In the absence of intentionally honest speech among those joined in this particular community of friendship over time, the initiation and delivery of good palliative care is impossible" (p. 303). While the context is different in ACP, I would argue that the principle of honest biopsychosocial-spiritual engagement remains the same—especially when considering the HPCO sponsorship of this website rooted in palliative care and the themes of death that are present in ACP reflection. I observe the same principle of honesty regarding struggles and the importance of fully informing patients and building trust. A discourse embracing the complexities of ACP and the potential for conflict can provide benefits of authenticity, integrity, and potential for unity in decision-making as complexities are being acknowledged instead of possibly avoiding them. The implication of evading challenges is a diminished and incomplete ACP process with potential challenges arising down the road.

Implication of Selective Death Acceptance and Lack of Embracing Mystery of Death. Overlapping with the implications of the discourse noted above regarding with ACP being easy and unproblematic, I also observe implications regarding a discourse of selective death acceptance. Above I outlined what I observed to be an acceptance of death in certain situations

including historical references, functional and technical references, and also references that are utilized for persuasion to engage with ACP processes. The implications of this limited acceptance of death includes a failure to acknowledge and accept the multilevel importance of death in many spiritual traditions. I return to the work of Sulmasy (2013) who suggests, "there is no spirituality of care at the end of life and no ethics of care at the end of life that does not presuppose some account of death that comes from a faith-like set of beliefs, often embodied in narrative, beyond the reach of bare reason or brute fact" (p. 448). What I think Sulmasy is saying is that death involves a unique account of death that includes a faith-like element that needs to be acknowledged as part of a bigger story. As noted earlier, Sulmasy (2006) suggests, "Life holds within it the seeds of death…Life is defined over and against Death—the ultimate expression of our finitude" (pp. 6 - 7). In this there needs to be an embracing of a larger existential account of death within life—not only a physical and bodily understanding. And as Northcott and Wilson (2022) suggest: "Death presents an existential problem for the living: as an individual becomes more and more aware of the inevitability of their death, questions often arise about the meaning and purpose of one's existence" (p. 133). This dovetails with the work of Yalom (2009a) who notes an opportunity in a sort of personal awakening when confronting one's death, while Watson and Thomas (2018) suggest a similar opportunity in the ACP process: "By their nature these discussions promote facing up to mortality, and as such could cause a significant impact. The process itself can change people's values if mortality is not something he or she has pondered" (p. 60). Hence, the implications of not opening up the conversation in ACP around death to all aspects—not just historical, physical or functional aspects—is not only limiting decision-making to certain bounded aspects of physical death but also limiting the potential for existential growth and transformation. This connects to the work of Thomas (2018) who suggests

that facing death presents an opportunity to "reset the compass to ensure we live now in accordance with our values, goals and aspirations" (p. 14).

And here I observe the connection to one's spirituality as is noted by Collier and Haliburton (2021): "If philosophers have asked questions about death and its meaning, it has often been religion that has supplied answers" (p. 340). I am asking—can death reflection in ACP meaningfully connect one to ultimate answers? With the shift in medicine's approach that suggests death has turned from a mystery to a problem needing solving (Sommerville, 2000), medicine has shifted its focus to dealing with the physical aspects of a final and literal death rather than embracing the larger mystery of death. What is at stake for ACP processes then is the potential for a patient-centred approach that invites the fullness of reflection that invites all of life—including the mystery—into the conversation to ensure one appreciates the fullness of a future health care decisions. The implications of a limited perspective on death include a limited engagement in value reflection leading to jeopardizing a full and informed consent process.

Implications of Medicine and Law as Central Authorities with Other Authority Absent.

Finally, I offer my observations regarding the implications of discourses where medicine and law are central authorities in ACP processes on the ACPO website, in contrast to an absent discourse of additional authorities being included. Above I have outlined the strong medical-legal language in places on the website including the "Resource Guide" (HPCO, n.d.-o) and other symbolic images on the website including a gavel and courtroom (HPCO, n.d.-h). I would suggest the implications of these legal discourses include one's response of thinking ACP is largely a legal endeavour. Data from a recent survey recent suggests 58% note a barrier to ACP was not being unable to afford a lawyer or professional help (Canadian Hospice Palliative Care Association et al., 2024). This suggests to me that many think of ACP as a legal transaction. But what is absent

is the larger moral and spiritual orientations in making a decision. And more than just legal aspects, I echo McCune and Rogne's (2014) suggestion of medical language adding to this dynamic of authority in saying, "Medical jargon is intimidating and off-putting" (p. 21). In this I observe that a legal and medical perspective, while important and even essential for legislative reasons, can also potentially diminish a larger lens regarding what other authorities may exist for individuals making decisions. The question becomes—beyond medicine and law, what other voices of authority may be helpful to one making a plan for future care? I am suggesting that for many belief systems there is an existing historic authority regarding making moral decisions. One example is the Roman Catholic tradition, as noted above, where moral law involves historic traditions of the Church involving deliberation, judgment, and choice (Cataldo, 2009). Others may lean into a Muslim tradition where authority involves a sacred text and the accepting of "the Koran to be authoritative" (Doka, 2009, p. 292). Additionally, the beliefs of Jehovah Witnesses "may prohibit certain medical practices, such as blood transfusions or blood-based therapies" (p. 285) or those from a Christian Science tradition "may eschew any medical treatment" (p. 285). What I am suggesting here is that for many spiritual traditions there is an authority in decision-making that is larger than medicine. And considering the clashes between medicine and religion at the end-of-life as observed in the Consent and Capacity Board cases referenced in Chapter 2, there are other authorities in the picture that need addressing. The implications of suggesting a solely legal or medical authority may jeopardize one's own personal integrity based on their own spirituality that holds alternative sources of authority—as well as one's place in a larger community. A discourse focusing singly on legal and medical factors suggests a narrow focus on authority that may exclude other expressions of authority involving one's spiritual beliefs.

Implications of Ideological Assumptions Embedded in Discourses. Having outlined above the potential implications of the presence and absence of certain discourses on the ACPO website regarding an openness or closedness to spirituality in value reflection and prioritization, I move now to a focus on the potential implications of the ideological assumptions embedded in these discourses. These ideological assumptions include my eight findings listed in Chapter 4: 1) individualism; 2) instrumental perspectives; 3) medical paternalism and legal authority; 4) a rationalist underpinning; 5) reductionist tendencies; 6) assumptions of science and naturalism; 7) secularism; and finally, 8) utilitarian leanings. Similar to the conversation above regarding discourses where I grouped discourses into clusters to avoid duplication and to increase integrative potential, I have taken a similar approach toward grouping ideological assumptions. Below I have grouped the eight ideological assumptions I observed in Chapter 4 into four groupings to focus the discussion. The four groupings I will discuss below include: 1) the potential implications of individualism; 2) the potential implications of reductionistic, utilitarian, and instrumental assumptions; 3) the potential implications of a paternalistic and legal focus; and 4) the possible implications of secular, rationalist, and ideological assumptions rooted in science. I begin with implications of the ideological assumption of individualism.

Potential Implications of Individualism. What are the potential implications of the ideological assumption of individualism? Considering Sommerville's (2000) description of an "intense individualism" (p. 5) in modern medicine and the suggestion of "individualism to the exclusion of any real sense of community", or stronger yet, "the institutionalization of a sense of disconnection from each other" (p. 5), the implications for ACPO resources may be this same exclusion of community. An underlying ideological assumption of individualism may diminish opportunities for value reflection that include one's community in discernment—an aspect that

may be important to many spiritualities. Beyond institutional understandings of spirituality like that of religion, Steensland et al. (2022) note the broadly social nature of spirituality: “Though spirituality is associated with individualism, it is not predominantly individuated and idiosyncratic; it is socially influenced, enabled, and patterned.” (p. 4). If this is the case, that spirituality has a significant social influence and patterning, an implication of focusing solely on the individual in ACP resources is a diminished reflection of the larger communities one may be a part of. This aligns with Sulmasy (2006) who suggests the importance of relationship in existential and spiritual conversations in health care with questions arising in one’s illness such as, “How does this affect my relationship with others? Upon whom can I depend?” (p. 167). These kinds of questions are not included in ACPO resources, and the implications include the potential limiting of communal factors in value conversations with their focus on the individual.

But more than just social aspects and one’s community being important for connection, a focus on individualism neglects some of the realities of serious illness. In addition to Sulmasy’s (2006) suggestion of relationship being important to existential reflection, Farber and Farber (2014) go even further to suggest that serious illness inspires dependence and interconnection: “By its very nature, serious illness diminishes personal autonomy and increases interdependence within our community. We live in a web of reciprocal relationships” (p. 112). I do not observe this interconnectedness and interdependence referenced in ACPO resources with its individual focus. The implication may limit some individuals from decision-making in connection with loved ones, or there may be a downplaying of one’s interconnectedness with larger webs of relationships that may result in an incomplete value reflection. McCune and Rogne (2014) summarize the work of Holstein et. al. (2011) to suggest an embracing of vulnerable aspects of care and dependence in ACP: “Accepting our vulnerability and embracing relationship and

mutual interdependence, not individual choice and self-control, they suggest, should be at the foundation of an approach to ACP that takes into account the wide variation in how people want to participate in decisions related to EOL care" (p. 25). There is an interdependence that is valued in this thinking that is beyond just one's independence. This dovetails with the suggestion by Sommerville (2000) who suggests, "humans cannot live fully human lives without having a sense of belonging to a community" (p. 5) and the need to "see ourselves in a larger context than just ourselves" (p. 7). And there are implications here for decision-making as well. As reflected in the passage from MacIntyre (1981/2007) noted in Chapter 1 where the response to the question "What am I to do?" is contingent on a first question, "Of what story or stories do I find myself a part?" (p. 216). These stories suggest a larger community that one may be a part of. And the implication of excluding one's larger story and their communities of wisdom from ACP resources and processes is a less full perspective for reflection. This potentially diminished perspective focused on the individual may unintentionally close opportunities for meaningful reflection and value prioritization rooted in one's spiritual community or family.

Potential Implications of Reductionistic, Utilitarian, and Instrumental Assumptions. In addition to the implications of an ideological assumption of individualism, there are additional potential implications regarding the interwoven ideological assumptions of reductionistic, utilitarian, and instrumentalist leanings that I observe in the ACPO website. Broadly speaking, I observe the implications beginning with the reductionistic lens offered in ACPO resources. Despite Sulmasy's (2006) suggestion that healing means to "make whole" (p. 16) which suggests a deeply holistic vision for healing, I note that Sulmasy also observes the reductionistic tendency in medicine to view patients as "specimens rather than human beings" (p. xii). What is the implication of a patient being treated as a specimen? Not only is the hope of this fullness of

"healing" jeopardized with only a partial focus on the physical healing of certain parts of a person, but the larger project of healing to "make whole" is neglected. In ACP reflection this may mean only a partial view of the human person is considered in processes involving the very high stakes of decision that involved serious illness or death. What is absent in this potentially reductionistic view? I return here to the implications of reductionism in medicine noted by Balboni and Balboni (2019) who suggest the consequences as being the abandonment of mystery and the dehumanization of the patient. Overall, the potential consequence for ACP processes offering a reduced lens to decision-making is an incomplete decision-making process that fails to provide opportunities for the fullest and strongest discernment of decisions in ACP processes.

Dovetailing with the implications of reductionism in ACP processes that risk contributing to an incomplete and reduced discernment of decisions, utilitarianist bioethical leanings also reduce the lens of decision-making to factors privileging pain avoidance and pleasure seeking. And while both pain and comfort are extremely important pursuits in medicine, and undoubtedly important to patients facing serious illness, they are not the only factors. The potential absent aspect for many spiritualities is the role of suffering in one's larger life and how this might intersect with one's healthcare journey. The implication of suffering being avoided in decisions links to Frankl's (1946/2019) perspective that embraces suffering as a meaningful part of life: "The right kind of suffering—facing your fate without flinching—is the highest achievement that has been granted to man" (p. xxi). And while alleviating pain and suffering is of utmost importance in medicine, the implication of not inviting reflection around suffering into ACP conversations has the potential to exclude those belief systems, who, along with Frankl,[258] believe there is meaning in suffering. By subtly eliminating suffering as a factor in value

[258] I note here the strong words of Frankl (1946/2019) who offers a critical view of the pleasure principle by suggesting it has potential to "devaluate every genuine moral impulse in man" (p. 36).

discernment, altogether, ACP may indeed be eliminating a key value that many spiritualities may seek to lean into when making end-of-life decisions.

Finally, there are implications to the instrumentalism noted in Chapter 4 characterized by a task-oriented, efficiency-driven and achievement-motivated approach to decisions. The implications of this approach include the avoidance of some of the tumultuous themes that may be present for them, and the challenges inherent in decision-making—including themes related to exploring one's own morality in regard to decisions. Taylor (1989) suggests this terrain is not easy to travel, describing a "tentative, searching, uncertain nature of many of our moral beliefs" (p. 10) where "Most of us are still in the process of groping for answers here" (p. 10). Could excluding these moral challenges through instrumentalist approaches eliminate opportunities for this deeper level of discernment of one's moral beliefs? Elsewhere, Taylor (2007) notes the presence of cross pressures where people may be "suspended between" (p. 598) conflicting belief systems. With an instrumental approach that leans towards reductionism and avoidance of challenges there may be an incomplete picture provided for Ontarians regarding reflection and prioritization. There may be little opportunity for this "groping for answers" that the theme of death and complex health care decisions may necessitate for the fullest informed consent. I return to the thinking of Collier and Haliburton (2021) who describe the high stakes of decision-making in contemporary health care that involve a decision of death in a very real way: "If the natural progression toward death from disease has been stopped by technology, someone has to make the decision about when to stop the technology" (p. 347). This is important because someone will need to grapple with the morality of these decisions involving death. With an incomplete ACP evaluation process that is instrumental, reductionistic, and utilitarian, the danger is a lack of opportunity to explore one's strongest evaluations leading to incomplete decisions.

Potential Implications of Paternalistic and Legal Focus. What are the implications of the ideological assumptions of paternalism and the legal aspects of authority I observed on the ACPO website? One implication is the underlying suggestion that the medical community knows what is best for you and a legal underpinning that suggests a level of authority regarding one's care. Considering a statistic I have mentioned earlier, that as high as 58% of Canadians suggested a barrier to ACP was the inability to afford a lawyer or professional help (Canadian Hospice Palliative Care Association et al., 2024), I observe that many participants already consider ACP to be a legal process. And I would suggest that ACPO does little to dispel this legal focus with its resource guide (HPCO, n.d.-o) and legal references in videos (HPCO, n.d.-h) that meshes with strong medical language that also suggests authority. And here I return to the decades long debate about paternalism in medicine as outlined by Pellegrino and Thomasma (1988) and the question of who might decide what the best interests of the patient might be. Certainly, this intersection is a busy one with legal aspects and also physician response as referenced in Chapter 2 where Chidwick et al. (2013) note the professional and ethical challenges facing physicians where potential clashes of professional values and ethical expectations may arise regarding patient values—especially regarding what the best interests of patients. I suggest these dynamics are simmering below the surface in bioethics; and ACPO resources are no different. But what might be the implication of these dynamics?

While ACPO processes are positioned as patient-facing resources on a website to be utilized broadly by Ontarians without a physician or health care practitioner to guide or direct, I do observe elements of bioethical paternalism that does have potential implications. For example, there is the potential for bioethics to unknowingly place limits on value reflection by offering a preferred version of what values are most important—including independence and

dignity. And by leaving spirituality vague and at the periphery of conversations there is a subtle suggestion that spirituality is not a central part of this conversation and relegated to the outskirts. And here I return to a conversation regarding the potential conflict between spirituality and bioethics that I introduced in Chapter 1. I suggested earlier the description by Kuczewski (2007) regarding spirituality in medicine as being a "chasm between provider and patient/family in stark terms" (p. 5). And while spirituality has not been excluded altogether from ACPO resources the peripheral, vague, and largely avoided situatedness to spirituality, along with the narrowing of focus to several preferred values suggests a subtler kind of paternalism that would limit opportunities for full reflection and value discernment within these tools. The implications of these subtle forms of paternalism, and even peripheral treatment of spirituality, can certainly include clinical limitations regarding spiritual inclusion, but I also suggest there is an impact to the trust of Ontarians to be able express the diversity of their spirituality. Can Ontarians feel like ACP resources truly accept their belief system and spirituality in medical decision-making? Are there opportunities provided for meaningful spiritual reflection that move beyond the immanent to the transcendent and ultimate that is important to many spiritualities?

Implications of Secular, Rationalist, and Ideological Assumptions Rooted in Science.

In addition to the implications of the ideological assumptions above, I note potential implications of the interwoven secular and rationalist ideological assumptions rooted in science. Some implications of these assumptions rooted in science aligns with the thinking of Sommerville (2006) who notes a hostility "to ways of knowing other than reason" (p. 31) or the work of Taylor (2007) who observes in modernity a "package of epistemic and moral views" (p. 562). This invites the question—what is the package of bioethical views underpinning ACPO resources? And here I return to the conversation of immanence and this immanent frame that

provides “the spiritual shape of the present age” (Taylor, 2007, p. 539) and a contemporary “moral attraction of immanence” (p. 547) where transcendence cannot happen because of naturalistic assumptions. In this space of rational science there is no mystery. And here is the limitation of the ideological assumptions of rationalism and science—there is a lack of acceptance of other ways of knowing or a larger story beyond the immanent that may limit access to one’s “furthest interpretive horizon” (Stanworth, 2006, p. 28). An immanent approach to ACP rooted in science may limit exploration of transcendence and other ways of knowing that may be important to some spiritualities. But what is the implication of this scientific assumption to ACP processes? Limits may be placed on ways of knowing outside of the scientific and some perspectives may be excluded. And the danger is that opportunities for transcendent reflection regarding one’s values may be limited, which may lead to a diminished decision-making ACP process for those whose spirituality is important to them. If only rational and scientific examples are provided for value reflection and prioritization then a significant source of reflection is absent for many people related to their spirituality. This may mean exclusion of one’s spiritual beliefs in value prioritization. It may mean an incomplete assessment. And considering that serious illness and death may hang in the balance with one’s decisions, one’s strongest evaluations and furthest interpretive horizons may not be included because they may involve other ways of knowing. The possible result is an incomplete ACP process that excludes deeper themes that may matter most.

In this section I have outlined my response to my third research sub-question focusing on the implications of discourses and ideological assumptions and their relation to an openness or closedness to spirituality in value discernment and prioritization. I return next to my larger overarching research question in this dissertation—how is spirituality situated in ACP resources found on the ACPO website?

5.2.4 Spirituality's Situatedness on the ACPO Website

Having discussed responses to my three research sub-questions above, including themes related to the presence and absence of discourses related to spirituality, death, and values on the ACPO website; the embedded ideological assumptions within these discourses; and then the potential implications of both of these discourses and ideological assumptions; I now move to reflection on my overarching research question—how is spirituality situated in ACP resources found on the ACPO website? I will now summarize my response to this larger research question.

Considering the title of my dissertation being, *Examining the "Black Box" of Spirituality in Ontario Advance Care Planning Resources: A Multimodal Critical Discourse Analysis*, I sought to critically examine the ACPO website to explore this question about spirituality's situatedness. Mindful of the complex and multidimensional qualities of diverse spiritualities, and the implicit conflicts with bioethics with regard to its inclusion, I took a discursive lens in examining the ACPO website that included a critical examination of possible underlying ideological assumptions. In taking this critical approach, I sought to explore the complexity of spirituality within its larger social context on the ACPO website to provide opportunity to explore potential underlying conflicts with bioethics regarding an openness to spirituality. In Chapter 4, I offered my formal findings, and in the first part of Chapter 5 I discussed my research sub-questions. Here I aim to bring all these threads together in responding to my overarching research question—how is spirituality situated in ACP resources found on the ACPO website?

So, how is spirituality situated on the ACPO website? Congruent with the discourse named above, aside from First Nations, Indigenous, and Métis focused resources, I observe spirituality to be situated peripherally on the ACPO website with only vague articulations of what is actually meant by it. Overall, spirituality appears largely absent, is not positioned

integrally, and not given a place of prominence. Additionally, in considering my suggestion of spirituality's interwovenness with death and values, I suggest an overall perspective of immanence in how spirituality is situated in alignment with thinking of Taylor (2007) as well as Balboni and Balboni (2019). In this I observe spirituality to be situated within a secular and immanent frame that seems limited to bodily and physical understandings with little opportunity for diverse understanding involving transcendence or ultimacy—or as Taylor (2007) suggests, as noted above, there is a "naturalistic rejection of the transcendent" (p. 548).

Additionally, with an overall secular, natural, scientific, and rational focus on the website that privileges these immanent understandings of spirituality, when addressed at all, I observe a leaning in ACPO processes that may limit ultimate and transcendent understandings of spirituality through utilitarian, instrumental, legal, and rationally focused processes. And with this focus on science, naturalism, rationality, and instrumental perspectives, I observe that other ways of knowing, including emotions and intuitions that are central to many spiritualities are largely excluded from discernment and reflective processes. Hence, I observe spirituality on the ACPO website to be not a prominent part of ACP value reflection, prioritization, or decision-making. Rather, I observe spirituality as being a peripheral and immanent activity positioned on the outskirts of the website with little opportunity for larger exploration of transcendence.

With this immanently focused version of spirituality grounded in the physical, reflection on one's values and health care on the website becomes more instrumental, legal, and utilitarian, essentially limiting opportunity for deeper levels of value reflection rooted in transcendent expressions of spirituality—especially regarding themes of morality where there is no mention on the website at all. In all of this I observe a lack of complication or complexity given to spirituality's position on the website that seems to avoid potential conflict, emotional messiness,

or moral struggle. Finally, spirituality and the interwoven aspects of values and death, are situated individually with little attention given to the impact of decision-making on one's larger communal story. Despite the importance of the relational aspects of spirituality for many participants, the ACPO website situates spirituality, death, and values more individualistically. One's larger communal story is largely absent in these resources focusing on the individual.

Finally, I address the territory dispute I referenced in Chapter 1 and 2 regarding spirituality and bioethics. Do I observe this dispute regarding how spirituality is positioned on the larger website? I must answer both yes and no to this question. While I see an overall peripheral situatedness of spirituality and a tendency for content-producers to largely avoid it, I see no evidence of an ominous or conscious exclusion of spirituality. Spirituality is indeed mentioned. But it is situated on the periphery as an immanent factor with no special need for prominence or integration. Based on my own observations, I do not see this as an intentional exclusion of spirituality. Rather, I observe the peripheral situatedness of spirituality to be a natural outpouring of embedded rational, secular, naturalistic, and reductionistic mindset of the field of medicine and the larger bioethical community that trickles down to the ACPO website. And here I return to the notion of power I outlined in Chapter 2. There is a perspective in ACP that reflects the view of the powerful regarding spirituality. It is the content-producers, influenced by the ideological underpinnings I have named, that hold the power to shape how spirituality is presented. But whether spirituality's peripheral situatedness is purposeful or not is of little importance. The theme that should be of greatest importance to health care is the safeguarding of the fullness of each patient's decision-making process. But I observe a closedness to spirituality and a lack of opportunities to explore the fullness of one's values rooted in transcendent expressions that are important to many spiritualities. The good of the

patient needs to be at the centre of ACPO resources—not the good of bioethics. And currently, aside from First Nations, Indigenous, and Métis resources that do invite spirituality more prominently, spirituality is limited to the periphery, is vaguely addressed, and lacks integration for deeper value prioritization in ACP.

Having addressed the answers to my research questions in this section, including the presence and absence of discourses related to spirituality, death, and values; the embedded ideological assumptions within the discourses I observed on the ACPO website; the potential implications regarding openness or closedness to spirituality in value reflection and prioritization; and finally, a summary of how spirituality is situated on the ACPO website, I move now to providing some recommendations with hopes they can help increase the fullness of ACP reflection by providing greater opportunity for individuals of diverse spiritual orientations to explore their values aligned with their sense of ultimate good in ACP decision-making.

5.3 Recommendations

Having outlined in the section above the absent discourses relating to spirituality, death, and values; the ideological assumptions present within these discourses; the potential implications of these discourses and ideological assumptions; and finally, some broader reflection on how spirituality is situated on the ACPO website, I will now translate these findings into eight recommendations specific to ACPO resources. And while I identify eight recommendations in this section, I am also aware that several of them contain sub-recommendations for greater clarity and suggestions regarding how the broader recommendations may be carried out. I hope these recommendations can translate into new perspectives in ACP processes that invite opportunity for the fullest reflection for patients regarding decision-making intersecting with the high stakes of serious illness and death. At the

heart of all my recommendations is a sense that the ACPO website is a resource that addresses many important aspects of ACP and the healthcare journey—but it is incomplete. There are missed opportunities to invite the fullness of value reflection and discernment that integrate the diversity of spirituality in a patient-centred way. I offer these recommendations to improve ACPO resources examined in this thesis.

5.3.1 Recommendations for the ACPO Website

Recommendation #1.

Increase Prominence, Integration, and Articulation of Spirituality in all its Diversity.

In order to cultivate an openness to spiritual integration in ACPO resources, for those whose spirituality is important to them, my first three-part recommendation is to move spirituality from the periphery to a more integrated and central location with increased attention given to articulation of spirituality in all its diversity—be it immanent, or transcendent expressions. First, in contrast to the peripheral location of spirituality I observed on the ACPO website, I am suggesting a prominent positioning of spirituality in alignment with the work of Frankl (1946/2019) who suggested the importance of starting with the spiritual in therapeutic work, and the work of Pellegrino and Thomasma (1988) who also suggest privileging the highest level of good in medicine as being a spiritually-oriented "ultimate good" (p. 81). If medicine is truly focused on the good of the patient and the deepest and fullest decision-making process, then opportunities for spirituality need to be located more centrally. This positioning will send a message to participants that spirituality may be a central factor for the good of the patient and linked closely with ethical decision-making—not just a peripheral add-on. As a moral obligation in healthcare, as Sulmasy (2006) notes, spirituality needs a central location to ensure opportunity is clearly provided for those who desire to engage in holistic reflection when facing potentially

deep moral questions. I acknowledge that spirituality may not be important to all participants, but for those who see the spiritual domain as being an important domain in their life, providing a central opportunity for reflection sends a strong message that the holistic domain of spirituality is both welcome and accepted as a key component for decision-making.

Secondly, in addition to being more centrally located, I also suggest an opportunity for increased integration of spirituality within value reflection and prioritization processes. If spirituality is truly "embedded in the fabric of life", as Pargament (2007, p. 21) suggests, it needs also to be embedded in the fabric of ACPO resources that requires participation in the fullness of life. Considering the very definition of healing put forward by Sulmasy (2006) that means to "make whole" (p. 16), the goal of processes like ACP should also actively seek to integrate this holistic objective. This involves exploring perspectives regarding spirituality that echo the work of Schneiders (2003) who describes spirituality as a "project of life-integration" (p. 166) as well as the integrative conviction of Gula (2000) who notes, "Spirituality and ethics cannot remain two separate spheres" (p. 19). Ethics and spirituality need to be connected. Rather than leaving spirituality on the periphery, a focus on wholeness can invite new integrative possibilities inspiring a fuller and richer value reflection process involving one's strongest evaluations.

Thirdly, along with the importance of locating spirituality more centrally, and increasing integration as noted above, I suggest increased articulation of the diversity of spirituality throughout the ACPO website. Considering the challenge of defining spirituality that I outlined in Chapter 1, and the clusters of features of spirituality I outlined in Chapter 2 that included qualities like transcendence, meaning, and connectedness, a broader articulation of spirituality is needed in ACPO resources that invites opportunities for diverse expressions of spirituality—both immanent and transcendent—to feel welcome and included while increasing the chance of

having a truly patient-centred tool. By extending possible understandings of spirituality beyond just immanent perspectives, greater opportunity will be provided for the inclusion of a diversity of beliefs and with it a deepening of the discernment process for those who wish to engage in this way. The greater the opportunity for diverse understandings of a complex notion like spirituality, the greater the possibility to invite the fullest discernment possible in ACP processes.

Recommendation #2.

Model Fuller Acceptance of Multidimensional Aspects of Death and Dying. Having noted a selective acceptance of death in resources on the ACPO website, I am recommending a fuller acceptance of the diverse and multidimensional aspects of death and dying in these resources. I reference the work of Zoloth and Charon (2002) who I have noted previously in this thesis. They suggest the importance of death in bioethics in saying:

> bioethics is the profession committed to facing death directly, calling out its name, and finally, unlike medicine, finding meaning in the lost places in the clinical world where death has established its dominion… The bioethicist—not the pathologist, not the geriatrician, not even the chaplain—is the holder of death's portfolio. At our best (and bioethics can fail terribly at this moment), bioethicists must create room among the living for the one who is dying so as to be alert to the idea of death. The task is to call attention to the limits of the triumphal arguments of medicine…to learn and to teach the knife edge of discernment, the narrative of closed borders and tragic endings. (p. 29).

This is a compelling vision for bioethics as the custodians of death. I am not disputing this aspiration. However, I observe that the ACPO website does not live up to the fullness of this aspiration. If bioethics is to be the holder of the portfolio of death—and ACP processes seem to meet this description with its context related to death and dying—then it should embrace the

fullness of death. And this means being self-aware and transparent in its own disciplinary biases regarding death while acknowledging the importance of the spiritual and moral aspects of death that inform one's decisions. If bioethics seeks to hold the mantle of death it must invite a radically patient-centred view that invites all aspects of death—including transcendent themes that intersect with one's spiritual and moral beliefs as well as one's beliefs in an afterlife. This means moving beyond a discourse of immanence that I observed in the ACPO website that sees only the physical aspects of death rooted in naturalist and secular assumptions, and the embracing of what might be important to the patient.

Adding to this is an openness to the larger mystery of death in ACP resources. Sommerville (2000) notes a conversation has happened in bioethics and contemporary medicine with a shift from approaching death as a mystery to seeing death as a problem to be solved. But considering the finding I have cited at different times in this thesis that 66% of Canadians believe in life after death—a number that has even increased slightly since 1985 (Bibby, 2017)—I observe that most Canadians believe death is not the end of one's life. I believe there needs to be more acceptance and integration around the mystery of death and what it means to Ontarians as they carry out their future planning. In this recommendation I see the potential for creating opportunities for greater reflection around questions regarding moral decision-making and how ultimate themes like reward, judgment, punishment, meaning, providence, eternity, and suffering might impact ACP decision-making involving the mystery of death. I echo the importance of inviting reflective questions for ACPO that move beyond the empirical and propositional, to one's larger life. As Zoloth and Charon (2002) suggest, "Although we are tempted to ask only questions that might be answerable, narrative methods—and the desires exposed by them—give us the heart to ask questions without answers, that is, questions that do not end" (p. 31). In asking

questions in ACPO resources that invite openness to death and all its dimensions, through narrative or other means, there may be an engagement with what Sommerville (2006) notes as an ethical imagination where, "Ethics in science involves a combination of the mystical, moral, and scientific imaginations" (p. 10). But in carrying the aspiration of bioethics as being the stewards of the portfolio of death, as Zoloth and Charon (2002) suggest, a greater openness is needed regarding the fullness of the conversation around death that invites the expansive mystery of one's beliefs and values with potentially diverse ways of knowing that are unique to each person.

Recommendation #3.

Address the Potential for Moral Conflict and Spiritual Struggle in Decision-Making.

Dovetailing with the suggestion to engage in the fullness of the mystery of death and all its dimensions, I also recommend that the ACPO website address the potential presence of moral conflict and spiritual struggle. In observing discourses regarding ACPO resources as being easy, unproblematic, and conflict-free, as well as my observation of a tendency for the ACPO website to offer instrumental and utilitarian perspectives on decision-making, I am suggesting there is little room provided for the complexity and multidimensionality of moral themes involved in decision-making involving death and serious illness. Opportunity should be provided for authentic engagement in the depth of one's discernment and struggle. Pargament and Exline (2022) outline the notion of spiritual struggle as "among the deepest of all conflicts" that include "experiences of tension, conflict, or strain that center on whatever people view as sacred" (p. 6). Mindful of the struggles that arise in health care decision-making, opportunity to explore deeper themes of spiritual struggle in ACPO tools may provide participants with a fuller engagement with the difficult decisions intersecting with death. But more than engaging in struggles, the absent theme in the ACP website is moral conflict. Considered to be a type of spiritual struggle

by Pargament and Exline (2022), I observe an absence of the theme of morality in ACPO resources. Considering the suggestion by Taylor (1989) that I have noted above, that, "Most of us are still in the process of groping for answers here" (p. 10), in regard to finding meaning, identity and moral conviction, the question becomes—how might integration of moral reflection happen more intentionally in ACP resources to allow for opportunity for this kind of moral engagement to happen? Providing opportunity for reflection regarding what Taylor (1989) refers to as one's "moral horizon" (p. 28) offers space for discerning themes of moral conflict and potential for connection to Taylor's description of one's spiritual framework that connects one to their "deepest moral responses" (p. 8). Considering challenges implicit in ACP processes, the potential for moral distress, and a kind of moral consternation for many belief systems, opportunity must be provided for the fullest and strongest engagement in moral decision-making.

Recommendation #4.

Deepen Communal Spiritual Resources as Potential Voices of Authority. In contrast to the largely individualistic focus in ACPO resources, I recommend broadening resources to intentionally include communal spiritual resources as potential additional voices of wisdom and authority in ACP decision-making. This recommendation is rooted in the thinking of Liégeois (2021) who suggests a "radical consideration of a relational view of ethics" (p. 1), as well as Collier and Haliburton (2021) who note that people "exist in a web of relationships and that these relationships provide the context within which any of our choices are made" (p. 118). Considering the warning by Liégeois (2021) that "legislation rarely thinks relationally" (p. 4), this suggestion seeks to intentionally integrate one's relationships with the legal aspects of ACP in a complementary approach that embraces the interconnectedness of relationships. And specific to spirituality and community, I note again the work of Steensland (2022) who suggests,

"spirituality has a social architecture" (p. 339) and also Frankl (1949/2007) who makes the transcendent connection between spirituality and community, noting "The meaning of individuality comes to fulfillment in the community" (p. 71). This relates to the work of Sommerville (2006) who suggests, "All journeys of our imaginations involve both our individual imaginations and our shared (or collective) human imagination" (p. 11). There is a fullness to including one's community ACP discernment that may benefit many participants in reflection.

Additionally, communal spiritual supports could also include professional spiritual care providers or psycho-spiritual therapists. Acknowledging research cited in Chapter 2 that chaplains have not been included in ACP discussion (Kwak et al., 2021), I wonder whether spiritual care professionals may offer key links to community spiritual support or to help invite connection to one's spiritual community in the decision-making process. And considering the complex nature of spirituality noted in Chapter 2, and also the potential for moral and spiritual struggle in decision-making, perhaps spiritual care professionals could also help individuals explore the interplay between one's individual spirituality and communal identity and meaning. Opportunities to invite additional voices into one's decisions can only deepen decisions. And while there is a possibility that involving community spiritual support may extend the ACP process, perhaps the benefit of increased thoughtfulness and depth in decision-making is the higher good than efficiency in processes. By suggesting opportunities to deepen connections to communal spiritual resources as potential voices of wisdom and authority, I see potential for opening up conversations regarding the good of the patient within their largest web of support.

Recommendation #5.

Enrich Value Discernment and Prioritization Processes with Spiritual Integration. I also recommend the enrichment of value discernment and prioritization processes with tools for

intentional spiritual integration. It is here that I return to the theological perspective of Lonergan (1972/2017) and a scale of value preference. And the first step in this kind of prioritization is the very acknowledgement of the difficult task of value discernment rather than the suggestion that it is largely simple. For many, understanding values and their relatedness to spirituality, and possibly one's community, can be difficult. Liégeois (2021) notes the challenge in discerning values and seeking the "best possible balance of different values" (p. 73). But inherent in this thinking is an acknowledgement of the challenge. In making this suggestion I am asking—what structure might be brought to value prioritization that could integrate a scale of value preference to help with discernment? Could theology be a possible perspective to help deepen these processes—notably the work of Lonergan I have referenced at points in my thesis. I note a phrase used by Lonergan (1972/2017) in discerning values that, "Not only do feelings respond to values. They do so in accord with some scale of preference. So we may distinguish vital, social, cultural, personal, and religious values in an ascending order" (p. 32). And while many of the tools in the ACPO website invite a level of reflection, my observation is that the value reflection sticks largely to themes focusing on the vital aspects of discernment, not ultimate and transcendent aspects. I suggest that opportunities for discernment of values in ACP needs to go into deeper layers. Gregson (1988) describes this richer value dimensions in Lonergan's work where "More of us is at stake" (p. 20). Here reflection moves into deeper stages of consciousness—from the sensory experiencing of data, to understanding related to intellectual questioning, to aspects of judging that involves weighing options, and finally toward making a decision through the deliberation of one's values. Gregson (1988) notes Lonergan's description of inquiry as "the unfolding of a single thrust, the eros of the human spirit" (Lonergan, 1972, p. xix, as cited in Gregson, 1988, p. 16) that moves this process to deeper levels. And this deepest

level is described elsewhere by Gregson (1985) as a process where, "The human spirit in its development moves from the desire for truth to the desire for value. The desire for value is deepened and made stable through love" (p. 73). And more, at this decisional level, there is an "active moral response to value" (p. 76) and "engagement with the absolutely Transcendent" (p. 76). There is a depth here to these processes that move beyond surface levels toward integration of value reflection with spirituality. Conn (1988) describes Lonergan's same approach: "the transcendental notion of value which dynamically urges us beyond ourselves toward moral self-transcendence" (p. 42). I am suggesting there is a deeper value discernment process involving spirituality that needs to be explored in ACP that theology can possibly help address. It is a process of moving towards our deepest love noted by Gula (2000) as "the wellspring of morality…that the person we become and the choices we make express what we ultimately love" (p. 17). I am suggesting a deeper process that truly allows opportunity to draw on one's "furthest interpretive horizon" (Stanworth, 2006, p. 28) and leading patients to what they ultimately value, and, as Gula (2000) suggests, "our commitment to live in a way consistent with what our ultimate love demands" (p. 17). The high stakes of death, with its finality, irreversibility and uncertainty, that intersects with one's ultimate beliefs, demand the fullest value discernment.

Recommendation #6.

Cultivate Epistemological Humility and Respect for Diverse Ways of Knowing.

Another recommendation I have for the ACPO website is the cultivation of epistemological humility and respect for diverse ways of knowing. As suggested by Sommerville (2006), I observe opportunity for bioethics to aspire to "a new vision that can facilitate the marriage of science and our human philosophical-spiritual heritage" (p. 9), or as Sulmasy (2006) suggests, "a form of medicine that does not abandon science but also does not eschew the mystical" (p. xiii).

For this marriage to happen, I am suggesting the need to cultivate an openness to diverse epistemologies and diverse ways of knowing to ensure all are respected and included in ACP, and as Sommerville (2006) suggests, in a way where diverse ways of knowing are welcomed and "held in dynamic balance" (p. 29). I am suggesting bridging the chasm between spirituality and bioethics with a radical focus on patient-centred care that drives decisions. There is a need to cultivate epistemological openness in ACP resources to encourage inclusion of all spiritual beliefs in ACP reflection to encourage the fullness of truly patient-centered decisions. Sommerville (2006) uses the metaphor of a dance to ask, "What ethics do you dance?" (p. 12). This implies there are different dances and different tunes that people hear regarding how they make health care decisions—and different ways of going about discernment depending on one's spirituality and perspective. This includes the importance of opening up epistemological views in ACP resources—beyond the purely scientific view that is "intolerant of the belief that there is a mystery of human existence" (Sommerville 2006, p. 18), and towards a science-spirit approach. This approach could mean extending ACP resources in the direction of what Sommerville (2006) notes as "a language of the ethical imagination" (p. 53) where these tensions can exist together. But this first requires some disciplinary self-awareness on the part of bioethics to look in the mirror with humility to see their epistemological biases and then to ask what it truly means to focus on the good of the patient. While epistemological humility is exercised in the First Nations, Indigenous, and Métis resources, I suggest an overall openness to diverse ways of knowing across the entire website is needed to deepen reflection and cultivate patient-centred choices.

Recommendation #7.

Increase Attention to Cultural Sensitivity. Dovetailing with the recommendation above regarding respecting diverse ways of knowing, another recommendation I have is increasing

attention given to cultural sensitivity throughout the ACPO website. I wonder what can be learned from the clear presence of cultural sensitivity in the First Nations, Indigenous, and Métis resources? I applaud the cultural inclusion in resources to support First Nations, Indigenous, and Métis participants. And while these resources serve as an excellent example of increased openness to spirituality and integration, I recommend that ACPO content-producers draw inspiration from these resources to deepen the cultural sensitivity of the website more broadly. I envision a spirit of inclusion and sensitivity arising throughout the website that invites openness towards spiritual beliefs of diverse kinds with examples framing value conversations more broadly with opportunity for reflection on ultimate values that may intersect with one's culture.

Further, in the larger picture of ACP in Canada, could there be greater safety cultivated with increased sensitivity that would move the numbers of participants in ACP that consult their health care professional from 20% to an even greater number? Mindful of statistics suggesting 23% of Canadians in 2021 "were, or had ever been, a landed immigrant or permanent resident in Canada" (Statistics Canada, 2022, p. 1), I observe that the language of cultural sensitivity is needed to help all traditions in Ontarians to feel welcome and included. Again, while there are translations of a few resources into a handful of diverse languages, I am suggesting more engagement and sensitivity is needed in the broader language of the website with image and design that invites cultural sensitivity—changes that may also increase openness to reflect on one's spiritual beliefs that are important for many traditions facing end-of-life situations.

Recommendation #8.

Demonstrate Openness to Diverse Bioethical Approaches Beyond Utilitarianism.

Finally, I am recommending ACPO broaden its philosophical base to explicitly include other theories beyond the prominent utilitarian ones I observe. This recommendation seeks a deeper

and fuller menu of reflective options for participants in ACP in alignment with broader philosophical criticism of our time by Taylor (1989) who observes: “an instrumental society, one in which, say, a utilitarian value outlook, is entrenched in the institutions of a commercial, capitalist, and finally a bureaucratic mode of existence, tends to empty life of its richness, depth, or meaning” (p. 500). I too observe an entrenchment of utilitarian views that risk emptying ACP of greater depth and meaning. Further, Taylor (1989) notes a “cramped and truncated view of morality” (p. 3) in contemporary approaches that “has tended to focus on what it is right to do rather than on what it is good to be” (p. 3). This focus on “what it is good to be” opens the door to a virtue ethics approach that moves beyond a calculus in decision-making focusing on pain and pleasure and towards questions like, “*what kind of person to be*” (Stiltner, 2016, p. 30, italics theirs) or their focus on the kind of community one might want to help build. This inspires other possible bioethical frameworks including an ethics of care lens where Liégeois (2021) suggests, “radical consideration of a relational view of ethics” (p. 1).

Additionally, in suggesting this broader base of options for participants to utilize, there is a greater chance that a model of bioethical reflection will align with one’s spirituality. I believe that offering differing bioethical perspectives might invite decision-making in alignment with what might be important to one’s own existential or spiritual view—whether that be decisions focused on one’s community and relationships; one’s striving towards a virtuous life; one’s deontological adherence and faithfulness to the tenets of a belief system; or the pursuit of pleasure and avoidance of pain. A patient-centred view would make room for all perspectives. I am not suggesting utilitarian perspectives be eliminated, rather, that they be offered alongside others that might best align with the spiritual commitments of Ontarians making decisions involving death and serious illness. A broader variety of ethical perspectives in ACPO resources

may help align decisions with the good of the patient and the diversity of their spiritual beliefs. Having outlined my eight recommendations for the ACPO website above, I move now to the next section focusing on limitations of my study. This is followed by suggestions for potential future research.

5.4. Limitations of This Thesis

In Chapter 3 I noted the strengths and limitations of my research from the methodological perspective I took in this thesis. I named methodological limitations including: 1) suggestions of mundane, selective, and partial observations; 2) negativity; 3) lack of definition of discourse; 4) qualitative approach is largely interpretive; 5) real readers or listeners are not addressed; 6) lack of context in research; 7) sitting the fence between political activism and social research; and 8) a lack of structure and framework to carry out research. I addressed limitations focused on methodology in Chapter 3 and articulated how I built on these strengths and limitations in this thesis. However, there are some other practical limitations that are also worth noting. I note the following practical limitations in my examination of the ACPO website that I will briefly address in the section below: 1) limitation of self-reflexive journalling of the study; 2) limitation of the boundaries of research; 3) limitation of overlapping thematic content; 4) limitation of deductive theoretical knowledge emerging; 5) limitation of navigating the diverse ways a website can be consumed; 6) limitations of diverse perspectives on a single website making analysis difficult; 7) limitation of knowing how best to sensitively approach Indigenous resources; 8) limitation in seeking consistency in examining the website over time; and 9) limitations of the examination with a single researcher. I begin this section by addressing the limitation of self-reflexive journalling in the study.

5.4.1 Limitations Encountered in This Study

Limitation of Self-Reflexive Journalling in the Study. One of the limitations I articulated in Chapter 4 included my approach to self-reflexive journalling in alignment with the methodological approach that was utilized in this study. Acknowledging the importance of self-reflexivity to both MCDA, and also reflexive TA, I sought to carry out this activity throughout the research process. While numerous entries were created, I became aware of both the diversity of the approach I took to journalling and also the diversity of thematic content in this study. While my reflections emerged more spontaneously in the current study, in future study it would be important to seek out additional approaches where thematic content could be explored with increased structure. While a strong body of self-reflexivity emerged, other structured approaches might have helped increased focus and would potentially have broadened reflection. Additionally, I was also aware of the tangential tendencies and irrelevant nature of some of the journal entries that inspired some questions regarding how best to include these in my dissertation. A structured approach may have helped in organizing these reflections. While I outlined my discernment process in greater detail at the end of Chapter 4, for future planning it would be important to be intentional in seeking additional structures to focus this reflection.

Limitation of Acknowledging Boundaries of Research. In addition to self-reflexivity, another limitation I observed in my research involved analyzing multiple layers of discursive and ideological content and the challenge of acknowledging the scope and boundaries of my research. This was most prominent for me in analyzing ideological assumptions and principles. While I was certainly mindful of prominent themes like neoliberalism that surfaced frequently in critical research (Fairclough, 2006), or emerging themes of colonization that related to spirituality and care (Lartey & Moon, 2020), I was also aware of the limited scope of my

dissertation with the methodological I utilized. While tempted to follow thematic tangents connected to larger ideological themes, I also observed the need for academic restraint, focusing on the methodology I used and on the research questions I sought to answer. In summary, I see my research as only a starting point in exploring both discourse and ideology in ACP. While there are potentially larger ideologies in the bioethical landscape that deserve attention, additional examination was outside the scope of this study. I will return to this in my suggestions for future study below.

Limitation of Overlapping Thematic Content. Another limitation in the research process was the challenge of discerning overlapping thematic content. One can see the evolution of discursive and ideological themes in my examination outlined in Chapter 4. But even in my final eight discourses and final eight ideological assumptions I observed a potential for overlap in content. I especially observed this challenge in the section focused on ideological assumptions. While all eight assumptions named were unique, many could be housed under a similar umbrella. A secular ideological assumption, for example, could also include rationalist perspectives, reductionist tendencies, as well as science and naturalism under its thematic heading. Likewise, a heading of science could also include rationalism, reductionism, and secularism. This challenge forced me to carefully examine the meanings of these terms to ensure the categories had precision and adequate differentiation. While the overlap of themes was a challenge, I observe it to be an overall challenge in reflexive TA more broadly and the difficult task of naming and grouping viable and identifiable themes (Braun and Clarke, 2022) based on one's observations.

Limitation of Deductive Theoretical Knowledge Emerging. As noted, both in Chapter 3 and also Chapter 4, I was mindful of my approach as being "strongly informed by existing theoretical constructs" (Braun & Clarke, 2022, p. 208). And while I sought to research

inductively through MCDA processes that were used to examine the ACPO website, I was also mindful of the unavoidable influence of my pre-existing theoretical knowledge. Some of this bias I described in my self-reflexivity journal where I reflected on the inescapable bias of subjective research where my observations were rooted in strong theoretical thinkers like Taylor (1989; 2007), Sulmasy (2006), Sommerville (2000; 2006), Pellegrino and Thomasma (1988) and Balboni and Balboni (2019) who were frequently referenced in my research. True to the thinking of Braun and Clarke (2022), their theoretical influence was impossible to extract from my inductive interpretations and I acknowledge this. While the focus of my study was inductive, it was impossible not to be influenced by the broader deductive knowledge that was rooted in my research. Mindful of the subjective nature of my methodological approach, I lean into this unavoidable tension and celebrate the interpretive nature of the methodological approach I took as well as the self-reflexivity that informs this approach.

Limitation of Navigating the Diverse Ways a Website Can Be Consumed. A technical limitation to the study that I must acknowledge is the dynamic nature of the website and how different digital platforms might display different aspects of the ACPO website. In utilizing different web browsers like Google Chrome, Microsoft Edge and Apple Safari, and also utilizing different devices including a laptop computer, a smart phone, and tablet device, the suggestion arose that there could be diversity of viewing experiences with each modality that would reveal different perspectives.[259] While I acknowledge these different digital experiences may impact a viewer's perspective, I also acknowledge the differences in experiences would be minimal and this kind of digital assessment was outside the scope of this project. These digital dynamics were not something I included in the methodological approach I took that focused largely on text,

[259] I owe this reflection to digital forensic expert, Bruce Nikkel, PhD, who brought this factor to my attention.

image and video. For future research it would probably be wise to assess other digital dynamics that may also inform discursive or ideological messaging on a website. But in this current research I acknowledge this as a gap to be focused on in the future.

Limitation of Diverse Perspectives on a Single Website Making Analysis Difficult.

While my study examined discourses and ideological assumptions across the ACPO website as a whole, what I observed as I began to carry out my research is the diversity of perspectives within the same website. While I observed overarching discourses and ideological assumptions across almost the entire website, the outlier I named at several points in Chapter 4 was the unique perspective of the smaller First Nations, Indigenous, and Métis section. And while representing only a fraction of the website's content, this outlier that offered a very different voice than the rest of the website, made universal conclusions across the entire ACPO website difficult. While a discourse like spirituality being on the periphery of the website fit for my examination for most of the broader website, the outlier was the First Nations, Indigenous, and Métis section that positioned spirituality more centrally. While I observed a strong presence of individualism across the larger website, I noticed a different communal spirit on the First Nations, Indigenous, and Métis portion of the website. And while the methodological approach I took in this study was not empirical,[260] I observe the ongoing exception to many of my observations being the smaller First Nations, Indigenous, and Métis section and their example of inclusivity, openness to spirituality,

[260] By suggesting this study is not empirical, I return to the work of Braun and Clarke (2022) who suggest "the researcher's subjectivity and skill are at the centre of good reflective TA" (p. 9). Wodak and Meyer (2016) too suggest a critical focus of one's examination in critical discourse analysis where the researcher's own position and interests are explicit. With a critical lens I have offered to the ACPO website I have been open with my positionality and interests in both Chapter 1 and Chapter 3 and that my observations are rooted in my own biases. For additional reflection on these biases I have also included a self-reflexivity summary in Appendix B.

and sensitivity. The benefit to this ongoing comparison throughout the dissertation was having a tangible example of approaches to ACP processes integrating spirituality that I am suggesting.

Limitation in Knowing How Best to Sensitively Approach Indigenous Resources. While I observe the main focus of the ACPO website being a mainstream bioethical approach that does not specify any particular cultural group, as mentioned in the section above, a small part of the website included several First Nations, Indigenous, and Métis resources. What became apparent to me early in the research process was the thoughtful example of spiritual openness, inclusivity, and communal inclusion that was evident on the First Nations, Indigenous, and Métis resources. But the question arose for me regarding how I could approach the analysis of these few resources with as much cultural sensitivity as possible within the methodological approach I utilized. I decided to sensitively assess text and symbols in these sections by only identifying observable content with concrete elements like words, images and music. And in my aspiration towards cultural sensitivity, I intentionally reserved any interpretive meanings of text or image found on the website to Indigenous voices in the literature. While involvement of communities was not within the methodological approach I utilized in my research to answer my research questions, future studies would benefit from exploring the results further with First Nations, Indigenous, and Métis communities and other groups whose voices may not be heard. I include this in suggestions for future research in the section ahead.

Limitation of Seeking Consistency in Examining Website Over Time. While I endeavoured to approach the website examination in an ordered and consistent way, this was not always possible. Readers may observe my attempt to access the website on a certain date to ensure consistency of the website within my study. Despite my best attempts to examine the site in April of 2024, I soon discovered several pages were missing in my initial analysis requiring

me to go back to the website in July of 2024 to assess the site again in what appeared to be the same website without changes—but I acknowledge there could have been minor changes to the website that were unnoticed by me during this time. While the methodological approach I took is not an empirical one, I am also mindful of the importance of transparency in how I went about my research. In acknowledging the subjective approach I took to examining the ACPO website, I suggest my analysis of the website provided sufficient concreteness in helping reveal important findings around spirituality's situatedness, and that my findings may also be applicable to other settings outside of Ontario for helpful analysis of other ACP resources more broadly.

Limitation of Examination with a Single Researcher. The research design I utilized intentionally included the perspective of a single researcher. While appropriate in terms of the methodological approach of MCDA, and also reflexive TA, I recognize the findings are limited to the experiences and reflections of a single researcher who is invested in the very conversation regarding spirituality as a leader in the field of spiritual care. While I do acknowledge that for further study additional involvement in analysis involving other voices might be very helpful to test these results, I do reiterate that the current study with its critical and theoretical focus is ideally suited to a single subjective researcher. Intersecting discursive and ideological lenses focusing on philosophical, bioethical, and theological aspects required a specific theoretical knowledge base to carry out the study with the methodological approach that was utilized. And while external engagement of communities was outside the methodological approach taken to answer my research questions, future research would benefit from testing these theoretical findings with communities to translate theory into practice in future ACP research.

Having outlined some of the challenges and limitations of this research study, I now turn my focus on the future and make some suggestions for meaningful next steps for future research beginning with the testing of theoretical findings in qualitative studies.

5.5 Research for the Future

Having outlined above some of my recommendations, and also some of the challenges of my study, I now look to the future and offer some suggestions for future studies that could extend the research of this current study in fruitful directions for transformative change. I begin with testing the findings of this study with diverse populations.

5.5.1 Suggestions for Research in the Future Regarding ACP

Test the Findings with Qualitative Research Involving Diverse Populations. Having engaged in this study using MCDA as a methodological approach where my focus has been on theoretical aspects of discourse and ideology as it relates with the multidimensionality and complexity of spirituality, and potential territorial disputes with bioethics, an extension of this in future research could involve qualitative aspects to test these findings. While the current study was theoretically focused with the lens of a subjective researcher, future study is needed that tests these findings with diverse individuals and groups to offer their lived experience. The discourses and ideological assumptions I have observed could be examined through the experience of individuals including spiritual groups, marginalized populations, and cultural groups including First Nations, Indigenous, and Métis communities. By testing these theoretical findings with individuals and groups in the future, this research has potential to move beyond theoretical aspects towards a greater analysis of spirituality in ACP resources that extends further than the theoretical landscape and into lived experience.

Future Study of Diverse Bioethical Approaches to ACP. Adding to the suggestion of utilizing bioethical approaches beyond those of utilitarianism, I see the potential for future research regarding the integration of other bioethical approaches. I have suggested the inclusion of approaches like virtue ethics and ethics of care—but more research is needed regarding how these might be integrated into ACP theoretically. And further, additional study is needed regarding what barriers might exist to not including these diverse bioethical approaches. Not unlike diverse approaches in psychotherapy that blend different approaches in relation to a client, future study might help assess how the field of bioethics might adapt to clients and situations in a patient-centered way. This deserves future study to align with decision-making that respects the uniqueness of each patient who is participating in ACP.

Examine the Potential for Spiritual Care's Involvement in ACP in Ontario. While I am aware of my own bias as a leader in the field of spiritual care in Ontario, I am also aware of a gap I see within the ACPO website involving potential spiritual resources and community partners. Many hospital systems in Ontario employ a spiritual care team to help meet the spiritual needs of patients. But more research is needed into the opportunities and barriers to the inclusion of spiritual care in ACP processes. Could a spiritual care practitioner play a role in helping integrate spirituality into value-based decision-making? Experts in spiritual assessment and spiritual integration need to be at the table to help shape the future of a person-centered ACP process. Considering the important moral and spiritual struggles that may arise in ACP, future study is needed from an Ontario perspective that may look at the potential for spiritual care to provide support in the ACP process to help deepen decision-making processes.

Explore the Potential Therapeutic Opportunity in ACP. Future study is needed regarding the therapeutic potential in ACP processes. In addition to the practical task of ACP, I

am suggesting there could be a therapeutic opportunity in ACP discernment. Considering Pargament and Exline's (2022) talk of spiritual struggles being pivotal in creating "potential for transcendence and growth" (p. 18), and what Yalom (2009a) refers to as awakening experiences where one is "primed to examine existential issues" (p. 75), I am asking whether there could be a future opportunity to extend ACP as a therapeutic opportunity to learn more about one's values. Could a framework like Frankl's (1946/2019) paradoxical intention where one confronts their greatest fears be applied to ACP? Considering the pattern of low engagement in ACP, perhaps future studies could engage in ACP with opportunity for therapeutic benefit that might not only increase ACP engagement but also provide therapeutic benefits.

Explore the Link Between Moral Distress and ACP. Future exploration is needed around themes of moral distress and ACP. Mindful of themes like decision regret, moral injury, and moral harms, there are high stakes involved in this work involving morality and death that could open up a whole new avenue of thinking. But more research is needed in the future about moral themes and ACP. Sommerville (2006) brings up moral regret and the ethicists role to "make available to people concepts that can reduce harms such as bitterness, hostility, and further exacerbations of destructive conflict" (p. 27). But this is a gap that needs to be studied more intently with a focus on ACP. Future study is needed to explore the role of bioethics in mitigating themes like moral distress that are rooted in moral conversations suggesting a spiritual implication. How might moral distress intersect with ACP resources? More study is needed.

Explore Spirituality in the Ontario and Canadian Bioethical Community. More study is needed regarding the role of spirituality in both the Ontario and broadly Canadian bioethical community. While I have suggested throughout my thesis that there is a bias towards certain discourses and ideological assumptions related to spirituality, very little examination has

happened in the Ontario or Canadian context. The dispute regarding spirituality's presence in bioethics that I have referenced has largely been rooted in the American context. And while similarities exist, more research is needed in both the Ontario and Canadian context. Considering the present diversity and the uniqueness of our health care system in comparison to the United States a question arises—how might my Ontario findings be extended more broadly in the bioethical community in Canada? An examination is needed from a Canadian perspective that might examine cultural sensitivity and the intersection with spirituality.

Extend my Findings of Ideology to Deeper Levels. Additionally, more study is needed regarding the potential examination of deeper layers of ideological findings. While my focus examined bioethical assumptions including utilitarian, secular, rational, and reductionistic aspects, I am aware that there are deeper layers that include the assumptions underneath the bioethical assumptions I named. Future studies could include focus on larger ideological systems at play including geo-political models that influence the foundational assumptions in bioethics that expand past healthcare with notions like neoliberalism and colonialism. Future studies might extend the ideological work I have done and move the dialogue to even deeper levels of analysis to address some of the structural influences that were beyond the scope of this dissertation.

Examine How a Science – Spirit Approach Might Be Operationalized. Finally, having quoted the work of Sommerville (2000; 2006) throughout this dissertation and the striving for a science-spirit approach that is epistemologically open to both domains of science and spirit, future study is needed to take some operational steps towards this aspiration. How might bioethics take a leadership role in this possible relationship that moves beyond any territory dispute? Could our heritage of diversity in Canada, and the broad beliefs of Canadians inspire us to set an example for the world regarding how the secular and the spiritual can be

integrated. More study is needed to continue both theorizing and operationalizing this work that respects the deepest beliefs of Canadians in every decision being made in the health care journey.

Having outlined some of the directions for future research in the space above, I move now to the final section of my dissertation—my conclusion. Here I will recap the ground I have covered in Chapter 5 before offering some concluding comments regarding my research.

5.6. Conclusion

In this chapter I offered discussion around the discourses that I observed to be present and absent in the ACPO resources before reviewing the ideological assumptions I observed to be present on the website. I then explored some implications of these findings before summarizing my observations regarding how spirituality is situated on the ACPO website. I then turned my attention to my recommendations for the ACPO website, followed by some limitations I observed in this study, and finally I offered some directions for future study. I now come to the conclusion of this dissertation and offer some closing remarks. In conclusion, I propose that I have added to the body of knowledge with this thesis in utilizing a unique methodological approach to critically examining spirituality on the ACPO website with an MCDA approach that draws on the paradigm of CDA/CDS. This critical approach resulted in the unique identification of eight discourses and eight ideological assumptions underpinning the ACPO website. This examination also resulted in eight recommendations regarding resources on the ACPO website that may help to inspire future development in patient-centered resources that may inspire fuller and richer value discernment and spiritual integration in ACP processes. Additionally, I would propose that this examination regarding spirituality and ACP uniquely focuses on the province of Ontario—a context regarding spirituality and ACP that has been previously inadequately addressed. Finally, I suggest that this study uniquely addresses spirituality and ACP from the

subjective perspective of a researcher with clinical experience and knowledge integrating spirituality, theology, and ethics. I propose that all of these suggestions demonstrate a significant contribution to the body of knowledge.

As I conclude this thesis I offer some final reflections. Having examined the "black box" of spirituality on the ACPO website in all its complexity and multidimensionality in this thesis, I return to the picture I painted in Chapter 1 where I suggested spirituality as being an obligation in health care (Sulmasy, 2006) that should extend to ACP where one's ultimate values and strongest evaluations should be considered in value reflection to help patient orient the challenging and unknown landscape of future decision-making with uncertainties involving serious illness and death. As I have noted at different parts in this thesis, it is this presence of death that provides a context that makes ACP so complex and the spiritual so important. There is an expansive human picture that emerges when death is present. As Lazenby et al. (2014a) suggest, "The waters of death are treacherous, and navigation is perilous. Clinical, psychological, social, economic, political, and spiritual currents all converge on death" (p. 257). And this is the challenge faced when confronting death. With the idea that bioethics could take the lead as "the holder of death's portfolio", as Zoloth and Charon (2002, p. 29) suggest, a deeper, fuller, and more complete engagement is needed that integrates death and the interwoven spiritual aspects that are important to many beliefs. An integrative transformation is needed in ACPO resources that moves beyond immanent and physical understandings of serious illness and death, towards the opening up of opportunities for both science and spirit to function in unity together. This partnership can ensure that opportunity is provided for both the exploration of the essential medical aspects of decisions and also one's ultimate values that may be important for reflection.

And it is here that theologically focused approaches like the scale of value preferences put forth by Lonergan (1927/2017) may be helpful in providing some structure to exploring deeper levels of value reflection involving ultimate themes. Having outlined the current situatedness of spirituality in this dissertation, I close by suggesting that theology can come alongside modern medicine to play a key role in helping operationalize the spiritual aspects of value reflection. I believe the inclusion of theology may be transformative in making this bridge between science and spirit. I echo the suggestion by Lazenby et al. (2014a) that, "Technology cannot 'solve' the riddle of death. Morphine may control somatic pain, but it cannot begin to touch spiritual pain. Now, more than ever, the world needs a form of health care that can integrate the biomedical and the spiritual, particularly at the close of life" (p. 257). An integrative change needs to happen that brings together science and ultimate and holistic themes of life. As noted above, Sommerville (2000) suggests that it is, "only through an undivided science-spirit approach that it will be possible to tell a collective story—to create a societal-cultural paradigm—of sufficient depth, breadth and width to capture our collective mind, heart and imagination" (p. 21). ACP needs this depth, breadth, and width in its reflective tools and resources. The current ACP approaches are inadequate and incomplete. The path forward must inspire the imagination in bioethics to move beyond the binary choices of science or spirit towards living in the fullness of diverse ways of knowing that invite the whole person to decision-making processes. Berger (2015) suggests examples of this integration exist in other parts of the world where they observe, "peaceful interaction between its secular discourse and religious beliefs and practices" (p. 411). Berger is getting at this same science-spirit approach that some traditions in other parts of the world are already doing. And integrated into this approach bridging science and spirit I would also suggest is a seeking of a balance between

available resources that are both accessible, and at the same time, able to engage in the depth of value reflection that embraces ultimate themes and the fullness of human challenges. An approach with science and spirit, as well as both accessibility and depth, is possible with an ethical imagination and a lens to sensitivity and diversity.

But how do we create the conditions for this to happen in healthcare in Ontario and Canada? How can spirituality join science in an imaginative relationship that truly invites patient-centred decision-making? I believe the first step is humbly opening up space for different ways of knowing into our processes—processes that currently privilege science and the secular. I think change happens by making potentially small but significant changes in the language, images, and videos that invite diverse ways of knowing to be welcomed and included. I think change happens by increasing prominence, integration, and articulation of spirituality in all its diversity. I think change happens by acknowledging the profound role of spirituality in decision-making held by many belief systems. This is how a step is taken to deepen ACP models to be truly patient-centred. And by modelling a fuller acceptance of multidimensional aspects of death and dying I am suggesting the invitation to utilize a lens that focuses beyond just the immanent—towards the transcendent, where opportunities emerge for a diverse range of perspectives to feel truly welcome. And in opening up resources to the transcendent, I think there is also an invitation to authentic conversation around the struggles that exist and the potential for moral conflict in our decision-making. And in increasing authenticity, and in helping honour the integrity of every participant in ACP, I think there is a movement toward the heart of medicine that seeks to respect persons and inspire the fullest informed consent process. But this can only happen with the cultivation of epistemological humility and deep respect for diverse ways of knowing. These are the small steps needed on the journey towards spiritual openness and

inclusion. These are the small steps needed on the journey towards fuller decision-making for our patients participating in ACP processes. These are potential next steps in fulfilling the moral obligation of attending to the spiritual domain in health care put forth by Sulmasy (2006).

In closing, I extend a metaphor offered by Lazenby et al. (2014a) to ACP. They refer to the aspiration of "safe passage" (p. 261) when navigating end-of-life and palliative care situations. But I think the notion of a "safe passage" also has relevance in ACP as well. They seek to help guide the ships of patients navigating the waters of life and death, and describe the journey in the following way:

> That journey is both universal and particular, but it is a voyage that billions of human beings have made before and billions more will make in the future. Over the millennia of human reflection on the mystery of death, our great spiritual and religious traditions have learned much about how to prepare us for that journey. Clinicians should be, at the least, prepared to help patients and families access their particular spiritual traditions that can help them navigate these waters safely (pp. 261 - 262).

I extend this image to the ACP process. Patients and families are navigating the journey that may unfold over months, years, or even decades. They are looking to the horizon, unsure of the unchartered waters ahead and calamities that may arise. It is the work of ACP to ensure that patients and families can have an opportunity to access the fullness of their orienting systems—including their spiritual traditions—that can help navigate these waters of health care safely. This is the profound calling of bioethics in taking leadership toward a patient-centred ACP process that integrates what might be important to the patient in reflection processes. I fully believe that the fullest and strongest decisions depend on this integration. The constellation of technological and scientific advances that have improved health care must now be integrated with the spiritual

traditions that have helped billions of individuals navigate life and death in past millennia. This partnership of science and spirit can ensure the fullest and strongest navigation of the waters of life and death for billions to come. The time has come to invite the fullness of reflection in ACP resources with science and spirit—all in service to the "safe passage" of all humans navigating the challenging waters of contemporary healthcare.

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Appendix A

Website Map With Identifiers

Site Map with Number Identifiers

1.0 Home

1.1 Contact Us
1.2 About Us
1.3 Legal Disclaimer
1.4 Privacy Policy
1.5 Sitemap
1.6 Newsletter
1.7 Donations

2.0 Resources

2.1 Glossary

2.2 Educational Videos

- 2.2.1 Five Steps
- 2.2.2 ACP in Ontario
- 2.2.3 Conforming your SDM
- 2.2.4 I'm an SDM
- 2.2.5 Consent and Capacity
- 2.2.6 A 5-Step Process

2.3 Frequently Asked Questions

2.4 Resource Guide

- 2.4.1 Resource Guide Overview
- 2.4.2 Consent
- 2.4.3 Substitute Decision Makers
- 2.4.4 Advance Care Planning

2.5 Character Stories

- 2.5.1 Althea
- 2.5.2 Anaya
- 2.5.3 Bob
- 2.5.4 Jacob
- 2.5.5 Priya
- 2.5.6 Tran

3.0 Advance Care Planning

3.1 Advance Care Planning

3.2 What is the ACP Process? (5 Steps)

- 3.2.1 Overview Of Five Steps (Identify)
  - 3.2.1.1 Learn
  - 3.2.1.2 Think
  - 3.2.1.3 Talk
  - 3.2.1.4 Include
- 3.2.2 Identify My SDM
- 3.2.3 Learning About Illness
- 3.2.4 Thinking About What's Important to You
- 3.2.5 Six Questions
  - 3.2.5.1 Understand
  - 3.2.5.2 Find-out
  - 3.2.5.3 Value Most
  - 3.2.5.4 Concerns
  - 3.2.5.5 Trade
  - 3.2.5.6 EOL

3.3 Who is ACP For?

- 3.3.1 First Nations, Indigenous and Metis
  - 3.3.1.1 Brochure
  - 3.3.1.2 Poster
  - 3.3.1.3 Video
- 3.3.2 Children and Teenagers
- 3.3.3 Healthy Adults
- 3.3.4 Adults Living With Chronic Illness
- 3.3.5 Adults who are Not mentally capable

3.4 ACP Conversation Starters

3.5 ACP Workbook

- 3.5.1 My Decision-Maker Card
- 3.5.2 My Questions for Healthcare Providers
- 3.5.3 Complete the Values Exercise
- 3.5.4 Complete Your Answers
- 3.5.5 Workbooks

4.0 Substitute Decision Makers

4.1 Making Decisions for Others

4.2 Who is my SDM?

- 4.2.1 SDM Categories

4.3 When do SDMs make Decisions

4.4 How do SDMs make decisions?

4.5 Attorney For Personal Care

4.6 I am an SDM?

Appendix B

Thematic Summary of Self-Reflexive Journal Entries

In this Appendix I have endeavoured to observe some overarching themes I observed in the collection of 26 journal entries I completed during the research process. In the paragraphs to follow I outline highlights of some of the key themes that surfaced in my own journal reflection and include direct quotes from some of the 26 journal entries I documented during my examination of the ACPO website. I have summarized self-reflexive themes in categories beginning with my own feelings around the cognitive bias.

Tensions Around Cognitive Bias. Having outlined above the rational and cognitive ideological assumptions found on the ACPO website, I also observe my own qualitative biases. As one with a perspective related to ways of knowing that include feelings and intuition which aligns with my profession in spiritual care provision, I observe how this impacts my own examination and inevitably finding glimpses of rationality. In one journal entry I can sense my own frustration towards the thinness of value discernment I see with a largely cognitive approach lacking epistemological openness: “thinking isn’t enough, what about feeling? What about lived experience?” (Journal Entry 2). In addition to this emphatic response that reveals aspects of my own epistemological perspective that embraces feelings and intuition, I also articulate my own qualitative biases around this same theme and name it as my own epistemological perspective: the whole ACP resource is cognitively based and here is my bias. I am a feeler. I’m a spiritually-oriented person and a spiritual care practitioner….[but]…Anything mysterious, spiritual or cultural is avoided in favour of the layer of cognitive” (Journal Entry 1).

Interestingly, if I utilize my own tools of inquiry on my own journal entries, I see my own sense of oppositional squaring—or creation of an "us" and "them" mentality—toward the bioethical content-producers as I suggest, "These are good people trying to bring good resources to people, but it is just a little bit heady somehow" (Journal Entry 1). I see a tendency here of "us" against "them" that suggests my own positionality here in the field of spiritual care and my own feelings of being with patients at end-of-life where the cognitive is favoured and spiritual is lost.

Advocacy for Spirituality to be Included. Adding to the section above related to my reaction to the cognitive privileging in the ACPO website, in another entry I observe the need to advocate that intersects with my own work as a leader of a spiritual care department in a Catholic health care system that impacts my perspective greatly. I offered this reflection: "The more I interact with the data, the more I realize that this intersects with my work as a spiritual care manager. It feels like an ongoing struggle to involve spirituality in care" (Journal Entry 8). And further, I observe not only the challenge in just involving spirituality, but the difficulty of defining subjective notions like values and spirituality with an assumption that these notions are well defined and understood: "But more, I notice the nuances of spirituality and culture being left undefined…It's as if spirituality and values are known to all, and don't need any elaboration. But in fact, they are the contested terms that require a lot of engagement" (Journal Entry 8). Clearly, I am wrestling with this same lack of elaboration and the tendency for spirituality to stay on the periphery. Further, I suggest in another entry my own fatigue at advocacy that relates to a secular medical field that can exclude spirituality and avoid mystery. "There is a personal part of me that is tired of fighting for spirituality. But the fight for me is really about articulation. It is really about inclusion. It's that just because we can't easily articulate something doesn't mean it should be absent" (Journal Entry 7). I sense here my own struggle with the territory dispute involving

spirituality and health care that I reference in Chapter 1 and 2. And having examined the ACPO website, I am aware of my own biases arising in this very discussion. This conflict is noted in another entry where I articulate some of the struggle that meets patients where they are at:

> Considering all the conflict with regards to religion in the consent and capacity board and the references to conflict in the research with family and the health care team… I realize spirituality is a hot topic. But the ACPO tools avoid any of the hottest topics. They pretend everything is simple and easy. Nothing could be further from the truth. But can we name the complexity? (Journal Entry 8)

Researcher Bias and Subjectivity. Reading this above section regarding bioethics and bias, I am aware that I am wrestling with my own strong feelings of unfairness or even an epistemological injustice that I referenced earlier in this dissertation, of spirituality not being fully embraced in medicine and the rigidness to one scientific epistemological stance. I am aware of my own experiences with patients of all faiths who may feel unwelcome spiritually:

> I feel frustration at the lack of self-awareness in ethics. It feels like they are unable to see the strength of their own secular and scientific values that are just oozing out of every part of this website… And here again my own lived experience comes into play because I have lived this in the ICU where families don't always feel comfortable sharing their spirituality with the team…I have a hunch that some of it has to do with the lack of trust of them accepting them as whole people (Journal Entry 19).

I observe a sense of advocacy here that is also fueled by my own biases, values, and epistemological stance. Added to my own personal bias is the organizational bias I name and responsibility I feel in my role in leadership in a Catholic Health Care Organization:

> As the manager of a spiritual care department in a Catholic health care facility, I realize my work that focuses on spirituality closely impacts the lens that I take in my research. I am keenly aware of my attendance and commitment to Catholic bioethical educational events and investment in situations in the hospital regarding ethics from a Catholic perspective" (Journal Entry 20).

There is a clear bias I am naming in my own perspective from a spiritual care lens, a leadership lens—and a Catholic perspective that is inspired by my own positionality. In being aware of my bias, I continue to explore in other entries, naming my own subjectivity rather bluntly: "And to claim my own normative perspective in this. I am seeing rather clearly right now that I cannot separate my own bias from this" (Journal Entry 10). In another entry I zero in on this theme of bias even further suggesting: "Inevitably, you find what you are looking for. And as a spiritual care practitioner I am looking for where spirituality is positioned" (Journal Entry 9). Additionally, another entry inspires this same line of thinking:

> I'm struck in reflection on the bias I bring to this. I'm looking for values and finding them. But one could suggest other values are there. My perspective is from a spiritual care lens and someone who has watched Western bioethical values arise to the top. Is it any wonder that I'm finding any glimpse of this? (Journal Entry 16)

Value Reflection and Immanence. In addition to the cognitive focus, my own advocacy to include the spiritual, and my own bias as a spiritual care practitioner and leader in a Catholic institution, another theme arising in my self-reflexivity journal relates to my own reactions to values and the immanent nature of the ACPO website that could be seen as excluding transcendent perspectives. In one journal entry I suggest the following: "But it is the immanent piece that is most perplexing. I acknowledge my own transcendent view and the larger story I

feel that I am a part of…I want to be faithful to my values and religious tradition. But is there room in this for me?" (Journal Entry 14). What I observe in this again is my own biases in this territory dispute between bioethics and spirituality where I orient myself towards an ontological and transcendent perspective of spirituality that collides with a perspective rooted solely in the immanent—and ultimately the scientific, secular and rational. I observe the clash playing out in the field of medicine, and I also observe the struggle I am observing self-reflexively. It is an epistemological challenge that is appearing here where different ways of knowing and seeing the world are colliding.

Complexity of Articulating Discourses, Ideology and Implicit Bias. In addition to the personal biases I have observed, another theme I see arising in my self-reflexivity journal is the iterative nature of the task as expressed in the following note: **"**I am increasingly aware of the iterative nature of this project. I keep coming back to the materials with slight tweaks" (Journal Entry 12). The process of discerning discourses as well as assumptions, and ideologies across a website involved this ongoing iterative focus. Additionally, regarding the research process, in another entry I note the laborious task of dealing with hundreds of code labels with a sense of curiosity: "It feels a little overwhelming…What is the clustered meaning across the dataset? The authors suggest asking – where will this journey take me?" (Journal Entry 9). The journey, of course, is the adventure of doing research that involves a path that is in part subjective and unknown. Additionally, I note the challenge of doing ideological work: "I have found this process to be difficult—especially this ideology and assumption phase. These are larger underpinnings. These are connected to larger swaths of thinking. It is one layer underneath everything. But the more I function on this level, the more I think these ideological layers are the ones that need to be addressed" (Journal Entry 11).

The other observation I make in the challenge of this task relates to the multiple dimensions involved in this analysis and what I think is the central question—where is the patient?

> I'm aware of how many dimensions there are to this simple website. Not only is it multimodal, but it also has multiple audiences and multiple voices writing. I hear the medical voice, I hear the legal voice, I hear the advertising voice—but the voice I wonder about is the patient voice. Is the spiritual voice being heard throughout? Or the cultural voice?... I see a gap (Journal Entry 13).

Cultural Sensitivity in First Nations, Indigenous, and Métis Resources. Additionally, another theme I observed in my writing includes my reflections regarding the excellent example of cultural sensitivity I observed in the First Nations, Indigenous, and Métis resources. These observations were made in the later stages of my research as I reflected on the First Nations, Indigenous, and Métis resources on the website and the sensitive examples of inclusion an openness to spirituality. In one entry (Journal Entry 25) I suggest:

> These resources are exemplary! I see the spiritual openness, inclusivity, cultural sensitivity, the involvement of community…The rest of the ACP website seems so behind regarding cultural inclusion, and with a noticeable lack of reflection or sensitivity regarding diversity and culture. I see the First Nations, Indigenous, and Métis resources as an example to follow in their relationality, openness to spirituality and obvious authenticity with personal accounts of experience with ACP (Journal Entry 25).

The other theme that emerges in these journal entries is the larger conversation regarding healthcare and First Nations, Indigenous, and Métis peoples. I reflect on the importance of this topic, yet my own newness to this conversation is obvious for me in Entry 26: "It is so clear that

their resources are relational, spiritual and invite diversity with such humility. In so many ways I feel like I am so new to this conversation" (Journal Entry 26). I am hearing in my reflection a longing to engage with this topic of conversation in bioethics and learn from and grow in my understanding of First Nations, Indigenous, and Métis peoples—and for Canada to see the thoughtfulness and openness to spirituality in these resources that offer a fine example cultural sensitivity and spiritual integration for ACP.

Topics Left Unaddressed. Finally, my final entry that alludes to this same feeling of not being able to address the fullness of the human person as it relates to spirituality. I observed the ideological themes of decolonization and neoliberalism in Entry 15 and unaddressed layers, and I returned to this theme in Entry 24.

> What other perspectives are missing? What else impacts medicine at its bedrock? I think of the significant impacts of colonization and neoliberalism for instance that could intersect with the spiritual. And while themes like this may overlap with discourses and ideological themes I have suggested, they are left unexplored. I'm struck by the small scope of this dissertation and the justified narrowness of my thesis (Journal Entry 24).

Finally, observing the theoretical approach taken in this research, I see myself calling for additional research that extends research to communities in Entry 25: "My research design focused on theoretical aspects of assessing discourses and ideological assumptions embedded in resources and did not include opportunities for surveys, interviews or community engagement. While it wasn't an option in the methodology I followed that was more theoretically-focused, I see a huge need for future engagement. My research needs a second stage of this research, testing the findings I observed with communities (Journal Entry 25). And with this final reflection I end this summary of self-reflexivity.