About dying and death: Thanatology's place in medical curriculum

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Abstract

This study explored how healthcare providers engage in advance care planning and end-of-life care conversations. The research explored what shapes their understanding and the extent to which concepts from thanatology they intuitively bring in, explicitly bring in, and maybe fail to recognize. To achieve this, constructivist grounded theory (CGT) methodology guided the design, data collection, analysis, and interpretation of the findings, which allowed for iteration across interviews and analysis with existing theories and data in the literature. The CGT design encouraged further engagement with the literature in an ongoing iterative fashion as well as with the analysis of the data. The study engaged 20 healthcare provider participants. Most were interviewed on two separate occasions. Analysis was conducted after each interview. This two-phase semi-structured interview approach enabled ongoing, iterative exploration of the data. The findings revealed that thanatological concepts from these engaged participants came intuitively through experience. This further experience allowed us to gain some novel insights into places where thanatology concepts may support a better educational process for medical students to practicing physicians.

Keywords

Advance Care Planning; ACP; Anticipatory grief: Assumptive beliefs; Curriculum; Death; Dying; End-of-life; EOL; Goals of care; GOC; Living Cycle; Medical Assistance in Dying; MAiD; Medical Education; Palliative Care; Serious illness; Thanatology
Summary for Lay Audience

Discussing end-of-life care with patients can be difficult for healthcare providers. Many providers lack proper training for such discussions and may not be familiar with goals of care (GOC), advance care planning (ACP), Medical Assistance in Dying (MAiD), or Palliative Care, which makes these end-of-life conversations even more challenging. This study was about understanding how healthcare providers engage in advance care planning and end-of-life care conversations. The research explored what shapes their understanding and the scope to which concepts from thanatology inform their understanding.

Twenty healthcare providers participated in semi-structured interviews. A research design that allowed for constant interaction between the research literature, the participants and theories about death and dying allowed new insights to develop. The research provided some novel insights into places where theories of death and dying may be useful in the training and support of medical students.
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Land Acknowledgments

So much of my work has been influenced in some way by my origin. I would like to begin by acknowledging that I live and work on the traditional lands of the:

Anishinaabek (Ah-nishin-a-bek),

Haudenosaunee (Hode-no-show-nay),

Lūnaapéewak (Lennah-pah-wack) and

Chonnonton (Chun-ongk-ton) Nations.

I was born and raised on the lands referred to as Treaty 6, which encompasses the traditional territories of Cree Peoples and the homeland of the Métis Nation.

I am dedicated to ensuring that the work I share will be to use education as a tool for inclusion, equity, and for Reconciliation to be honoured and respected.
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Chapter 1

1 Introduction

The task of breaking bad news is a testing ground for the entire range of our professional skills and abilities. If we do it badly, the patients or family members may never forgive us; if we do it well, they will never forget us.

(Buckman, 1992, pp. 208-209)

Among the most challenging discussions practicing healthcare providers have to have with their patients, regardless of their specialty, relates to conversations about goals of care (GOC), advance care planning (ACP), medical assistance in dying (MAiD) or palliative care (PC). This study explored how healthcare providers engage in advance care planning and end-of-life care conversations. The research explored what shapes their understanding and the extent to which concepts from thanatology they intuitively bring in, explicitly bring in, and maybe fail to recognize. My participant sample included twenty heterogeneous healthcare providers, and I considered them in the following categories: physicians, which refers to all physicians who do not have surgical practice, surgeons are for those who have a surgical practice, residents are referred to as PGY3 and above (postgraduate year), and nurse practitioners. For this study, although there are multiple different specialties of medicine, I will refer to all participants as healthcare providers to be concise and consistent.

When healthcare providers need to lead these difficult discussions with their patients, their lack of training and experience in this area can make the discussions go ‘badly’, as Buckman cautions. As a student of thanatology, I wondered if the teachings of thanatology (Worden, 2018; Doka, 2002; Rando, 2000; Neimeyer, 2001; Morgan, 1997) might inform healthcare providers in ways that would help them “do it well.”

Death and dying are complex phenomena. Engaging in meaningful dialogue and supporting patients and their caregivers struggling with end-of-life decision-making requires a broader understanding of end-of-life care than has been presented in the dated work of Dr. Elizabeth Kübler-Ross (1969). Kubler-Ross’s early works on the five stages of dying theory: denial, anger, bargaining, depression, and acceptance provided a linear
identification of processes most people could expect to experience. Research in the thanatology and palliative care fields has significantly advanced our understanding of death, grief and loss in ways that go well beyond Kübler-Ross. Yet, despite these advancements in the literature, the ‘five stage’ theory persists as a dominant model in medical education (Downar, 2018). Downar argued that “undermined by the ‘hidden curriculum’ in medical education, interventions must be accompanied by continuing education and faculty development to create lasting change in physician behaviour” (p. 57), but continuing further education takes time. Advancements in thanatology literature (death systems, culture, grief, and bereavement) practices and training could offer physicians meaningful ways of enhancing the end-of-life support they provide.

The main objective of this study was to gain insights into what healthcare providers draw on and where there are gaps in end-of-life care conversations. Could there be intuitive or explicit understandings that helped them navigate these conversations more effectively? Additionally, we aimed to identify any challenges that healthcare providers face when engaging in end-of-life care conversations. By exploring the “absences” in their current knowledge and skills, we hoped to uncover new opportunities to educate healthcare providers and improve the quality of their patient conversations.

1.1 Research Questions

The overarching questions that guide the research are:

- What are the theoretical implicit and explicit perspectives, and personal or professional experiences healthcare providers draw on during end-of-life conversations?

- In what ways have these changed over time due to the introduction of MAiD in Canada?

- How might theories from thanatology specifically contribute to training or preparation in this area?
1.1 Organization

This monograph thesis is organized into six chapters. Chapter One introduces the overarching research focus, theoretical framework, approach, core topics, and some of the findings and conclusions. Chapter Two provides a literature review related to scholarly conversations on death and dying, focusing as much as possible on literature published within the last ten years in Canada. Chapter Three introduces the methodological approach, Constructivist Grounded Theory (CGT), which was selected for its focus on generating new theories from an inductive approach. Chapters Four and Five present findings in two parts: Chapter Four takes a broad look at the first two questions, and Chapter Five digs into participants' implied or explicit experiences as analyzed through a thanatological lens. Chapter Six discusses the research's findings, recommendations and implications for future healthcare education.

1.2 Extent or Scope of the Study

This project aims to support developing new training or preparation in this area of serious illness or end-of-life conversations for training healthcare providers. Understanding how healthcare providers have these conversations with or without prior experiences or training on serious illness or end-of-life conversations will facilitate sharing their experiences to improve the quality of end-of-life conversations they have with their patients.

1.3 Theoretical Framework

The theoretical framework explains how I view the problem, data, outcomes and solutions. Bringing a thanatological lens to the work is at the forefront, given my background and interest in this area and its relationship to the problem. I also bring a feminist and educational lens to this research as they have much to offer about how death and dying have been constructed or positioned in the past.
1.3.1 Thanatological Lens

Although discussing death and dying is recognized as an essential role for healthcare providers, surprisingly, in medical education, engagement is lacking, notably in physician training and research. Given the tremendous amount of literature published in the field of Thanatology, it would be relevant for healthcare providers to understand these principles. The role of a thanatologist is to pay attention to the desires of dying people and create an environment that will satisfy their needs (Chapple et al., 2017). It has taken the death awareness movement of the 1960s to facilitate more open conversations (Neimeyer, 2001). This includes exploring fears, misconceptions, priorities, religious or spiritual beliefs, concerns around pain, family and friends. Such conversations are learning opportunities that draw from people’s historical experiences and use the language that thanatology provides to understand those experiences; the ability to understand the participant allows a more profound experience.

In this case, I brought a thanatological lens to the interviews and analyzed and examined the theoretical positioning of physician, surgeon, resident, and nurse practitioner experiences. My awareness allowed participants to share their experiences, thoughts, and feelings and be more conscious of what they may or may not be doing in their practice. These thanatological threads came up during the first and second interviews when the participants were asked to reflect on an experience they had in a non-clinical situation. This meant they reflected on their personal lives and the experiences they intrinsically brought into their professional life.

In 1958, Dame Cicely Saunders recognized a desperate need for support through the dying, death and bereavement processes. Her observations and experiences with pain control for patients led her to publish research on the modern-day hospice. Her ability to treat the dying patient as a person - listening to them and informing them about pain management - made all the difference to the patient’s end-of-life experience. This ability created an “openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her own journey towards their ultimate goals” (1963, p. 319). Her approach led to reconsidering how the dying was “seen” and paved the way to include individuals and their end-of-life goals.
More formal calls to action were seen in the 1960s when Elizabeth Kubler-Ross introduced five stages of death and dying in her ground-breaking book, “On Death and Dying” (1969). Kubler-Ross and David Kessler (2005) subsequently claimed that the prescriptive nature of the stages was a consequence of providing descriptive meanings of each stage. However, critics pointed to the linearity of Kubler-Ross’s stages and argued for including other factors depending on the individual and the context (Doka, 1996; Stroebe et al., 2017; Worden, 1991). Closer to home, a movement in Canada was introduced in 1974 by Dr. Balfour Mount, based on Dame Cicely Saunders’s work, which he referred to as Palliative Care (Clark, 2007). Although Mount’s early work laid the foundation for palliative care programs for cancer patients in the mid-1970s, it was treated as a specialty and subsequently had little impact on the medical school curriculum (Downar, 2018; Seely et al., 1997). As a result, the healthcare providers in my research study supported patients at the end of their lives in their day-to-day practice, having had little to no specialized training in end-of-life conversations.

While there are necessary fields of research that inform healthcare provider's practices, they have emerged primarily in disciplinary silos, either inside or outside of healthcare settings (Saunders, 1996), leading to “poor communication and lack of information sharing across disciplines” (Kanjee & Bilello, 2021, p. 357). A disconnect between healthcare teams can create silos, which can be a symptom of systemic structures that have not yet made space for interdisciplinary or cross-disciplinary learning. Researchers have formally argued for interdisciplinary approaches to address society’s most complex challenges. According to Mansilla and Duraising (2007), interdisciplinary understanding is the integration of pieces of knowledge “and modes of thinking in two or more disciplines or established areas of expertise to produce a cognitive advancement...in ways that would have been impossible or unlikely through single disciplinary means” (p. 219). Despite well-intentioned interdisciplinary initiatives, the disciplinary structures underpinning these efforts can thwart the best intentions. In this research, it was clear there was room to create a space for improved interdisciplinary understanding that could bring advancements in knowledge from thanatology research to healthcare providers' practice.
1.4 What does Thanatology have to offer Healthcare Providers?

Healthcare providers need resources and support to provide the best possible care to their patients. Ensuring medical educators have the language and tools necessary to incorporate thanatology theories into their initial and ongoing medical training will mean that practicing physicians are better prepared for this all-too-common scenario. Learning about thanatology theories is not to be considered palliative care training. Palliative care training is a specialty and not to be confused with other psycho-social understandings that thanatology theories can bring into a healthcare provider’s practice. The context of the information will equip the healthcare provider with the necessary knowledge to begin their professional practice rather than attempting to figure it out on their own, as many participants in this study had to do.

1.4.1 Participants’ Theories-in-use

Argyris and Schön (1978) introduced terms for professionals to develop a “theory of practice”, which usually corresponds with an espoused theory and theory-in-use (p. 6-7). For example, when a healthcare provider was asked how they may conduct themselves in an end-of-life conversation, an espoused theory offers what an individual understands that they should be doing. Theory-in-use, on the other hand, reflects what they actually do when they have the conversations. Some people have implicit and consistent theories-in-use that align with their actions for these theories and practices. At the same time, other people may hold certain beliefs about themselves but behave in ways that contradict them. Some participants may have struggled to articulate their theories-in-use explicitly. Still, when further probed, they could describe practices that reflect an underlying theory gained through experience.

Many healthcare providers will be called on to engage in challenging conversations before developing the practice wisdom from “lengthy exposure to similar situations” (Scott, 1990, p. 564). As a healthcare provider, it is crucial to use language that does not cause any harm to patients. (Friedman & James, 2008). How they speak to patients and families can create meaning and help them adjust to the loss and change in their lives moving forward. Smith and Delgado (2020) explained that “variations of grieving are
dependent not only on the type of loss but also on how that non-death loss is understood and experienced by the individual” (p. 120). Sometimes, these profound conversations with a patient need time to build trust. The healthcare provider’s body language and how the patient and their caregivers receive these conversations also play a significant role in patient-caregiver-centric care.

1.4.2 Feminist Lens

Donna Haraway (1988) suggested that a theorized global world is unnecessary, but global connections that can translate knowledge and power differentials within different communities are welcomed. Drawing on a feminist lens brings attention to how social systems of power and oppression interact to connect these communities and demonstrates that much of the world has been planned from, by and for a particular kind of perspective – primarily rooted in the patriarchy (Harding, 2004). These considerations of connectedness and social and power systems go beyond gender and invite debate from diverse perspectives. A feminist lens explores the relationship between theory and practice. To consider feminist theories through a thanatological lens brings different perspectives. It draws attention to social problems, tensions, and perhaps what is unspoken or excluded, especially in historical dominance by gender, race, class, or other groups regarding death and dying. Haraway (1988) spoke about “how meanings and bodies get made, not in order to deny meanings and bodies, but in order to build means and bodies that have a chance for life” (p. 580) and understanding that everyone is different and paying attention to such difference allows people to plan for conversations with diverse participants. A feminist lens invites participants and researchers to see beyond the patient’s physical person; they are more than their disease, and that silence may speak volumes.

1.4.3 Educational Lens

Studies in education remind me that learning, like bereavement and grief, is not a static, linear, or monolithic experience. Education theorist John Dewey (1902) wrote about the many moving parts in the curriculum: “It is a continuous reconstruction, moving from the ... [learner]’s present experience out into that represented by the organized bodies of truth
that we call studies” (p. 11). Contemplating topics about serious illness or death and dying is unlikely to be a singular and prescriptive conversation between patient and healthcare provider. This may require more time, different approaches, and other contexts. Just as social psychologist Lev Vygotsky (1978) observed that “children’s learning begins long before they attend school” (p. 37), learning how to have these valuable conversations within communities continues across the lifespan as people “come to know” through interacting with others and their environments.

This study is interested in the interaction of people (e.g., belief systems, relationships) and context (state of wellness, state of a pandemic) and material resources (access to planning resources). While we can see that interdisciplinary lenses are essential, we too often see that many continue to practice in disciplinary silos. We may see, for example, units that form exceptional interdisciplinary teams but at the same time, are less able to share knowledge of an area that they have yet to articulate for themselves entirely.

For example, most medical healthcare providers are familiar with Kubler-Ross’s (1969) five stages of dying. They have been introduced to this work in courses, and virtually all research on the topic of dying, cites Kubler-Ross. However, our understanding has grown dramatically since this work was introduced. The field of Thanatology has expanded our thinking about people’s experiences to include more multi-dimensional components by locating death in the psychological, social, cultural, and spiritual realms that people experience. We have seen this expanded understanding making its way into practice. For example, Dr. Harvey Chochinov et al. (2008) created a screening tool that contemplates psychosocial considerations for those facing serious illness and end-of-life, with a series of questions. The process of developing a more robust understanding has been more happenstance than by design. Bringing new and relevant ideas from Thanatology into the medical education discourse can continue to shift the discussions and practices we see in patient care. The educational imperative can help researchers integrate knowledge into pedagogical practices that extend physician training.

In the larger context, incorporating and applying CGT to these three lenses when analyzing the data allows for a deeper understanding, reflexive exploration, and generating new knowledge to produce the best outcome for the participant. This theoretical framework constructed a successful triumvirate to collaboratively illustrate a
more extensive range of resources. Engaging in these conversations through these lenses provided opportunities to listen, observe, and understand the participant sharing their personal story through a professional and theoretical lens.

1.5 Limitations

Limitations will be discussed in greater detail in Chapter 3. The 20 participants were from a single healthcare centre and clearly cared deeply about the topic. While all 20 participants were invited to a second interview, the time and engagement of participants differed, leaving 14 of the 20 engaging in a second interview. Finally, it is worth acknowledging that the pandemic may have influenced people's perceptions and experiences, perhaps lending an urgency to the need for this work while also making it more difficult for others to engage in anything outside of the significant demands the pandemic placed on their time.

1.6 Assumptions

Before this work, I assumed there was little or no formal education or training in death and dying medical education. I learned that much information is available for healthcare providers, but only some access it. I also presumed that healthcare providers who engage in these conversations without formalized education or training would struggle to communicate effectively with patients and caregivers and cannot do it well. I learned through my participants that effective communication is possible, primarily related to their prior experiences or explicit modeling with a senior mentor over time. My previous belief was that only family physicians and oncologists discussed serious illnesses or end-of-life options with patients. I was surprised to learn how many healthcare provider specialties participate in these conversations. I used to assume that these discussions would occur immediately after receiving any life-limiting diagnosis. While these immediate conversations may be true for some, I now understand that individuals with life-limiting diagnoses can live for years as outpatients and maintain a good quality of life, so end-of-life conversations may not be a first discussion. Another assumption was that a palliative care physician could only introduce palliative care. I learned that
different specialties of healthcare providers provide palliative care for less complex patients’ needs.

Before interviewing participants for this study, I had ideas of what a good death looked like based on the personal experience of being with my grandparents when they took their last peaceful and calm breaths. Despite that personal experience, I had not considered the importance of an end-of-life conversation. In previous work from my master’s thesis, I documented talking to my granddad at Easter in 1999 and my experience of coming to acknowledge and accept his impending death (Dombroski, 2017). I wanted to have a meaningful conversation with him about how much he meant to me, but I did not want to cry in front of him to make him feel any worse, but I found the courage to tell him. I understood at that time the importance of being present and acknowledging his death, but I cannot be sure if that was more for me in an effort not to look back with regrets or for him knowing he mattered to me. Maybe both.

1.7 Summary

This study examined what theoretical perspectives and personal or professional experiences healthcare providers draw on during end-of-life conversations and how they might compare to existing thanatology theories. In a wide range of healthcare provider specialties, these participants shared their experiences of having end-of-life conversations with their patients. As the researcher, I could listen and learn from the participants as they processed how they organized themselves during these patient conversations. The opportunity to acknowledge their histories and examine experiences as part of a community heavily features how I sought to explore this topic to inform pedagogical support for training healthcare providers.
Chapter 2 Review of the Literature

2 Introduction

The research questions this study asks are:

• What theoretical perspectives and personal or professional experiences do physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners draw on during end-of-life conversations?
• In what ways have these changed over time due to the introduction of MAiD in Canada?
• How might theories from thanatology specifically contribute to training or preparation in this area?

My approach to answering these questions was to use a constructivist grounded theory (CGT) study (Charmaz, 2017). CGT guided the design, data collection, analysis, and interpretation of the findings. The methodology was chosen because it allows the researcher to bring their understanding to the design, analysis, and, ultimately, the emerging theory. It also allows the researcher to review and revisit the literature iteratively as they engage in the data collection and analysis processes.

The literature review began with an overview and summary of topics deemed relevant to the research. As the interviews were being conducted, I went back to the literature to review any new topics or information that arose in the interviews presented by the participants. During analysis, I returned to the literature again as new insights emerged through our conversations or reflection and memoing. This iterative approach allowed a deeper understanding of the topics discussed (Charmaz, 2017). The chosen topics arose prospectively throughout the CGT study because they either helped contextualize the study's findings or represented some of the relevant theories from Thanatology. This was an essential part of the process to deeply understand the participants’ responses and guide my subsequent follow-up of the second set of interviews.
2.1 Key Issues in Talking with Patients

For some healthcare providers, when discussing a life-limiting diagnosis, the shift may invoke a conversation to actively treat or support and treat their patients according to their values and wishes, understanding there is no cure. Societal and policy changes affect conversations around death and dying decision-making in Canada and how healthcare providers conceptualize and communicate them. The context for these conversations has many different and individual influences. For example, recent years have seen the emergence of research to understand what people understand of Advance Care Planning (ACP) (Taneja et al., 2019), Medical Assistance in Dying (MAiD) (Government of Canada, 2021; Dombroski, 2017), and palliative care (The Canadian Hospice Palliative Care Association, [CHPCA], 2020). More recently, significant interest has emerged in the literature surrounding the need for Advance Care Planning (ACP) as a “process, not an event … and encourages dialogue among a patient, their family, friends, substitute decision-makers and the healthcare team” (Teixeira et al., 2015, p. 40). Sharing and documenting these values and wishes for care at the end-of-life assures “that care is consistent with preferences” (p. 40). In Canada, where healthcare is a provincial mandate, documents are available to the public depending on the province in which the patient resides. These documents are referred to as Advance Directives, Advance Healthcare Directive, Advance Medical Directive, Directives, Healthcare Directive, Personal Directive, or Power of Attorney for Personal Care to include goals of care designation/do-not-resuscitate orders (CHPCA, 2020; the BC Centre for Palliative Care, 2020).

With ongoing policy changes, healthcare providers and their patients must navigate conversations that include new options for serious illness and end-of-life decision-making. As I started writing this dissertation during the global pandemic of the novel coronavirus (COVID-19), there was a need to improve our ability to preserve dignity in dying (Chochinov et al., 2020). The call for preparedness took on new urgency (Ersek et al., 2021), given the ever-changing policies worldwide in those early days. Considering how quickly this virus incapacitated a person, decisions needed to be made promptly and quarantine created conditions where a patient was alone without the time or benefit of
loved ones around. If available, some patients were fortunate to have access to the telephone to speak to their loved ones.

Here, I summarize the scholarly conversations in the literature relative to my research.

2.1.1 Goals of Care

The purpose of goals of care conversations in a hospital setting is about medical decisions and interventions for a patient (Myers et al., 2018). Diagnosis and prognosis have occurred for context, and treatment is the next step or underway. The goals of care conversation(s) explore how the patient wants to live with their medical crisis and a conversation that should be revisited with each medical appointment (LeBlanc & Tulsky, 2022). Goals of care sometimes need clarification while learning about resuscitation wishes (Do Not Resuscitate, DNR) or assuming it is the same as advance care planning. While both are extremely important, ideally, they should be discussed before a medical emergency.

2.1.2 Difficult Conversations

As the population ages and the pressures realized during the COVID-19 pandemic are considered, the ability of healthcare providers to skillfully have these conversations grows increasingly challenging and necessary. Statistics show that the proportion of baby boomers in Canada reaching advanced ages is increasing the pressure on the health and home care system (Statistics Canada, 2022). In 2021, changes to the MAiD legislation expanded the eligibility criterion (Government of Canada, 2021). The ruling removed the requirement that natural death was reasonably foreseeable. During the COVID-19 pandemic, reports of deplorable conditions in long-term healthcare facilities revealed that many vulnerable senior citizens were dying alone due to inadequately staffed care (Liu et al., 2020). Inadequate patient care has sparked increasing conversations about maintaining dignity at end-of-life. Insufficient staffing levels and more physicians working virtually led to advanced nurse practitioners engaging in primary care within long-term care (LTC) homes to reduce emergency and hospital visits (Vellani et al., 2021). Many of these challenges stem from fiscal constraints that do not create the conditions of care that many healthcare providers aspire to provide (Labrie, 2021).
Despite the inadequate fiscal conditions for providing care, the general expectation held by patients in 2023 is for healthcare providers to have in-depth, clear, conversations that address decision-making surrounding end-of-life choices with the patient. These conversations are critical for the entire healthcare team, including the ill person and their caregivers. However, there appear to be assumptions in the medical education literature and the public sphere that healthcare providers have received the appropriate training to have these end-of-life conversations. Despite these assumptions, the literature suggests that healthcare providers in the group I am focusing on in this study (e.g., physicians, surgeons, senior residents [PGY3 and above] and nurse practitioners) receive little, if any, training that prepares them to have end-of-life conversations (You et al., 2015). Instead, these healthcare providers may rely upon their interpersonal competencies, knowledge gained from their own experience with death, mentoring and modelling from senior, more experienced members in practice (Arora & Mukherjee, 2021; Downar, 2018; Hafferty, 1998). These chance opportunities to learn can be considered either a “hidden curriculum” (that which is not explicitly taught) or a “null curriculum” (that which is excluded from the curriculum) (Kelly, 2009).

The review of the literature helps us understand a couple of things: First, it can be helpful if patients and caregivers are familiar with having conversations about end-of-life care before they experience a healthcare crisis; and second, the healthcare providers themselves need to have the knowledge and skills to engage in these difficult conversations, whether or not patients are prepared for them. The capacity to have these conversations early and continuously depends on the healthcare setting and the precious time allocated for appointments in a busy practice. When patients are experiencing a health crisis, healthcare providers “…cannot take lightly what we are asking of patients’ family members when we ask them to participate in these decisions” (Thelan, 2005, p. 35), primarily if they have never engaged in the lengthy, difficult conversations before that moment. At the same time, offering treatment options and what that may look like (Vellani et al., 2021) require healthcare providers to be skillful in this kind of communication in everyday practice or a hospital setting, and they need to discuss goals of care, ACP, serious illness, end-of-life, MAiD, or palliative care.
Under the Canada Health Act (2023), each province and territory of residence provides and pays for healthcare services. This includes healthcare for Indigenous Peoples, with some addition to federal funding. Technology advancements have generated additional resources and services to support patients and healthcare providers. The website *Advance Care Planning Canada* (ACPC) is an example of a site that includes many resources that are freely accessible to everyone. ACPC is dedicated to educating healthcare providers on beginning and having challenging conversations. It provides printable workbooks to fit one’s choice of life-sustaining medical treatments or the differences in the conversations that may be needed (e.g., goals of care, advance care planning). The main objective of ACPC is to encourage people to have these conversations early - before there is an emergency and decisions need to be made quickly. Figure 1 provides a snapshot of what is available to help healthcare providers have meaningful conversations with patients and their caregivers. As this model directs medical teams to the treatment the person is willing or not willing to have (or the Substitute Decision Maker (SDM) is involved), it becomes clear that both patients (or SDMs) and healthcare providers would benefit from this information. However, while this website includes a great deal of helpful information, the individual healthcare provider needs to access the resources in a way that supports their professional practice. It is not part of a prescribed curriculum for healthcare providers nor a standard part of regular conversations in discussions held between primary care providers and patients during routine visits.
Person-Centred Decision-Making: Documenting Goals of Care Discussions

Advance Care Planning (ACP) differs from Goals of Care (GOC) Discussions. The purpose of ACP is to prepare people and their SDMs for future decision-making. ACP is not consent for future care. (for more information about how to help patients with ACP, see Speak Up Campaign).

Model of a Goals of Care Discussion

PREPARE yourself
- Start by knowing all available treatments, including the burden of the treatment, its risks and likely benefits.
- Think about how you are feeling about the conversation and spend a moment to prepare yourself.
- Next, leave your agenda at the door — you are there to help a patient make decisions — not convince them of your decision. Once you have understood their needs, understanding, values and goals, you will be in a better position to use your medical expertise to recommend a plan.

Explore your patient's ILLNESS UNDERSTANDING
- Explore what your patient knows and thinks about her illness and future. This step requires that you listen closely, ask questions to clarify and explore and use empathic reflections to prompt your patient to continue.
- Some patients will seem to have very little illness understanding initially, but with time and gentle enquiry, you will discover that your patient does in fact know a lot about their illness. Achieving a full illness understanding may take several discussions and may require emotional support.
- The most important thing to do is to listen and refrain from speaking — especially when the patient is thinking.
- Even if time is short (emergency decision to be made), spending a few minutes at this step will often provide information that makes all the next steps easier and quicker.

“I'm worried about your father – he is quite ill, and we may have to make some decisions very soon. But before that, tell me what you know about his cancer...”

For patient-centred decision-making to be fully realized, it would require information like this to be part of the training of healthcare providers. Ideally, when a health crisis occurs,
patients will have already had a documented conversation stating their ACP that expresses their values, wishes, or preferences for their end-of-life, and they will have discussed these with their family, caregivers or SDM. Having these discussions early can direct the goals of care conversations into the present circumstances the person is experiencing that guide the healthcare team.

2.1.3 Patient-Healthcare Provider Relationship

The importance of the physician-patient relationship has been documented since approximately 1850 B.C.E. in ancient Egypt (Ritner, 2000). Among the various healthcare activities, physicians have routinely made life-and-death decisions with and for their patients. By 200 A.D., Greek physician and philosopher Galen -- a follower of Hippocrates -- stipulated that physicians ought to “know all parts of philosophy: the logical, the physical and the ethical” (Jonsen, 2000, p. 10) but made no mention of the patient. By the fifth century, revived Hippocratic methods constructed the patient and physician relationship in moral terms: a physician should be a “gentleman” when around their patients, which in those social times meant to be “moral and upright” (p. 6). Historically, in Western cultures, medical knowledge was produced and held primarily by men, privileged with the ability to study and learn. Physicians routinely attended patients in their homes, often assisted by women or female children who followed their directions to prepare or apply treatments. Caregivers participating in caring for their loved ones were ordinary and necessary. Activities included caring for the seriously ill and dying in the home. Over time, as family members moved further away from home in search of work (Imogie, 2000) and new knowledge emerged about the need for sterile conditions to limit the spread of disease or reduce infection, hospitals and clinics emerged as the physical places where medical care and, eventually, end-of-life care took place. Removing those suffering from illness and dying from home away from family and friends had the unintended consequence of robbing subsequent generations of the opportunity to see death as a natural, normal, albeit difficult part of life (Imogie, 2000). The institutionalization of “dying” explicitly transferred the embodied knowledge of end-of-life care outside the family and the home to the institution (e.g., hospital, long-term care facility).
2.1.4 Patient-centred Care

As medical education was formalized over the last century, physician training has included content learning, developing the capacity for understanding and communication, and applying evidence-based medicine (Jonsen, 2000). More recently, theories of patient care have emerged in the literature and in practice. The patient-centred model appeared in the 1990s, beginning with a call to better educate patients about their treatments, treatment goals, and rights as a patient. Until then, patients’ participatory needs in decision-making processes were rarely considered (Hoving et al., 2010). While the goals of the patient-centred model were progressive, they located problems with understanding medical communication as a deficit in the patient primarily. Calls for health literacy became popular, with “literacy” defined as the extent to which patients could read/listen/understand/follow the advice of a healthcare team (Donelle & Rootman, 2021; Rootman & Gordon-El Bihbety, 2008). As information became more widely available via the Internet, the patient-physician dialogue became more complex. Healthcare providers had to consider how their professional discourse was sometimes inaccessible to patients or contend with patients accessing incorrect or decontextualized information online. At other times, they interacted with well-educated and resourceful patients who might bring new information to them.

In this continually changing context, the patient-healthcare provider relationship has continued to evolve in response to several factors: bio-medical advances leading to longer life expectancy, an ageing population with increased co-morbidities, more educated clients, a rise in well-respected online patient advocacy groups, and differences in expectations based on cultural diversity (Hoving et al., 2010). Healthcare providers have become increasingly consultative as healthcare expertise has progressively specialized in serious illness and disease, and patient-centred theories have evolved. Parallel conversations began to occur, promoting the use of healthcare teams to provide more care in the home rather than the hospital (Hoving et al., 2010). Part of this shift resulted from the introduction of advanced practice nursing in the 1960s. The introduction of the role of nurse practitioners (NP) into primary care roles helped address the shortage of physicians in remote and rural areas, which allowed for better patient care (Ellis & Morrison, 2010; Kaasalainen et al., 2010; Malko & Huckfeldt, 2017).
Nurses’ contributions and comprehensive responsibilities are essential to patient-centred care (Canadian Nurses Association, 2021). In particular, the nurse practitioner (NP) was created to expand nurses’ roles in healthcare settings into an “extended scope of practice that combines nursing (wellness activities) and medicine (disease diagnosis and treatment) …” (Hurlock-Chorostecki et al., 2013, p. 501). This transitional role helped to alleviate and “reorganize health service delivery, particularly in the primary care sector and in the development of home and community-based care options” (MacDonald-Renz & Bard, 2010, p. 8). As part of the healthcare team, a nurse’s shared goal is to continue or improve outcomes for the patient through interdisciplinary participation (Fewster-Thuente & Veslor-Friedrich, 2008).

A contemporary version of patient-centred care allows for a collaboration of knowledge to create healthcare plans jointly between the patient and their healthcare team. The awareness that grows from the interactions between healthcare providers and patients can develop embodied knowledge that emerges from these relationships (Campbell & Angeli, 2019; Ellingson, 2006). Shared experiences and understandings provide opportunities to learn together, allow for meaningful, informed decisions, and constitute “our most basic way of being in, and engaging with, our surroundings in a deep visceral manner” (Johnson, 2015, p. 1). Patients and their caregivers increasingly expect to collaborate in their healthcare plans within this relationship.

2.2 Selected Topics in End-of-Life Care

2.2.1 End-of-life (EOL)

In 2002, Peter Singer and Kerry Bowman questioned the calibre of end-of-life care “as a health system problem…” given the need for a higher standard of information and “quality end-of-life care” (pp 0-1). In 2023, questions remain about whether the quality of EOL care has improved, whether it is still a public health and health system problem, or how much better the information has become. Communication between healthcare providers, patients, and their caregivers is the most critical component of EOL decision-making (Murali, 2020). Attending to the communication about EOL early allows decision-making by healthcare providers to include the values and wishes of the patient,
thereby promoting “respect for the patient as a person” (Tanaka Gutiez et al., 2023, p. 636). Having a good death seems to rely on how the dying is perceived by the person with a limited life expectancy (Toscani et al. 2003). The influence of this perspective is mainly based on the person’s social milieu: “End-of-life decisions are influenced by individuals’ culture, religion and geographical location” (Tanaka Gutiez et al., 2023, p. 636). The perceptions of those around them also influence how they see appropriate EOL care for a good death. Research suggests that most of the communication and explanation about EOL decision-making happens with nurses (Bach et al., 2009) even though “the physician is the major decision maker in the end-of-life process” (Thelen, 2005, p. 29). Interdisciplinary approaches among healthcare providers are critical when making EOL decisions with the patient and their caregivers. Tanaka Gutiez et al. (2023) explained that “the transition from active, invasive interventions to comfort care for critical care patients is often fraught with misunderstandings, conflict and moral distress” (p. 636). The change in this purpose of care with interventions, to switch from active treatment to comfort care, would be challenging if there were no previous conversations about the patient's values and wishes. In many cases, when there is no EOL plan, patients undergo active or aggressive treatments up until the patient's death (Middlewood et al., 2001).

2.2.2 Palliative Care

A palliative care approach can improve the quality of life for those facing terminal illness. The World Health Organization states that palliative care is a human right, but research worldwide states that only 14% of patients receive it when needed (2020). Numerous studies show how introducing palliative care early benefits patients (Chochinov et al., 2016; Quill & Abernethy, 2013; Tanzi et al., 2022). Some argue there may be a lack of understanding about the differences between palliative care and hospice or a desire “to avoid uncomfortable conversations and emotions” (Schmit et al., 2016, p. 2). One challenge healthcare providers face is when to discuss palliative care or make a palliative care referral with the patient and their caregivers. Those without a cancer diagnosis, such as the elderly or those with a life-limiting illness, may not think of themselves as terminally ill (Chochinov et al., 2016). Some believe palliative care is only available to those dying imminently or those with a cancer diagnosis. When palliative
care is introduced with a cancer diagnosis, it appears to be more acceptable to talk about it because it is intended to improve the quality of life during treatment or to manage symptoms (Partridge et al., 2014). However, palliative care is also warranted for chronic pain and symptom management.

Dr. Susan MacDonald explains that palliative care is not just for the active dying at end-of-life. She traces the dramatic changes in palliative care over the past twenty years and points to its usefulness for pain and symptom management, spiritual, emotional, financial, and psycho-social support. These conversations focus on managing a person’s quality of life rather than waiting until a crisis (Canadian Virtual Hospice, 2017).

However, without a thorough understanding of what palliative care offers and ongoing conversations about ACP, the patient and healthcare provider may not have formed the required relationship and trust. In this context, a suggestion to receive palliative care could lead patients to believe that they are at the end of their lives and that the healthcare provider is giving up on them instead of working to improve their quality of life.

Although palliative care originated and was introduced to care for dying cancer patients, healthcare teams are now identifying how this type of end-of-life care can be implemented for those with chronic conditions earlier in their health trajectory (Sawatzky et al., 2016). Re-educating the public about the extended application of a palliative care approach is needed alongside healthcare provider education that includes “undergraduate and postgraduate training and continuing professional development (CPD) for those already in practice” (Pereira et al., 2021, p. 1).

People are living longer, and as “Baby Boomers” (those born between 1955 and 1964) age and serious chronic progressive illnesses increase, there will be further pressure on the healthcare system (Howard et al., 2023; Quill et al., 2013). Palliative medicine was not considered a specialty in Canada before 2016. However, in 2015, after a family medicine residency was completed, a one-year residency palliative care certificate was offered (Howard et al., 2023). The College of Family Physicians of Canada recognized the need for enhanced primary care and specialist skills (Howard et al., 2023). The idea was that primary healthcare providers with basic palliative care training could provide a palliative care approach for those patients with “less complex needs” (p. 29) within their communities.
2.2.3 Thanatology

Thanatology is “the study of death, dying, grief and loss” (Chapple et al., 2017, p. 118). Robert Kastenbaum (2004) also suggested that thanatology is “the study of life—with death left in” (p. 19). Thanatology emerged in mainstream society when societal adaptations and attitudes towards death and dying started to shift and change with the advent of Dame Cicely Saunders’s hospice and the conception of patient advocacy (1963) and patient-centred care (Hoving et al., 2010). Pop culture also helped expand the understanding of thanatology to reach people through media with reports of wars far from home and eventually showing up in television shows, movies, music, print media, recreation, and jokes with death and dying in some components (Durkin, 2003).

To re-normalize death, dying, and bereavement, Swiss sociologist Bernard Crettaz created Café Mortel in 2004, where people could speak freely about any topic on death in a relaxed setting. The effort to normalize talking about death became so popular that it generated a global movement and was renamed The Death Café. People gather in Death Cafés to speak about any topics surrounding death, dying and bereavement in an open but casual environment (Morgan, 2017). Participants at these cafes expressed that having a conversation about death and dying has been made easier considering the efforts of resources and the increased availability of public speaking forums. Normalizing these conversations, especially for people not exposed to death (Imogie, 2000), was one of the goals. Educating people about death, dying, and bereavement moves beyond a formal classroom to achieve competencies (Nguyen, 2021) and includes more informal or unplanned conversations and interactions with family, friends, and social media (Corr et al., 2018). Corr et al. (2018) believe there are four dimensions related to teaching death, dying, and bereavement education includes: “what people know, how they feel, how they behave, and what they value” (p. 11). Practically speaking, death education requires active participation for the student to reflect, be vulnerable, bring a willingness to see resiliency in loss and develop the ability to move through these elements and, as a result, make sense of death and, in turn, be available for those who may need to discuss (Morgan, 1997).

Thanatology theories are not one-size-fits-all. Just like grief, they are as distinct, diverse, and unique as the individuals researched to create these theories, so there is not just one
theory. As a result, many thanatology theories in the literature on death loss can be comparable to non-death losses despite not being as evidence-based (Chapple et al., 2017). However, given that many thanatology theories have been written with death loss in mind, death-loss theories appear more available and associated with bereavement and grief than non-death losses, which can address losses that may happen before a person’s death. Realistically, bereavement and grief are present in non-death losses, especially when a patient first hears their diagnosis of a non-malignant serious illness or a life-limiting disease. Dr. Katherine Shear (2015) described bereavement as “the experience of losing a loved one (to death); and grief, which is the response to bereavement” (p. 153) that is different for everyone.

As Zisook and Shear (2009) pointed out, grieving is not a static state but a process that ebbs and flows. This process involves shifting one’s focus between the harsh reality of death and other aspects of life. This is a difficult journey that is necessary for healing and moving forward. How grief manifests for the dying person and those who love them depends on those attachments, relationship bonds, and assumptive world views (Janoff-Bulman, 1989). Coping with bereavement can oscillate between the everyday experiences between loss-oriented and restoration-oriented processing (Stroebe & Schut, 1999).

Anticipatory grief (Lindemann, 1963), anticipating the loss, is an example of a non-death loss. The nature of a death-denying society also may add to why palliative medicine only became legitimized as a sub-specialty of medicine in 2013 (Mount, 2021) and why talking about dying is difficult for so many (Spitzenstatter & Schnell, 2020). More readily available theories include mourning tasks that outline four tasks associated with processing loss (Worden, 2018). Meaning making is about reconstructing and redefining ways to engage with the world people lived in before their loss occurred (Neimeyer, 2001). People can experience ambiguous loss in two ways: a physical absence and a psychological presence; for example, when a person is physically missing and their loved ones are waiting for their return, they are psychologically present. The other ambiguous loss occurs when there is a physical presence but a psychological absence, such as dementia or addiction (Boss, 2010). But when grieving is perpetuated by a person’s inability to adapt to the loss and has a negative impact, it can be called complicated grief.
(Shear, 2015). While this list is not exhaustive, Chapter 4 will discuss some salient theories grounded in the data in greater detail.

2.3 Legislative Change, Training and Available Support

2.3.1 Advance Care Planning

According to Taneja et al. (2019), Advance Care Planning (ACP) intends to document and guide medical decision-making powers given to the Substitute Decision Maker (SDM) if the patient cannot speak for themselves. The need for guidance was reiterated in a recent grief webinar series (Dying with Dignity, April 2021) when speakers pointed out that conversations about death and dying need to start earlier and that awareness should be brought into medical education. The lack of prior physician-patient relationships, context, beliefs, and an understanding of the patient’s wishes leaves healthcare providers inadequately positioned to guide decisions that can best address their patient’s values and wishes if they are not known (Chochinov et al., 2020). Little or no prior knowledge of goals of care, ACP, MAiD, or palliative care often leads people in crisis to turn to the healthcare team (in particular to physicians, surgeons, residents, nurses, and social workers) to provide the answers about “what to do”. Anyone can have these conversations, but not everyone can have these conversations well.

As noted with the ACPC website, there are increasing supports (many online) available for the public who may wish to learn more. Free access to education and training is open for all Canadians seeking the opportunity to enter hospice palliative care at the Canadian Hospice Palliative Care Association (CHPCA, www.chpca.ca, 2023), and Canadian Virtual Hospice (CVH, https://www.virtualhospice.ca, 2023). Resources for ACP are available to all on a website called Advance Care Planning Canada (www.advancecareplanning.ca, 2023; see Figure 2).
Despite free access to resources on how to have ACP conversations and the documents needed, only some Canadians are engaging with them (Downar, 2018). While research has produced a great deal of information to help people understand how to have these difficult conversations, many take the approach that, if nothing is currently wrong with them, “why worry about it?” (Carrese et al., 2002, p. 3). This belief could reflect our culture's “death denial” (Tucker, 2009) or a lack of public knowledge and understanding of the resources and why people should engage with them early. When deciding what someone values and wishes at their end-of-life, Figure 2 offers an overview for individuals to consider in the absence of a crisis in the comfort of their home. The organization helps the public to understand how completing ACP while healthy and of sound mind can be a gift to their healthcare providers and SDMs.
2.3.2 Medical Assistance in Dying (MAiD)

Politically, Canada has shifted its thinking about “the right to die” significantly. In June 2016, the Canadian Government introduced Bill C-14, an amendment to the criminal code decriminalizing medically assisted death. Medical Assistance in Dying (MAiD) allows a physician or nurse practitioner to actively administer for a patient (or support a patient to self-administer) a substance that causes their death (Canada, 2016). Bill C-7 was passed in March 2021 to update the law to include people whose death was in the reasonably foreseeable future and to consider the eligibility of those who have mental illness (Government of Canada, 2021).

On March 9, 2023, Bill C-39 was introduced to extend the exclusion of eligibility for those persons seeking MAiD solely due to mental illness until March 17, 2024. This extension gives more time for all parties to consider factors associated with the implications of this Bill.

These Bills and the extension of Bill C-39 have forever changed Canada's political and healthcare landscape, given the resulting polarization of public and professional opinion over a person’s right to die. While some favour one’s right to die, the opposition’s concern is that if the patient’s values do not align with the healthcare provider’s, unconscious bias may happen when MAiD is offered to the patient (Chochinov, 2022). In this case, a healthcare provider may declare conscientious objection and not be involved further with the patient’s interest in MAiD. Still, they must also provide the patient with further information to access the services (Heilman & Trothen, 2020). The perspectives surrounding MAiD are essential for healthcare providers to understand when speaking with patients and their caregivers. In addition, understanding the legal and ethical considerations also supports the shared goals of providing the best patient-centred care according to the patient’s values and wishes when having end-of-life conversations.

2.3.3 Role of Substitute Decision Maker (SDM)

The Canadian Substitute Decisions Act 1992 recognizes that someone other than the patient can legally speak on their behalf regarding property or personal care if they lack
the capacity or cannot make decisions for their care (Substitute Decisions Act, 1992). In the healthcare context, substitute decision makers (SDMs) are called upon to provide or refuse consent for treatment on behalf of the ill person. This is a legally binding role, and the responsibility can weigh heavily on the SDM, especially when they have not had a prior conversation with the patient about their wishes. SDMs are called upon when a patient is incapacitated, and this is especially true in the Intensive Care Unit (ICU), where SDMs feel supported by the healthcare providers and can be provided with complete medical information helpful during decision-making (Heyland et al., 2003; Tan & Manca, 2013). Although healthcare providers may be able to offer active treatments to a patient, the healthcare provider’s assessment may be that the treatment option would not benefit the patient or, is not medically appropriate or is considered medically futile. As a result, they might refuse active treatment (Downar et al., 2019).

Although the healthcare provider and the SDMs have the patient’s best interest, challenges can arise in these complex situations. During these moments, ethics and the legal system can become part of a patient’s story (see, for example, Wawrzyniak v. Livingstone, 2019). Conflicts between the two perspectives can conjure up impressions of a bad death versus a good death, especially when the SDM holds different expectations or understandings of the patient’s health (Tan & Manca, 2013). However, when there is adequate time to build trust, share information, and create shared decision-making between the healthcare provider and the SDM, expectations may be met collaboratively (Tan & Manca, 2013).

2.3.4 Available Courses and Tools

In this section, there is a sampling of courses and assessment tools that the participants mentioned or available to healthcare providers.

In Canada, Pallium Canada (www.pallium.ca) has created education courses to incorporate a palliative care approach into the healthcare provider’s practice (Seow et al., 2023). Considering that these courses are not part of the curriculum and are taken by the healthcare provider on their own time, there is a need to create more virtual education courses to serve a national audience (Seow et al., 2023). Out of necessity due to COVID-19, in-person training needed to be adapted and moved to online programs to
accommodate learning for healthcare providers (Mehta et al., 2020). An effective strategy is intentionally integrating these tools into Continuing Medical Education courses, which are mandatory for ongoing professional development.

With best patient practices in mind when caring for patients with a life-limiting illness, healthcare providers rely on palliative care screening tools based on numeric scores. All screening tools consider the patient’s care and “their emotional, physical, and spiritual needs” (Churchill et al., 2020, p. 327).

Some of the most commonly utilized tools include:

SPIKES is a six-step protocol for breaking bad news. The acronym refers to SETTING up an interview, the PERCEPTION the patient has of their illness, INVITATION for the patient to consider how they want to hear the news, giving KNOWLEDGE to the patient, acknowledging the patient’s EMOTION with empathy, STRATEGY AND SUMMARY with a clear plan (Baile et al., 2000; Buckman, 1992).

The Edmonton Symptom Assessment System (ESAS) is a paper given to in-patients twice a day who are already in palliative care, using analog scales “to indicate the levels of pain, activity, nausea, depression, anxiety, drowsiness, appetite, and sensation of well-being” (Bruera et al., 1991, p. 6). This is translated as a symptom distress score, and, depending on symptoms, the patient may also be assessed further. Since 1991, this tool, with some minor additions to represent the patient more clearly, continues to be used for its screening and longitudinal monitoring of patients (Hui and Bruera, 2017).

The Serious Illness Conversation Guide: The Canadian Virtual Hospice website has numerous conversation guides for the public and healthcare providers. This guide helps guide conversations between healthcare providers and patients about illness, prognosis, and goals of care (Ariadne Labs, 2021; Canadian Virtual Hospice, 2023).

Heart to Heart is a one-day in-person retreat helping healthcare providers with their communication skills when caring for patients with advanced illnesses (Rehabilitation Sciences, University of Toronto, 2023). CAPACITI training program (pilot study) is a virtual training program with 12-1-hour lessons for primary healthcare providers to learn how to recognize and provide an early palliative approach to care (Seow et al., 2023).
Learning Essential Approaches to Palliative Care (LEAP) – Pallium Canada has many courses available for healthcare providers in all settings (Pallium Canada, 2023). Patient Dignity Therapy Inventory is a list of twenty-five questions first introduced in palliative care for patients or their caregivers to help measure and reduce psychological suffering at end-of-life. It also serves as a legacy meaning making document (Chochinov et al., 2008), and has since been translated into numerous languages and expanded to include those facing serious illness (Chochinov, 2022).

The literature review has emphasized and highlighted the importance of effective communication and the healthcare needs of patients and caregivers at diagnosis, prognosis, and the transition to end-of-life. Providing patient-centred care includes a clear understanding of courses and assessment tools to improve communication and guarantee excellent care. Healthcare providers are not all equally trained in these conversations. Creating a standard of care in these conversations will effectively promote better patient-centric care within the healthcare facility.

2.3.5 Artificial Intelligence (AI) in Medicine

One of the participants indicated an issue of how AI may be changing end-of-life conversations between patients and healthcare providers. Using AI in medicine was not something I was aware of, nor was it suggested in other literature I had searched. This compelled me to also pull in some of the literature on this, which I had not thought would be part of this conversation.

In 2018, the Royal College of Physicians and Surgeons created a task force to help medical professionals lay the groundwork for the incoming AI and digital technologies in the training and delivery of care. One of the main findings from their report assured the public that: “AI and emerging digital technologies will not replace a physician’s presence, intuition, creativity, judgment and compassion” (Task Force Report on Artificial Intelligence and Emerging Digital Technologies, 2020, p. 3). But what it could do is help: “in diagnosis, clinical decision-making, training, early prediction and prevention, treatment and personalized medicine” (p. 4). In late November 2022, ChatGPT took the world by storm, prompting a call for papers on how this will inform medical education (Eysenbach, 2023). Machine Learning (ML) has already been
developed to “mimic (and perhaps, exceed) human capabilities” (Cipriano, 2022, p. 147). While AI is not new in medicine, its use is emerging in ways that demonstrate an ability to analyze data that also supports decision-making (Cipriano, 2022). Still, its major limitation is how the decision-making is given with no personal information on the patient. Still, much is unknown regarding how AI will benefit the patient, especially without understanding patient values, goals, wishes, culture, and decision-making.

2.4 Formal Preparation and Training of Healthcare Providers

2.4.1 Death and Dying in Medical Education Curriculum

In 1980, Perez et al. wrote about how the subject of death and dying was finally being published more in academic medical journals. This highlighted a need for these topics to be in the medical curriculum. Still, only five Canadian medical schools offered this information through a four-hour seminar. Today, medical students feel that learning about death and dying is equally essential when learning about prolonging life (Wynter & Brignall, 2020). Their belief in learning about death and dying in the medical school curriculum prepares them to approach death and dying conversations “without the worry of upsetting people at a time they will remember for the rest of their lives” (Wynter & Brignall, 2020, p. 1066), can better prepare them for their future careers.

The competencies must be discussed to move successfully through a medical education program and professional training. The Canadian Society of Palliative Care Physicians (2018) (CSPCP) recognized that physicians are not adequately prepared to achieve these competencies, which is in line with what Downar reported in 2018 when he stated that “the existing resources are not being accessed sufficiently” (p. 58). These anecdotes became apparent as the pandemic lingered, and medical students were insufficiently prepared “emotionally and mentally for caring of their dying patients and families” (Ho et al., 2020, p. 2). When patients need medical attention, they tell a story and try to convey meaning to the physician through their narrative of what they think is going on and what they believe the physician needs to hear (Coulehan, 2003). The priorities of
diagnosing and making sense of the narrative being shared with the healthcare provider and offering medical interventions must coincide with the need to be present with the patient and listen to their story (Coles, 1989).

Many articles about death and dying education use a cancer lens (Hui et al., 2022; Partridge et al., 2014; Tanzi et al., 2022; Zimmerman et al., 2023) and offer less about life-threatening chronic progressive illness trajectories. My research found no articles regarding death and dying education for those who may have sudden deaths and how important it would be for the healthcare team to know how to support those people in the same ways as people in palliative care. What emerged is how siloed these areas are. Even though the recommendations have been made to have more interdisciplinary overlaps (Visser et al., 2021), these recommendations have yet to become part of regular interdisciplinary programming. Only palliative care articles were populated in searches for the death and dying curriculum. Much of the literature focused on the competency of diagnosing and medically helping the patient rather than assisting them through the psycho-social aspects of the illness experience.

2.4.2 Death and Dying in Nurse-Practitioner Curriculum

The search for death education in nurse practitioner curriculum or death and dying in nurse practitioner curriculum education yielded limited results. However, Downe-Wambolt and Tamlyn (1997) published an article on the subject, albeit with a limited sample size through questionnaires. Interestingly, the article found that learning happened through patient experience primarily, and Elizabeth Kubler-Ross was cited more often than Cicely Saunders in Canadian nursing and medical programs. In line with searching for articles in medical education curriculum on death and dying, the primary focus in nurse practitioner curriculum was on palliative care education (Kriebel-Gasparro and Doll-Shaw, 2017; Wheeler, 2016), or both palliative care and MAiD (Gibbons et al., 2022). These articles focused on simulation sessions of didactic learning in clinical settings (Kriebel-Gasparro & Doll-Shaw, 2017), with a few hours focused on instruction (Jensen-Seaman & Hebert, 2016). According to the College of Nurses of Ontario (2018), in the most recent competencies for nurse practitioners, the expectation of education is
placed on the NP that “…includes but is not limited to educating self, clients, the community, and members of the healthcare team” (p. 7).

2.5 Summary
The literature explored interconnected themes related to patient and healthcare provider relationship, patient-centred care, the role of the substitute decision maker, difficult conversations, goals of care, advance care planning, MAiD, palliative care, EOL, thanatology, death and dying in medical education curriculum, courses and tools, and artificial intelligence in medicine. Increasing attention has been paid to patient-centred care, engaging conversations, and developing collaborative relationships. Most of the literature referred to studies of patients admitted to the hospital. There were no studies that looked at having end-of-life conversations with out-patients. In some of the literature, palliative care provisions were more often provided to a patient with a cancer diagnosis than to a person with a chronic progressive illness. Many articles also noted that palliative care is offered far later in the stages of a patient’s illness than used for pain symptom management earlier in their health trajectory. While multiple educational resources are available to healthcare providers to support how they learn to have these challenging conversations or certify as palliative care providers, the onus is on the individual to locate and engage in learning.

The literature did not provide examples of interdisciplinary knowledge building between thanatology and medical education for healthcare providers as part of their initial and specialized training before practice. With the emergence of AI in healthcare, it is too early to know the role and effect AI will have on patient care with end-of-life conversations and care. Based on these gaps and the call for more research, it will be imperative to continue studying AI’s impact on this area. The review of the literature pointed to three main issues:

- Formalized training is limited to either the initial undergrad training or as part of an expected post-graduate qualification in their continued professional training;

- There is a need for a theoretical bridge to bring the recent knowledge of death, dying, and grief education into the curricular culture of medicine and healthcare;
• Thanatology is well-positioned to serve as the theoretical bridge, combining all the discussions reviewed in the literature with both an approach and resources supporting healthcare providers, patients, and caregivers.

The study's design will provide an opportunity to learn from the healthcare providers what knowledge is currently informing their practice, what they express as needs and where they identify gaps.
Chapter 3 Methodology: Constructivist Grounded Theory (CGT)

This chapter describes the CGT design used to explore the participants' experiences during end-of-life conversations. The decision of which methodology to use is bound up by decisions that relate to the purpose of the study, intended audiences, theoretical imperatives, and desired outcomes. Since my research focuses on an under-theorized area exploring relational work, the methodological approach needed to capture and document its findings in ways that can generate new theories and provide insights into improving pedagogical support for training healthcare providers who have end-of-life conversations. Constructivist Grounded Theory (CGT) was selected for its fit with this study. CGT “locates the research process and product in historical, social, and situational conditions” (Charmaz, 2017, p. 34). The study took place over seven months, from April 2022 to October 2022, during the later stages of a global pandemic. Participants included physicians, surgeons, residents (postgraduate year [PGY] 3 and above), and nurse practitioners. Recruitment, participants, methods, data collection strategies, and results are described in this chapter.

3 Introduction to Constructivist Grounded Theory

This qualitative study used Constructivist Grounded Theory (CGT) to explore healthcare provider's experiences with patients during end-of-life conversations. Ontologically, CGT is a methodology that acknowledges that everyone brings different personal and social experiences from their history(ies) to the research. The participants have varied professional and personal experiences, values, and knowledge. Epistemologically, this study honours and accounts for multiple realities, making space to construct new knowledge.

CGT assumes that we, the researcher, as opposed to the researcher in Grounded Theory (Glaser & Strauss, 1967), are very much embedded in the research. Our reflexivity is critical because it helps us acknowledge where we come from, who we are and what we bring. Using reflexivity can help us enhance the rigor so that we not only bring our assumptions and biases and interpret everything from our lens, but we do acknowledge it
is impossible not to. If someone else were doing the same interview, they would ask different questions, probe differently, and interpret it differently. The interaction between the participants and their environment is central to this methodology. Moreover, the researcher's reflexivity in co-creating the knowledge produced during the research process, combined with the interaction between participants and their environment, leads to a relationship in which the researcher demonstrates transparency and openness in coming to understand differently (Charmaz, 2014). The researcher must reposition and probe participants’ “values, beliefs, and ideologies” (Mills & Francis, 2006, p. 26). Through this probing, the researcher “embeds the narrative of the participants in the final research outcome” through analysis and text for the “reconstruction of experience and meaning” (p. 31).

Reflective practice, a term refined by Donald Schön (1983), refers to an activity in professional practice when one draws “on multiple sources and conceptions of knowledge – before, after and in the midst of professional actions” (Ng et al., 2015, p. 462). Reflective learning is embodied in medical training, and technical rationale (Schön, 1983) is not the only source of knowledge in medical training.

3.1. Constructivist Grounded Theory’s Roots

Grounded Theory emerged from the field of sociology in the 1960s. Glaser and Strauss (1967) introduced Grounded Theory methodology to generate theory from empirical data. Their concern acknowledged that many studies up until that point tested theories, but they were more interested in generating theories. Many of grounded theory’s core principles remain embedded in the procedures of CGT: “theoretical sampling; constant comparative analysis of data; elaboration of memos; differences between substantive theory and formal theory” (Santos et al., 2018, p. 2). Building on those principles, CGT makes space for more critical inquiry into the research location, the researcher's positionality, transparency of the processes, and clear documentation through tools such as memo writing (Charmaz, 2017). CGT promotes social processes where knowledge is constructed between participant and researcher (Charmaz & Keller, 2016).
3.2. Characteristics of Constructivist Grounded Theory

3.2.1. Pragmatism

The shift from Grounded Theory Method (GTM) to Constructivist Grounded Theory (CGT) was partly an attempt to contend with critiques about the “emergence” of themes and to both acknowledge and make explicit the genuine role that researchers and participants play in advancing interpretations. Key among the responses to these concerns was an issue that first emerged in John Dewey’s (1917) work on pragmatism, where he argued that knowledge is temporal, partial, and situated and that people can judge its usefulness, in part, by its applicability to the community it is intended to address. Pragmatism offers a practical approach to working toward critical qualitative inquiry. A pragmatic CGT approach interrogates “the taken-for-granted methodological individualism” (Charmaz, 2017, p. 34), asking researchers to take a reflexive stance “to scrutinize their data, actions, and nascent analyses” (p. 34) to raise understanding and self-awareness. One of the more frequent critiques of the original Grounded Theory Method lay in the juxtaposition to the positivist tradition, where researchers assume objectivity and do not acknowledge their privileges and positions or focus on what is happening without exploring the experiences of both participant and researcher. CGT is intentionally “reflexive” in its insistence that researchers “scrutinize their data, actions, and analyses” (p. 34) and their “position, privileges, and priorities” (p. 36), all the while assessing how this affects our analysis and our participants. In this way, CGT brings a criticality to all experiences, allowing interactions between participant and researcher to produce new knowledge through an iterative, systematic coding and analysis process (Charmaz, 2017), leading to a more rigorous exchange of experiences.

3.2.2. Reflective Practice

A CGT approach aligns with exploring the experiences of how the participants engaged in conversations they have had personally or professionally concerning end-of-life care, death, and dying. To do critical qualitative work like CGT, researchers are called upon to develop and maintain vigilant subjectivity (DeLuca, 2000) throughout the study. They must “detect and dissect their worldviews, language, and meanings revealing how they
enter their research in ways they had not previously realised…their tacit individualism becomes visible” (Charmaz, 2017, p. 36). As researchers engage with their participants, both need to be aware of the positions and roles each holds, as their “ways of knowing are embedded in these locations” (p. 36). The latitude that CGT offers: “rethinking and redirecting the research process” (p. 36), is part of the experience and helps to address any forms of “oppression, inequity, and injustice” (p. 35) in roles, social or cultural positioning, age, level of experience and so on. Sensitivity is required for a researcher in this field, where conversations address experiences and beliefs surrounding death and dying (Charmaz, 2017). Without reflexivity or sensitivity, the participant may feel uncomfortable sharing vulnerable experiences.

Despite our best efforts to be present and reflective in conversations, the participant and researcher also must consider that “the theories they espouse are not the theories they use” (Argyris, 1976, p. 44). In the context of this research, this means that how a participant behaves in the world according to their theory in action may not always result in how they portray it. However, with an openness for further learning, Argyris (1976) described how the “findings are relevant to the design of re-education activities at all levels of our society” (p. 43). Bringing the discrepancies between researchers’ beliefs and their practice to a level of conscious awareness presents an opportunity for growth and further learning.

If the researcher is unaware of their positions and values before the research, they ask the participants very different questions. Charmaz (2014) contended that “initial sampling in grounded theory gets you started; theoretical sampling guides where you go” (p. 197). Questions build on what and how and then lead to why. CGT intentionally uses open-ended questions to pursue a more profound and active understanding before and during the research process to allow “discoveries along the way” (Charmaz, 2017, p. 35). After the initial questions have been answered or discussed, new thoughts from the researcher and the participants may arise as the “researchers’ interrogation of data and the context in which these data are situated” (p. 40). These uses of CGT tools to study temporality are an effort to trace researchers’ assumptions about time and actions and to map change over time at micro, meso, and macro levels of analysis (Charmaz, 2017).
As a non-clinician who brings a thanatological, feminist, and educational lens to the research, I am aware of the various discourses and the implications that diversity can have on communication in non-stressful times. To better prepare for this research, I needed to spend time immersed in the context of conversations between healthcare providers about serious or terminal illnesses. To do this, I spent the second year of my doctoral studies collaborating on a project about Advance Care Planning with Dr. Mark Goldszmidt and Dr. Ravi Taneja. The project explored patient resuscitation wishes. During this preparatory year, I recognized that I was drawing on my thanatological lens as I engaged in the analysis. While that lens was outside the scope of their project, the experience significantly informed my understanding of the role prior knowledge and understanding bring to the research process.

Figure 3 Theoretical overview

In Figure 3, while contemplating the theoretical implications of this research, women’s studies, thanatology, and education were underpinnings and informed the exploration, understanding, and collaboration between participants and researchers.

3.2.3. Situating the Researcher

Theoretical sensitivity requires that the researcher understands how their theoretical perspectives and experiences necessarily lead them to notice or attend to nuances of their participants’ words and actions (Mills et al., 2006). As a starting point, researchers can determine which theories they are most likely to draw on and be influenced by. This allows the researcher, the participants, and the reader to understand the origins of analytic insights better and allows the participants a “way in” to the discussions about the findings.
with the explicit knowledge of at least some of the operating theories informing the researcher.

Experiences with death and dying are unique and can perhaps be understood only through multiple perspectives. The three lenses I brought stimulated my thinking and analysis as I understood the data analysis with participants (Strauss & Corbin, 1998). My studies in thanatology, women’s studies, and education purposefully inform this research. This allows me to position myself and my location as a researcher to examine what thanatology might contribute to supporting participants in their training.

Consistent with CGT, it is essential to be aware of the researcher's influences on the interactions with the participants and the data.

3.3. Methods

This CGT study had two phases and four data collection strategies over seven months, starting in April 2022, with data collection completed by October 2022. One of the research questions asks what theoretical perspectives, personal or professional experiences the participants draw on during end-of-life conversations and how they might compare to existing theories. The goal was to progressively “flow from the research question and where we go with it” (Charmaz, 2014, p. 27) to understand the participant’s perspectives and experiences.

This is precisely what it did. As the interviews developed, the questions and probing questions became more modified, purposive, and theoretical. Exploring this research question helped develop “theories-in-use” that explain, predict, and control (Argyris & Schon, 1978) to describe the professional’s use of theory in practice, then merge it with the broader set of theories. With this perspective, CGT uses an iterative approach that sees data collection, memos, identification, comparison, and the analysis of codes undergo ongoing and repeated discussion, reflection, analysis, and modification (Charmaz, 2014), which made this methodology best suited for this research.
The process of data analysis involves working with data, organizing it, breaking it down, synthesizing it, searching for patterns, discovering what is important and to be learned, and deciding what the research will tell others (Bogdan & Biklen, 1982).

3.3.1. Participant Selection using Purposive Sampling

Following approval from the Research Ethics Board at Western and Lawson Research, recruitment letters were emailed by a Clinician, a Key Informant known to the research team (Appendix F, G) from a mid-sized university hospital in southwestern Ontario. All participants were given Letters of Information and provided informed Verbal Consent before data collection (See Appendix A & B). Recruitment of participants adopted a “passive snowball” process initiated through professional networks (Cohen et al., 2007, p. 116), which increased the research sample. After two amendments, twenty participants participated in individual semi-structured interviews, and fourteen participated in follow-up second semi-structured interviews for thirty-four interviews.

The final inclusion criteria were healthcare providers who engaged in meaningful end-of-life conversations between the participant and their adult patient or in their personal experiences. The exclusion criteria were healthcare providers in pediatrics or did not speak English.
Within CGT frameworks, this study steered clear of any generalizations leading to a more transparent and profound understanding to “illuminate the questions under study” (Patton, 2002, p. 273). This sampling also helped ensure that the data being collected is rich, meaningful and reflects a diversity of perspectives. Recruiting participants who led discussions with patients about an end-of-life prognosis initially only included physicians, senior residents (PGY3-5), and nurse practitioners. After the first recruitment letter was sent from the Key Informant, I received an email from an interested resident who was PGY6 and would not have qualified for my recruitment. I sent an amendment to include residents PGY3 and above. This would be the first of two amendments my research would undergo. By June 30, 2022, my recruitment had plateaued as there were only nine participants, and more participants were needed for a rigorous study. Utilizing a snowball process, I expanded my criteria. Initially, I only included specific specialties with end-of-life conversations with patients and their caregivers. In July 2022, I completed a second amendment to include surgeons and deleted the specialty groups to include any specialties engaging in end-of-life conversations. This added 11 more participants to the research, providing further depth and breadth of experiences shared. Identifying gender was not part of this study, nor was gender bias a prominent finding. However, years of practice and specialty played essential roles in each participant’s experiences learning from patient interactions. The twenty participants had a wide variety of years in practice, and the focus was on sharing most of their learning on how to have meaningful conversations. The conversations included conversations about their education and clinical practice. The participants included 1 PGY6 physician – internal medicine, cardiology; 1 PGY3 physician - emergency; 2 nurse practitioners – neuromuscular, emergency, ICU; 11 physicians – emergency, ICU, palliative care, critical care, trauma, obstetrics, NICU, nephrology, gerontology; 5 surgeons – trauma care, acute care, general, and oncology. The experiences of these participants from different professional backgrounds provided a more profound understanding during these semi-structured interviews. I had two interviews with 14/20 of the participants, and as a result, this allowed for a degree of co-construction that is not typically possible. In a CGT study based on one interview, the co-construction is between the interviewer and the data - not with the participants. Given
that I had two interviews with more than half of the participants, this allowed something unique and different in that I could follow up with the participants and share some of the preliminary understandings from the first round of interviews. Purposive sampling from this group of people who have personal or professional experience with conversations on death and dying yielded participants who can express and share their “lived curricula” (Aoki, 1993, p. 265).

3.3.2. Interview #1

Virtual interviews were conducted privately on a password-protected encrypted computer using Western’s Corporate Zoom account. Interviews were audio-recorded and transcribed verbatim by a professional transcription service (Trint), and all files were uploaded into Western’s OneDrive. In my letter of information, I indicated that should the conversations become stressful or triggering, I could connect the participant with appropriate support services (Appendix H), and they could stop at any time or ask for the recording to be finished.

Initial individual interviews were sixty minutes long. The invitation to join this research asked the participants to share their personal and professional experiences with end-of-life conversations. Some discussions linked the participants’ personal experience with death and dying to their professional roles. The data generated through the individual interview(s) informed the refinement of the questions developed for subsequent interviews. The refinement flows from an initial coding process that documents the knowledge and experience they describe having with death and dying.

In the first set of individual interviews (Appendix C), I engaged in open-ended, semi-structured dialogue with 20 participants (Charmaz, 2014) as they described their experiences having end-of-life conversations with their patients; the process is outlined in Figure 5.
3.3.3. Interview #2

After the first set of interviews and throughout the iterative process, I returned to these initial findings to explore any evolving theories and expand upon participants’ previous answers, allowing for a deeper collaborative analysis and ensuring ample opportunity to reach the sufficiency of themes. Before our next meeting, I sent a copy of the participant's transcript for them to reflect on, comment on, change, or elaborate on before we met for our second interview to member-check (Harvey, 2015). No specific number of participants is relegated to a proper research pool as CGT suggests that saturation depends on context: “study, revise, develop your interview questions and skills” until reaching saturation (Charmaz, 2014, p. 108). I invited all 20 participants for a second interview (Appendix D), and 14 participants participated in the second interview, which was conducted and recorded on Zoom. The time allocated for the second interview depended on the participant and lasted between ten and ninety minutes.

The second interview process can be seen in Figure 6. I used theoretical sampling in the second interview by answering questions informed by the initial set of interviews. Seeing
the same person a second time allowed me to promote what I heard from other participants and have new insights and interpretations, which allowed further probing of the conversations I heard from them the first time differently.

Personal histories and experiences with death and dying and how the participants grappled with the complexity of how people understand death and dying were at the heart of each conversation. This was essential to the methods used as an iterative process. This iterative process included collecting data, analyzing using coding strategies, and constant comparison methods between sources at each step of the analysis in developing a meaningful theory about what is being researched (Charmaz, 2014). With an open mind and flexibility, I worked within this framework of personal, possibly tricky, and perhaps existential, first-time conversations and considerations.

Figure 6 Interview #2 process

3.4. Data Analysis

CGT follows some of the same Grounded Theory data collection methods and data analysis to allow for analytical questions of the gathered data (Charmaz, 2014). CGT applies a two-step process using initial coding and focused coding. Initial coding
continues the researcher's interaction with the participant during the interview process, allowing for a first-level interview analysis. Focused coding happens after studying and comparing the initial codes, watching what emerges, and creating categories for further analysis (Charmaz, 2014).

3.4.1. Initial Coding and Focused Coding

After the first interview, I started the initial coding using the GT analysis process. Codes started forming by going word by word, line by line, with gerunds to look for ideas and meanings expressed by the participant (Charmaz, 2014). Focused coding became more targeted, selective, and conceptual to explain more significant data segments (Santos, 2018). As concepts emerged more frequently, central themes remained while keeping the participant visible and connected to the experiences.

3.4.2. Theoretical Coding

With the initial and focused coding, the iterative process emerged with theoretical codes that “help theorize your data and focused codes” (Charmaz, 2014, p. 150). This is a short stop to check and see if anything emerging shows relationships between these codes as the researcher moves through the analysis. After thirty-four interviews, numerous hours, and hundreds of pages of transcriptions, twenty-one relational concepts were noted from this initial iterative process (see Figure 7).

**Figure 7 Word cloud of initial categories**
The original and lengthy list was shortened as I coded and documented the themes, topics, theories and relevant constructs. (See Table 1).

Table 1 A sample of the analytic process: From 21 categories into 3
Further quotes representing all three categories in theory building are included in Table 2.

<table>
<thead>
<tr>
<th>Prognosis</th>
<th>Breaking bad news</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I realize that it's not my fault. As one doctor always said, the patient has the disease. You can't feel responsible for that. And so, I think ultimately, at the end of the day, me breaking bad news in a kind but very honest way, like being empathetic, but also being honest is actually helpful for that patient. And that is the best thing I can do for them. I actually get people who thank me when I'm very honest when someone else hasn't been (P06, May 6, 2022)</td>
</tr>
<tr>
<td>Reflection</td>
<td>It made me reflect a lot and how I've come to where I am today. I'm not saying I'm perfect at it by any means, but how all of those experiences I've had in the past have informed me on how to best manage patients who are going through life-threatening, or life-limiting illnesses. So, it was a nice reflection for me. And I think that maybe an important difference between someone who does it well and maybe someone who doesn't do it well, is that do we have enough time to reflect? (P17, October 28, 2022)</td>
</tr>
<tr>
<td>Metaphors</td>
<td>...cancer is a funny thing. And one of my mentors explained it to patients as having dandelions in your yard. You try to pull out the dandelion, but, in the spring, there may be more. And the seed was there at the time you pulled the dandelion out and none of our tests are able to detect those seeds right now (P11, August 11, 2022)</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Goals of Care and End-of-Life Early Conversations</td>
<td>…we're overly aggressive with what we do to patients, especially elderly ones. So, my approach has been to have an end-of-life conversation much earlier in my care than I would have previously. I think as we've talked about several times in a conversation with someone who is elderly comes in. When I was a junior resident, it was just like, let’s do everything we can medically because that's what you're trained to do, that you're sort of a robot who wants to learn how to do all these things. And I think even now, it is much more at the forefront of my mind and my thoughts, even compared to some of my colleagues who are still: I just want to medically do everything I can for this patient, but I have brought the level of goals of care. What are we going to do, what’s the trajectory, [these are] higher into my conversations than previously (P05, June 10, 2022)</td>
</tr>
<tr>
<td>Reflection</td>
<td>There is one thing I was reflecting on that I think I commented on the fact that these conversations should be happening as an outpatient with the chronic care providers. But I was reflecting on how I, in my own practice, struggle with that… in a perfect world, I should be having more of these conversations. And I think I mentioned in passing that I don't do it as frequently because of time. But I was reflecting on, I also wondered it sometimes harder to see when you're in it (P19, October 18, 2022)</td>
</tr>
<tr>
<td>Interconnected</td>
<td>I think the biggest thing about my process, I think that I find helpful is to just have that conversation. I think the biggest issue is that, have that conversation in a meaningful way and not in a kind of a checkbox way, and then I think is the biggest. And so always putting palliative care and end-of-life as part of your issues-based list (P01, July 20, 2022)</td>
</tr>
</tbody>
</table>
Palliative Care

Supported

…making sure people understand that once they make their decision to be palliative or comfort care or that they get the bad news, to tell them that the team will support them through that entire process. I think it comes from an ICU background I think, not that everybody is in the ICU, of course, but there's a real and again, it comes down to language. There's a thought about withdrawal of care. And we don't withdraw care, we might be withdrawing life support or changing our goals of care, but the patients are cared for throughout their entire dying process (P14, October 4, 2022)

Holistic care

I've done baptisms at the bedside where the baby is about to die, and the parents have requested that. And so, for sure, spiritual care is part. We talk about physical, mental, social and spiritual is a part of who we are. It's looking at the patient holistically. And we care about a family (P16, October 13, 2022)

All levels of palliative care

Really if we think of palliative care as a quality-of-life lens for people that are living with serious illness, then it really should be that palliative care, whether it be specialty palliative care, primary palliative care can have involvement of the appropriate at any stage from time of diagnosis until death (P02, October 15, 2022)

Topics were collapsed and characterized, and new insights emerged. With the support of memos (See Table 2) and storying the data for cohesion and congruence, I understood that the analysis pointed to a new theoretical approach. Participants identified that the traditional approach was conducted in terms of diagnosis, treatment, and cure. Generating a prognosis and offering alternatives to active treatments were not discussed as readily when patients faced a serious progressive illness. The theoretical coding pointed to an alternative: an integrated pathway that was inclusive of the entire living cycle, including death – as a ‘goal of care’ from the outset. All the training, preparation and expectations then align with the realistic expectation that death is the natural conclusion to the life people seek to preserve.
3.4.3. Memos

Memos were written in parallel to the rest of the research process. Memo writing started as early as the beginning stages of the research project and allowed me as a researcher to be involved in the raw data and develop codes into categories earlier in the research process (Charmaz, 2014). These beginning memos are reflective and “will give you material to ponder, explore, revise, and sort” (p. 168). Watling and Lingard (2012) suggested that the process should be free and informal as researchers explore the data. As the analysis transpired, so did the memo writing, which allowed the ability to compare and explore the different code ideas, which allowed for further data-gathering (Charmaz, 2014).

Memo writing during the interviews was also beneficial when observing non-verbal cues of the participant’s responses to questions, answers, or silence. Writing a memo from the researcher’s observation of the participant allowed space to come back to the memo to develop and check it if needed (Charmaz, 2014), which was the case for many of the second interviews. In Table 2, many of these memos were taken during the interviews to note further probing questions or comments the participant brought up that I could bring up with my next participant if they experienced a similar situation.

Table 2 Selected samples of memos

<table>
<thead>
<tr>
<th>Interviews – April 18 – October 28, 2022</th>
<th>Jill’s memo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Euphemisms: passed away, lump, mass, spot</td>
<td>Direct language, “die” VS. passive language, “pass away”. What language do they mostly use when speaking to patients and SDMs (July 20, 2022)</td>
</tr>
<tr>
<td>Participants speak about moral distress, burdens, and burnout</td>
<td>Balance or self-care. What does the participant do to disconnect? (September 7, 2022)</td>
</tr>
<tr>
<td>When participants hear end-of-life discussions go poorly</td>
<td>Does participant go back to patient or family to reframe? (October 3, 2023)</td>
</tr>
<tr>
<td>Personal loss in participants lives</td>
<td>For some, the loss of their loved one informed how they had these conversations, and for one participant, it was their years of practice that informed the conversation for their loved one (September 11, 2022)</td>
</tr>
<tr>
<td>Perinatal loss</td>
<td>How do physicians talk about early term loss and how is talked about? (June 10, 2022)</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Stigma of palliative care</td>
<td>Such a loaded word for many healthcare providers, patients and their families (June 7, 2022)</td>
</tr>
<tr>
<td>Late prognosis for patient as participant reads patients chart that they are the 3rd or 4th to read their chart and they have an incurable disease, but they are still being treated to be cured and are not aware of their prognosis</td>
<td>This was a common theme with participants after first hearing about this, to which I started to ask each participant after that. Some participants said whether the news didn’t sink in, denial, or they really were not told, this was unbelievable for me to hear: “your interview changed the game for my research and the surgeon perspectives that followed” (August 5, 2022)</td>
</tr>
<tr>
<td>Always treating</td>
<td>Treatment and cure VS. stop and palliate (September 1, 2022)</td>
</tr>
<tr>
<td>How did you learn to have these conversations?</td>
<td>Experience is the biggest resource from patients and families – stated in each interview (April – October 2022)</td>
</tr>
<tr>
<td>Sitting in silence is tough to do</td>
<td>Some participants talked about how other team members would just keep talking so there would be no silence, while others learned to create that space and just sit with their patient (October 28, 2022).</td>
</tr>
</tbody>
</table>

3.4.4. Theoretical Sampling and Sufficiency

The research intended to have approximately 20 - 30 healthcare providers. I could not attract more participants, so I had 20 participants in total, with 14 of those same participants engaging in a second interview. Using theoretical sampling for this data came in the earlier and later stages of the research (Charmaz, 2014). Once I was halfway through the first interviews, categories began to emerge, and I realized that some participants had had personal experiences, but it was almost bidirectional. In Chapter 4, I refer to this bidirectional way of being as the participants having dual knowledge or insider/outsider information. Their experience in clinical practice helped shape how they engaged in their personal life when it happened, and their personal lives also made them see holes or gaps in practice as a healthcare provider that then shaped their future interactions.
While still interviewing participants with that theory in my mind, I mentioned to the next participant how other participants talked about the bidirectionality of having personal experience and if they have had any personal experiences with death or dying that may have shaped both that experience and their future experiences.

I immersed myself in constant comparative analysis using the raw data through the initial coding, focused coding, and written memos of the participant’s present voice. I made meaning in the theoretical outcome of how they construct their professional lives concerning end-of-life conversations, which is consistent with the way Mills et al. (2006) described the close relationship of keeping “the participants’ presence throughout” (p. 32). Numerous categories needed further development for clarity and fine-tuning (Charmaz, 2014), which proved helpful for mapping concepts on the whiteboard (see Figure 8) and fruitful for theory building, as shown in Table 1.

Theoretical sufficiency was attempted, but no matter how hard I tried to attract more participants, I did not get the theoretical sufficiency with 20 participants in a heterogeneous area. Realistically, it was not feasible within the confines of a Ph.D. thesis but recognizing the context of a pandemic and the ability to attract people to this research, it was the best that could be done, and this was a limitation.

**Figure 8 Mapping concepts from theoretical sampling**

3.5. Limitations

CGT assumes that social reality is complex, constructed, and requires reflexivity of both the participant and researcher (Charmaz, 2014). The study was not designed to be
generalizable to broader populations but to deepen the understanding through careful documentation and analysis of events in one context that may resonate with others’ experiences. The focus was on healthcare providers who care for the adult population. The sample size of 20 participants was far too limited to represent the wider field of healthcare providers. Everyone involved in the study was passionate about the topic, but their perspectives may not accurately reflect those of their colleagues. Unfortunately, we could not attract others to participate; it limited our ability to gain a greater understanding from the perspectives of those who may be or are less invested or believe that this health system is adequate in its current form. Moreover, the study only focused on a single center, and even though some participants had received training elsewhere, it was not enough to understand how medical schools are currently addressing this issue at the student and resident levels. Additionally, not all participants had equal amounts of time and engagement. It is crucial to note that the pandemic could also have influenced their perspectives, as we know that people who are exhausted or frustrated with the system may have different stories to tell.

3.6. Trustworthiness

To enhance trustworthiness, the first set of interviews demonstrated initial and probing questions in the transcribed interviews. After completing the first interviews, the data analyzed created more questions for a second interview. This interaction of member-checking during the progression of analysis once transcribed and analyzed, according to Harvey (2015), was when participants were invited to review the transcribed interviews to confirm and validate their texts or change or add anything they chose, which added to the trustworthiness and ethics.

This iterative checking triangulates the analysis with my literature review, memo writing, and member checking to strengthen the study's trustworthiness. Comparing my results to relevant literature focused on what was unique to this community, as memo writing allowed me to document my evolving thinking throughout the process and provide a text to reflect upon during each stage of the study. Memos also provided a transparent audit of the process undertaken and recorded any adverse events or insights as they occurred.
Making the data available for the participants to review throughout the process allowed participants to engage in the possible refinement of thematic categories (Charmaz, 2014). CGT’s methodology focuses on eliciting the best representation of the participant’s narratives to understand their perspectives and experiences deeply. With this approach and collection of the data, I could adhere to the participant’s social and cultural milieu while allowing myself to support developing new training or preparation in this underdeveloped area.

The conversations respected the time participants wanted to engage; some were shorter, and some were much longer. I allowed them to speak as long as they needed to. The research took place over six months. This allowed me to reflect on the data as I analyzed the transcribed participant interviews. The second interview took place, on average, six weeks after the first, giving participants a chance to reflect upon our discussion as they engaged in their practice. The opportunity to engage participants not only on the accuracy of their transcripts but on what was said and what they wanted to discuss further allowed me to remain faithful to the data – their words – in a way that contributes to confidence in the overall trustworthiness of the process and, therefore, the results.

3.6.1. Rigor in Data Collection

Despite one of the limitations of this research, which ended up being a smaller participant size than anticipated, one of the strategies was to engage in purposive sampling for a rigorous recruitment component for this study. A known Key Informant to the research team emailed prospective participants on behalf of the research team to invite them to participate in the research study, whom they believe regularly hold and take part in end-of-life conversations and may provide valuable insights into having these critical conversations. The inclusion criteria were healthcare providers who work with the adult population and speak English. Members of the research team were contacted via email by prospective clinicians who expressed an interest in the study, and two reminder emails were sent out.

All interviews were recorded through Zoom and uploaded to Trint, a transcription company, and were rechecked for correctness by the researcher before sending them to
the participant. During transcription, memos were noted, and then the transcription was sent to the participant to check over and change or add anything.

Once the participants had time to reflect on their first interview transcription, they shared their reflections during their second interview. The researcher shared probing questions related to the second interview, which led to further questions to ask the researcher, and the participants refined some of these reflections in practice. Allowing participants to reflect upon and add or change anything and making space for the researcher to follow up to clarify elements of the interviews was helpful for analysis. Virtual interviews were more convenient for many participants as they could work around their busy schedules over a lunch hour, after work, or on the weekend.

3.6.2. Rigor in Data Analysis

Through my research, I utilized CGT methodology to guide my findings' design, data collection, analysis, and interpretation.

Each participant interview was reviewed in the order the interviews happened, sometimes intermittently between the first and second interviews, allowing for the participants who were having their first interviews to be included in some of the insights from participants sitting for their second interview. In these cases, the probing questions were more direct. Constantly comparing interviews and creating categories from the experiences the researcher was reading and memoing helped decipher abstract concepts to place them into categories and themes that remained true to the theoretical framework in a CGT study.

By utilizing CGT, I was able to gain a deeper understanding of the topic at hand and generate insights that are both relevant and meaningful. This approach allowed for iteration across interviews and iterated analysis with existing theories and data in the literature, using memos to guide these insights. This allowed us to further engage both with the literature in an ongoing iterative fashion as well as with the analysis of the data. As someone with an Honours degree in Thanatology, I have become familiar with various thanatological concepts. Through my research, I gained a deeper understanding of what participants said and how their experiences related to overarching theories. During the literature review portion of the CGT, I gained valuable insight into how
thanatology concepts could be applied in practice. Ultimately, our findings highlighted the importance of incorporating thanatology concepts into medical education, from student to resident to practicing physician. Seeing how these insights were gained through real-life experiences was fascinating, providing a unique perspective. Regular meetings were held between my supervisor, Dr. Hibbert, and myself to give updates on the study's progress and work through the data and concepts. Updates were emailed to the committee at more progressive stages of the study. No one withdrew from the study. Twenty participants participated in the study, and fourteen agreed to participate in a second interview.

3.6.3. Statement of Reflexivity

As a researcher, I reflect on how my experience as a former Massage Therapist influenced my ability to be present. I had the experience of being around clients who shared vulnerable conversations with me while I shared their space. As a thanatology academic, I have the training and expertise to understand the lens of the thanatological approach and the process is never the same experience in the same sequence. I also reflect on how my first career as a Massage Therapist had a hand in developing the listening, observing, and skills that come with CGT research intrinsically. Connelly and Clandinin (1990) observed that “people are both living their stories in words as they reflect upon life and explain themselves to others” (p. 4), which is what I observed as participants shared their experiences.
Chapter 4 Findings

4 Introduction

In the following two chapters, I will present the findings of the research analysis. I have organized the findings to reflect the questions that I have asked as follows: Chapter 4 will respond to the first two research questions:

- What are the theoretical perspectives and personal or professional experiences physicians, surgeons, residents (PGY3 and above), and nurse practitioners draw on during end-of-life conversations?
- In what ways have these changed over time due to the introduction of MAiD in Canada?

In Chapter 5, I will focus entirely on the findings that address the final question:

- How might theories from thanatology specifically contribute to training or preparation in this area?

I have opted to separate findings for two reasons: First, it is the primary area of focus in my theoretical framework and presents a goal of imagining how thanatology can be more meaningfully taken up in the healthcare setting. Second, as a separate chapter, Chapter 5, I have opted to add the unusual step (for a CGT approach) of developing scenarios that may illustrate the concepts more clearly and provide pedagogical tools for future educators.

4.1 Introducing some helpful terminology

Even though the healthcare providers in this research were not aware of thanatology theories per se, their responses suggested that they implicitly supported their patients through things like anticipatory grief and assumptive beliefs – which are core concepts in thanatology. Although I could infer many instances of references to thanatological concepts, in this research, I include only references grounded in the data. Some of these thanatology theories are referred to in death loss.

Here, I introduce some terminology that readers may find useful as we engage with the dialogue in the following few chapters. The way it is defined for the purpose of this
Anticipatory grief – Feelings of grief before the loss happens for the patient and caregivers when everything changes from a future imagined to be in, comes the anticipation of the illness and an abundance of losses such as intimacy, physical activities, recreational activities, and loss of the future with loved ones (Large & Slinger, 2015).

Assumptive beliefs – Even in the most meaningful conversations, the patient and caregivers may be working through the assumption that what they expected was not the negative outcome they received. Janoff-Bulman (1989) suggests there are three assumptive beliefs: (1) perceived benevolence of the world, (2) meaningfulness of the world, and (3) worthiness of the self (p. 117).

Caregivers – family and friends of the patient who may be in a role of caring or advocating for the patient.

Complicated grief – When grieving remains prolonged after the initial loss and affects one’s ability to adapt (Shear, 2015). One participant used the term complicated grief when family members were making goals of care decisions for their loved one when there were unresolved issues within the relationship:

So those are some of the complicated factors that complicated grief really makes things difficult…if people haven't been able to reconcile the relationship with the person …they're trying to make a decision for them…extremely difficult because they're like, I don't want them to die…we never sorted out our stuff…so now they're unable to really reconcile with those wishes. They can't engage cognitively with the question at hand because they're still so engaged with the emotions. (P20, October 17, 2022)

Death denial – people would rather not think about death than consider their mortality (Cozzolino et al., 2014).

Family meetings – conversations between healthcare provider teams, patients, family, and caregivers about the patient’s healthcare.
Five stages of grief – Initially developed for those facing death: denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). Despite being largely discredited, this older theory has managed to maintain its dominance in medical education.

Healthcare providers – are referred to physicians, surgeons, senior residents (PGY3 and above), nurse practitioners.

Health trajectory – the pattern of health over one’s life span (Henly et al., 2011).

Life-limiting illness – an incurable disease that will reduce one’s life span.

Non-malignant chronic progressive illnesses – are life-limiting illnesses that are not cancer.

Palliative care - An approach that seeks to relieve pain and symptom management to enhance the quality of life of patients with life-limiting acute or chronic conditions. It involves preventing and relieving suffering using early identification, assessment, treatment of pain and other physical, psychosocial, and spiritual symptoms (CMA, 2016)

Patient – person under medical supervision.

Participants – are physicians, surgeons, senior residents (PGY3 and above), nurse practitioners from this study and also referred to as healthcare providers.

Serious illness – chronic illness or life-limiting illness that is not cancer.

Sudden death – an unexpected death that happens suddenly.

4.2 Overview of Findings

As I reviewed the overall findings, I found that my participants were all deeply invested in talking about this topic. At the same time, their professional experiences informed their approaches to their patients, and personal experiences aided in their understanding and ability to empathize. Together, these two factors informed how they interacted with patients, took a patient-centric approach, questioned the system and structures in place, and sought additional information.

4.2.1 Memos of the Participants

I maintained research memos throughout the study as part of the CGT approach. I found the memos helpful in that they enabled me to focus on the questions, concerns and
insights gleaned from my participants. I noted points that I wanted to return to or where there was more literature for me to go and investigate. To give the reader a sense of what I observed and noted, I have shared a sample of my notes (see Table 3). As you can see, the memo captures almost the essence of the interview.

Table 3 - My memos of the participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Jill’s memos</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 PGY6 Physician</td>
<td>Meaningful conversations are a priority and has learned the importance of bringing in the palliative care team as part of patient centered care.</td>
</tr>
<tr>
<td>2 Physician</td>
<td>Shared how the “good death” seems to be a one-size fits all Westernized model to make everyone look peaceful and be sedated. Non-malignant palliative care tends to have poor equity, so had more exposure to malignant palliative care conversations with cancer patients. And describes the importance of having a conversation that centres around their patient as a human being.</td>
</tr>
<tr>
<td>3 Physician</td>
<td>Many patients with a limited life trajectory have paid for their funerals but haven’t discussed with anyone how they get to that point. This participant shared how the dying body leads the way and the importance of having these conversations early.</td>
</tr>
<tr>
<td>4 Physician</td>
<td>This participant has experience over a few specialties with daily end-of-life conversations and mentioned they get more “thank you’s from dead people” given their ability to understand and meet the needs of their patients.</td>
</tr>
<tr>
<td>5 Physician</td>
<td>Previous chart notes can be a challenge to understand a patient’s prognosis, and the patient’s understanding, all the while valuing and being deeply reflective on patient conversations.</td>
</tr>
<tr>
<td>6 Physician</td>
<td>I learned early in the interviews that challenging conversations are sometimes left for someone else to have, and this participant says it is the kindest and helpful thing you can do for the patient, and the patients are thankful for the honesty.</td>
</tr>
<tr>
<td>7 Nurse Practitioner</td>
<td>If your practice allows for longitudinal trajectory care, building relationships over time allows trust for easier end-of-life discussions.</td>
</tr>
<tr>
<td>8 Nurse Practitioner</td>
<td>Explains medical treatments in layman’s terms for patients to understand what resuscitation wishes have been documented. Seeing these conversations done well and poorly has helped shape how they speak to patients.</td>
</tr>
<tr>
<td>9 Physician</td>
<td>Participant connects asking questions to patients as not only for one kind of ‘care’ and how some of the questions can help for patients to understand what options of care might be, are not always big treatments. Reflective that the family will always remember them as the person that came and told them something that they weren’t expecting.</td>
</tr>
<tr>
<td>10 Surgeon</td>
<td>I was blown away at how often a surgeon has end-of-life conversations. Sometimes patients think seeing them is the last hope of curing them, so will speak about quantity and quality of life values and feels a duty and responsibility to be open and honest.</td>
</tr>
<tr>
<td>11 Surgeon</td>
<td>Educate patients often on the stages of their disease and has carved out clinic days to accommodate some of the tougher conversations that allows time and space to process it. Their patient may not remember what was said, but they will remember how they felt after leaving the appointment.</td>
</tr>
<tr>
<td>12 Surgeon</td>
<td>Having tough conversations is an important skill to develop and doing it badly is unfair to the patient but will ask patients why they are there to have an understanding of how much they know about their disease.</td>
</tr>
<tr>
<td>13 Surgeon</td>
<td>Will be direct with patients if they want to know their prognosis despite sometimes being the 4&lt;sup&gt;th&lt;/sup&gt; specialist to see the patient as they didn’t know they could ask. The participant also shared that one can still be empathetic without being really emotional, and just because a medical option is available to the patient, they don’t have to do it, but you need to ask what they want.</td>
</tr>
<tr>
<td>14 Surgeon</td>
<td>Specialty crosses over into different areas but spoke to the importance of being direct, use of language and the team is supporting through the entire process.</td>
</tr>
<tr>
<td>15 Physician</td>
<td>Experiential learning by watching senior nurses, patients and mentors. Witnessed the power of being present for a patient who had suffered loss by sitting in silence.</td>
</tr>
<tr>
<td>16 Physician</td>
<td>The conversation with the patient and family was incredibly important to be done compassionately and aware of body language and being direct. Spiritual care can be part of the practice if the patient asks for it.</td>
</tr>
<tr>
<td>17 Physician</td>
<td>Has a longitudinal relationship with patients, so goals of care conversations are mandated even though these conversations are expected and updated regularly, trust plays a part. Learning to have the conversations well, is a skill, but finds it very rewarding to have those crucial conversations.</td>
</tr>
<tr>
<td>18 Physician</td>
<td>Has had to be creative when introducing palliative care to patients and their families, and how you say it, the patient or their family may focus on how it was said, not the actual news of the prognosis.</td>
</tr>
<tr>
<td>19 Physician</td>
<td>Brought up how frailty has more to do with questioning code status than age of patient. Caring for patients at end-of-life is rewarding while keeping people alive using medical treatments, is the struggle.</td>
</tr>
<tr>
<td>20 PGY3 Physician</td>
<td>This participant had years of patient experience prior to medical school so there was already an awareness of finding out the values of the patient. Reflected on the responses of patients and their family on the mindset of death. When I asked if they have the opportunity to see patients again, their response likened it to being the character in the movie from the Usual Suspects, Keyser Söze: [the patient] they’re there, and then they’re gone. I pass through people’s lives and then disappear. And with any luck, they never see me again.</td>
</tr>
</tbody>
</table>

Despite participants’ varied roles and background experiences with death and dying professionally and personally, the common trait they all seemed to share was a deep investment in disrupting linear treatment pathways for patients. They all saw the current system as flawed in some way. They could sense something was missing, despite not being able to articulate it. Each cared about having an honest conversation about their patient’s values and wishes, and I understood how these challenging conversations with
patients meant to them as healthcare providers. I will now look at the findings relating to the first question.

4.3 What are the theoretical perspectives and personal or professional experiences physicians, surgeons, residents (PGY3 and above), and nurse practitioners draw on during end-of-life conversations?

4.3.1 Findings of Personal Experiences:

Personal experiences can be precious in shaping how healthcare providers approach their practice. However, it is important to recognize that everyone's personal experiences will be different, which can lead to a wide range of approaches. We noted several participants had personal experiences that influenced their practice in interesting ways. For some, their professional background played a significant role in how they interacted with patients, while for others, their personal experiences shaped their approach to future situations. Personal experiences can be a powerful tool in healthcare, but it is vital to approach them with an open mind and a willingness to learn from others. For example, personal experiences shaped by religious beliefs are unlikely to translate well to patients with different beliefs. On the other hand, personal experience with the death of a loved one can be instructional in ways that no amount of medical education can provide.

Participants also recognized the value of dual knowledge as the patient's family member and healthcare provider. Some of these experiences with their family members were very challenging, and the lack of detail about their loved one’s care influenced how they supported patients in similar circumstances to ensure they had updated information and knew the options available.

Participants shared stories of having to fill in the blanks of a prognosis for healthcare providers who did not share all the information with their loved ones. Their role was to support their loved ones, yet they also witnessed the frustrating gap in patient care. For Participant 19, this influenced how they communicated with patients about delirium,
especially after their loved one underwent surgery and had a poor outcome. While some of these personal experiences impacted the participants’ practice even more, Participant 6 emphasized how the practice with their patients’ influenced goals of care and end-of-life care decisions for their loved ones. Even though the participants were grateful for their unique insight and privilege into their loved one's healthcare journey, this dual knowledge also brought a sense of sadness and grief.

Atul Gawande speaks to his dual knowledge of being an insider-outsider as a healthcare provider and a family member during his father’s illness and eventual death. In his book, *Being Mortal*, he explains: “Helping my father through the struggle to define that moment was simultaneously among the most painful and most privileged experiences of my life” (Gawande, 2014, p. 262). The deaths of previous loved ones taught Participant 20 to be vulnerable and comfortable in the uncomfortableness. They chose to stay and talk themselves through sitting and waiting at their parent's bedside, and they felt fortunate to have those experiences when their parent was dying. I asked how the deaths of loved ones and having realistic and thoughtful conversations have impacted their life:

…it all impacts; it all feeds into experience. It's a technical and non-technical skill, the ability to connect with people and I don't think it's an innate ability. It's something that has to be practiced and developed, has to be something that's mentored and is often mentored by the people you talk to.

For some participants, the peripheral impact happened through a learner’s observation. While a medical student was present in Participant 13’s clinic, they spoke to a patient about their life-limiting prognosis that it was not curable, some options of treatments, and the limited time they had depending on what course of action they chose. After the patient left, the medical student commented on the participant's discussion style with the patient and how different it was from their parent’s health trajectory. The Medical student shared that when their parent was diagnosed with life-limiting cancer, the healthcare provider acknowledged that their parent would undoubtedly die from the disease but brushed over it. They focused more on pursuing active treatments, not dying or how to prepare for it. Gawande (2014) experienced this as well and compared active treatments
with a poor outcome as a fantasy: “Discussing a fantasy was easier-less emotional, less explosive, less prone to misunderstanding-then discussing what was happening before my eyes” (p. 169). The Medical student’s parent was not introduced to palliative care, and therefore, when they died, no one was prepared and felt the loss of time that could have been otherwise spent knowing their parent would soon die and prepare for that outcome sooner.

4.3.2 Findings of Professional Experiences

An influential teacher for all participants was found in their professional experiences. They learned through observation at family meetings and the conversations that went poorly and those that went well. Interactions with patients and caregivers took pieces of what resonated with them to make into their own end-of-life conversations. Participants mentioned how some learners showed unease by making the goals of care more of a checklist instead of asking questions about what matters and what is suitable for patients in a medical emergency. The participants reminisced about their earlier days and how medical school is structured so that the students are inundated with an enormous amount of technical information and knowledge in their first four years of medical undergrad. As they started their residency, they applied what they felt was technical textbook learning knowledge into their training. Reflective practice had a starring role with the participants and their perspectives when discussing prognosis or end-of-life conversations with patients and families. The participants described part of their process of speaking with patients as engaging in reflective practice, allowing them to have honest and meaningful conversations regarding their prognosis. Elizabeth Kinsella (2001) contended that,

> Reflective practitioners are concerned about the contexts of their practice and the implications for action. They reflect on themselves, including their assumptions and theories of practice, and take action grounded in self-awareness. Finally, reflective practitioners recognize and seek to act from a place of praxis, a balanced coming together of action and reflection. (p. 198)

They were keenly aware of not having a paternalistic approach and creating meaningful conversations through their direct language, body language, explaining treatments,
outcomes, having the choice of no treatments, learning what works, what does not work, and what they can do better. This knowledge, practice wisdom, is gained through hands-on experiences in the workplace rather than “formal teaching” (Rothwell, 2019, p. 257). Sometimes, participants advocated for both the patient and their caregivers separately. When the healthcare provider was alone with the patient, the patient did not feel they could tell their family how they felt for fear of disappointing them. One participant was willing to be the “bad cop” and suggested to their patient’s family that they were too unwell to travel, as the patient did not want to let down their family (P09).

Some participants felt that the work they trained for years to do was technical, yet they always had to find creative ways to explain to their patients and caregivers in a way they would understand. Especially when participants found that previous healthcare providers may not have shared a life-limiting prognosis with the patient. Schmidt & Rosenberg (2014) summed up that “Their common characteristic is that they work hard and are willing to question the status quo and attack things differently. This is why they can have such an impact” (p. 80). They would make time to have that informative conversation with the patient. For example, Participant 10 shared:

…you do have to understand that sometimes we look at our job as surgeons as being highly technical…taking people apart, putting back together a lot of anatomy, a lot of this, a lot of that. But at the end of the day, that’s a human being. (August 5, 2022).

Some participants were surprised at how often they were having end-of-life conversations without realizing the steps they were taking their patients through when having them:

…it was interesting to read a conversation about the way in which that was made explicit through your questions. Having to answer questions, I don't know, it just made visible something that isn't visible to me anymore. And you're … Oh, that's interesting, I have a lot of experience in this… actually, there's a fair bit of that (end-of-life conversations), and I've had a fair bit of experience, and I've been thoughtful about it. (P15, October 12, 2022)
However, these conversations took time and effort. Some noted power differences emerged in the interviews between more senior healthcare providers and the participants. These theoretical underpinnings are present in conversations the participants observed or participated in as students or early healthcare providers. Many mentioned that while in medical school and residency, they observed the conversations in family meetings or during rounds, but they felt they could not speak up and stayed silent. They immediately learned from those interactions what to do and what not to do when speaking to patients and their families from what the senior leaders were saying or not saying to the patients and caregivers (P12, August 12, 2022). They learned the importance of mentorship, body language, and silence when having these conversations with patients and their caregivers, which impacted the power dynamic within the sacredness of these conversations. Audre Lorde (1980) spoke about silence as a patient with her cancer diagnosis not speaking up: “…my silences had not protected me. Your silence will not protect you” (p. 18-19). Participants said that sometimes patients said very little. Still, in the participant context, the patient's silence did not necessarily mean they had nothing to say other than they were processing the information. Allowing a space for silences, which participants learned through their experiences, empowered them to stay available for the patient and caregivers. Participants mentioned a sometimes uncomfortable stillness during these conversations. However, they noted how they learned to lean into that vulnerability of silence and give the time for patients to process the information. Participants pointed out that this only happened with more years of experience. Once they became senior health providers, they witnessed the importance of this and could model it to their learners (P16, September 14, 2022).

All participants said they used direct language with the patient and caregivers when communicating the reality of the patient’s condition. However, metaphors and the language used during the conversations impacted the interactions between healthcare providers, patients, and caregivers. Participants spoke with irritation when euphemisms (mass, spot, lump) and metaphors were used (we got it all, fighting, outlier), and they did not want to be caught in the “hero archetype” that might happen (P11, August 10, 2022). Participant 18 recounted that using metaphors can sometimes effectively communicate
when the patient or their caregivers are having difficulty coping with the reality of their loved one’s deteriorated health condition.

4.3.3 Findings of Theoretical Knowledge Invoked

The participants all had a clear and unified goal: to elevate the level of patient-centred care. Their shared desire was to surpass the quality of care previously provided to their patients.

In many interviews, something experiential seemed to impact the participant’s evolving practice. They used their experience to improve or do better for the next patient interaction. A discordance emerged as I reviewed the analysis and returned to the research questions. The discordance was the gap in patient care, but the gap was in the differences told by the participants from different specialty groups that have end-of-life conversations. Fifteen participants said they had no formal training in having these conversations. However, over the years and observations of seeing good and bad conversations with patients, they made their communication approach their own and modelled this for their junior learners.

Participant 13's impact came with further interdisciplinary learning that revealed tools they already had but provided different ways to use them in their medical practice.

I loved doing that master's degree because it got me back to my background in engineering. So, I love numbers and stats, and even though while I was training, I was always looking for numbers and stats, I didn't have the tools to really do it. So going to [University X] gave me those tools. (October 4, 2022)

During P13’s second interview, they explained how critical thinking changed their view of their medical practice and how the importance of being a critical thinker helped improve patient care.

Early in Participant 18's palliative care career (before palliative care was considered a medical option), they saw a gap in the acute care setting. They sought to bridge what (at
the time) was considered “rescue medicine” while in the ICU, and they “brought the palliative principles into the acute care setting” (October 6, 2022).

The participants varied in their specialties; only three were trained as palliative care specialists. The other seventeen participants identified themselves as engaging in end-of-life conversations without specific palliative care training. This led to a probing question if they were surprised at how often they had these conversations with patients and caregivers despite not having had a palliative care rotation. Participant 20 observed:

I think everybody knows they're supposed to do it, but a lot of people have a lot of trepidation about approaching them, and they don't like it. And if you're avoidant to these conversations, you're not gonna be good at it. (October 18, 2022)

They had many insights that helped them understand how they navigate the system and their insights into navigating those challenges differently than their colleagues struggle with.

4.4 In what ways have these changed over time due to the introduction of MAiD in Canada?

I initially assumed that MAiD would transform the conversations and play a greater role than it appeared for my participants. While we did ask about it, and it did play some role, its prominence across their conversations was small.

Some participants talked about patients who sought a medically assisted death as a treatment option but still “faced barriers of it being taboo, despite no one being suicidal, and it should not be considered a dirty secret” (P04, June 9, 2022). Another participant shared that, depending on the institution or the patient not wanting to bring this discussion up with family, there are still obstacles for people who seek MAiD. When patients mentioned their family doctor would not support them or say they were not a candidate without giving them an assessment, Participant 19 expressed they “see those as opportunities to really respect someone’s wishes and get them assessed. Because I feel really strongly that if you want to hear about the options, that you should be able to” (October 12, 2022). Although a few participants indicated their involvement with MAiD,
it did not appear to have transformed the healthcare conversations around end-of-life care or any other pieces, as I had assumed.

4.5 Summary of Findings

CGT and the theoretical lenses of feminist theory, thanatology, and education brought this work to life. CGT supported the conversations and uncovered how the participants made meaning while reflecting on their experiences with patients and caregivers. My feminist theory background allowed me to see what they were saying and what they were not saying. The silence of their patient or caregivers could have many meanings, such as when it is not contemplated silence, processing the information in silence, or silence of a power differential. Those were moments when I could probe and ask a participant more about the silent experiences, and the participant was able to reflect on that interaction further. My research in thanatology also allowed me to see that the experiences my participants had with patients and caregivers were thanatologically based without the participants realizing what their conversations and actions were grounded in. The educational lens was a large part of the interaction between the participants sharing how they have these conversations with patients and caregivers, and how they also made opportunities for themselves to learn more and be better healthcare providers for each patient they saw.
Chapter 5 - Findings within the Thanatology Lens

“Why didn’t anyone teach me how to die? We are taught at our mother’s knee how to live but not how to die” (Corr et al., 2013, p. 12)

5 Introduction

Death, like birth, is the most natural occurrence in a person’s life. Given the lack of predictability and intense emotional implications of death, it is poorly understood and often taboo to discuss. This can be especially true in medical education, where the focus is primarily on diagnosis, prognosis and treatment plan with the goal of providing a cure. Where death is the only available outcome—even a peaceful one, maybe even a good death—can be seen as a failure.

In this chapter, I have elected to attend only to the findings noted when explicitly looking at the data through a thanatology lens. I discovered that after sorting and reviewing all of the other data presented in chapter four, there were still statements made that spoke to the silences, the losses, the regrets, and the workarounds that led me to realize that this yearning was, in fact, for the very things that thanatology has conceptualized and could provide.

Brené Brown, an internationally renowned researcher who has studied courage, vulnerability, shame and empathy over decades, has noted: “In my experience working with clients, the ability to name [an] emotion or experience is essential to being able to process it in a productive and healing manner” (2021, p. xxv). I realized that my participants (only one of whom had studied one course in thanatology) were grasping for the language to express what they had come to know in an embodied way through practice, experience and living their lives.

To bring this to life for the reader, I have elected to story the data through four short vignettes representative of each participant showcased here. As you will see in their dialogue, despite what often felt like elusive challenges, they found ways to capture their care, concern, approach, and desire to be inclusive of patient-centric care. In this way,
Chapter 5 responds to my final question: What might the field of thanatology offer healthcare providers to support these critical conversations with patients in ways that also support patients at a profound point in their living cycle?

5.1 Participant Vignettes

In the following four vignettes, I have elected to illustrate the presence of thanatology in the participant’s practice and the engagement of the thanatological theories in patient interactions. The participants presented in this chapter were selected based on their alignment with thanatological approaches in the patient interactions they described, and all names are fictional.

5.1.1 Dr. Wesley: A Focus on Care

Dr. Wesley arrived for their morning shift to see a patient, Anne, who had been admitted overnight, and, despite the patient’s fragility, the chart showed all boxes checked for a full resuscitation. Dr. Wesley lamented that some of the biggest challenges in their work are the number of patients who have not thought about their end-of-life before being admitted or that, if they have, they cannot remember what was said to them in the middle of the night when they were admitted.

Dr. Wesley expressed frustration that, too often, junior team members review the goals of care with patients without explaining what the interventions may mean for the patient. Dr. Wesley learned, through this experience, the importance and value of the end-of-life discussion as a treatment option since patients may otherwise automatically accept the available drugs and treatments without fully understanding the short and long-term consequences. However, Dr. Wesley also noted: “I've had a greater realization that when you have these conversations about end-of-life trajectory, you can be wrong. And so, there are some patients who I've talked about end of life and said, you're on an end-of-life trajectory, and that's where we're heading. And patients have turned around and are no longer on that trajectory.”

To orient patients for these challenging conversations, Dr. Wesley notes that it is hospital policy to have “goals of care” conversations to understand their values according to what medical interventions may be needed and what the patient wants in those scenarios.
Although Dr. Wesley finds this an excellent point of entry in learning the patient’s values and wishes, they recognize that there can be misunderstandings when patients, unaccustomed to these conversations, interpret them as signals that they must be dying imminently. When this happened with the patient admitted overnight, Dr. Wesley quickly followed up with the patient and their family to review their previous conversation, allowing the patient to process the information better. They reflected: “That's something that I've changed about my approach is to be upfront with patients that we're going on this trajectory, but it's not a one-way street. If, for some reason, you improve in the future just because you say that you want to pursue palliative care, end-of-life now, that doesn't mean that if, in a couple of weeks, you're doing much better, that you can't change your mind”.

5.1.2 Dr. William: Understanding and Communicating Palliative Care

An acute patient, Frederick, was brought in by ambulance on Dr. William's busy Emergency Department shift. Frederick’s wife, Rosalie, had just arrived and was waiting to speak to the healthcare team about their medical intervention plans to cure her husband.

Dr. William observed that they have often found a disconnect between what the patient with a terminal illness understands and what their family members understand about where they are with the disease. Sometimes, the families believe that their loved one is receiving treatment to get better. However, when Dr. William read through Frederick’s chart, it confirmed that Frederick was deemed palliative and was receiving pain and symptom-control treatment. Dr. William found Rosalie seemingly unaware of her husband's illness despite his fragility, as she expected all life-saving measures.

Dr. William shared the medical interventions available to her dying spouse during the initial visit, “I launched into a very sort of typical conversation that I would for someone in terms of what we can do for them”. However, with more time, Dr. William re-assessed their earlier (and perhaps hopeful) options after seeing their chart and presentation. The patient was likely hours away from death, and Dr. William had a choice to proceed with the active treatments per Rosalie’s wishes. However, Dr. William recognized that an
active treatment would expedite Frederick’s death. Dr. William instead decided to re-frame the active treatment of procedures in a way that presented what was more appropriate for Frederick, given his current state, “I didn't have all the information from his chart because it was a fairly acute situation, and I should have backed up and just offered what was appropriate for him. And I have learned from that”. This included explicitly describing that the choice of active treatment meant Frederick would have to be in another room to undergo the procedures and would almost certainly die once he started the treatment. This allowed Dr. William to propose a choice to Rosalie: allowing the inevitable death to occur naturally while she is with him, sitting and holding his hand as he dies with the healthcare team nearby. Rosalie was taken aback as no one had told her that her husband was dying; she had understood that he was receiving curative chemo. Dr. William empathized with this common reaction, “She didn't understand he was dying, and no one had told her that his death was coming up soon...this man was emaciated, he had terrible cancer. She thought it was being treated. She thought he was starting chemo for it. She thought his cancer was going to be cured. So, I think that right from the get-go, her interpretation of his current status or what she had been told or what she'd been perceived, I don't know, was not accurate. And I think that made things very challenging in the moment”. Dr. William discussed the situation further with Rosalie as she processed this news and allowed time to be present in silence. After processing the information, Rosalie chose her husband to stay with her to die naturally until his last breath (P05, June 10, 2022).

5.1.3 Dr. Lothringen: When there are No Options

Patient referrals from other specialties often occupy Dr. Lothringen's surgical clinic. Some patients come to see Dr. Lothringen to surgically remove cancer in hopes of being cancer-free. In some of Dr. Lothringen's clinics, patients bring family members with medical knowledge to their appointments for more support. This was the situation on this clinic day; the patient was coming for a surgical consult following a cancer diagnosis and bringing a guest while their spouse was on the phone. The patient, Dixie and her guest asked about treatment options but did not seem to understand that surgery was not curative. Given the particular cancer prognosis, this was a life-limiting cancer.
Dr. Lothringen had a few options for managing these patient expectations. They could tell the patient they could not help and send them back to their family physician, or they could go ahead and do the surgery because that was what the patient wanted. However, Dr. Lothringen proposed a different approach. Dr. Lothringen talked with the patient about the risks and benefits of available or no treatment options and introduced a palliative care referral, “I think my discussion with them was more just about reorienting them to where reality is, not honestly robbing them of hope…and giving them a sense of what they're up against”. In our interview sessions, Dr. Lothringen explained that they see a human in front of them regardless of whether they are in their clinic or at the operating table, “There's a person there. That person has relationships. That person may have children. That person may have other people in their lives. So, you have to get a sense that there is a person in all of this”. They also asserted the duty and responsibility to be open and honest with patients, especially those with a non-curative disease. Hence giving the patient all the information needed to make the best decision. Dr. Lothringen helped the patient understand and process their prognosis to make decisions accordingly and how treatment options may affect their quality and quantity of life. In this situation, Dr. Lothringen told the patient that the surgery would not be curative and that their quality and quantity of life may not be improved. They explained that surgery was a riskier option, given their overall health. Even though there was nothing more that Dr. Lothringen could offer the patient besides re-directing the reality of their choices, they felt that being as honest as possible allowed the patient to be aware of the entire picture and make informed decisions based on what they valued most during the end of their life, “I think the way that I break that news is kind and compassionate.” Their patient thanked them for giving them all the options. They would go home and discuss what was best (P10, August 5, October 11, 2022).

5.1.4 Dianne: Different things for different people

Nurse Practitioner Dianne is part of a specialty practice with longitude complex patient care, including serving communities located hours away from patients. Their patients have chronic illnesses, mobility challenges, and life-limiting conditions. Given the distance for some patients, Dianne’s clinic schedules extended appointments. Dianne
believes that extended appointments are necessary to have the time required to build trust and work through the conversations about goals of care and end-of-life care conversations. For one patient, Iman, Dianne requested to start the introduction of support for palliative care in their community. Even though Iman’s health was on a slow-moving downward trajectory, it also was unpredictable. The primary care physician and Dianne agreed to access a community palliative care team for symptom management so that when Iman was experiencing acute symptoms, they would be familiar with them. This would also allow Iman to be cared for mainly within their community and reduce the need to travel hours to see Dianne at their clinic. Despite this request, community palliative care was rejected as the community healthcare team did not believe they had a role in the patient’s care, “…I think you have a role. You don't think you have a role. And so, I guess our definition of what the palliative care team has to offer in the community is different”. Although Dianne could have stopped advocating for their patient, they believed there needed to be more clarity in how the clinic defined palliative care and how the community healthcare team defined it. Dianne assured Iman’s family they would speak with their local community healthcare team to seek clarity. Dianne's suspicions turned out to be accurate, “[their] idea of palliative care isn't symptom management for complex patients who are on this trajectory to end-of-life where they might need support. So, we just weren't speaking the same language, so I just explained a little bit about these people, and that I had connected with palliative care programs in different communities”. The community healthcare team understood that palliative care meant imminent end-of-life, “and it was helpful to the patients because they could then remain in their community and not have to come to the acute care center or call us for acute issues that probably could be dealt with locally with the family doctor”. By engaging in a conversation, Dianne re-oriented how the community team understood palliative care and end-of-life, opening up a new pathway for their patient’s care (P07, June 7, September 12, 2022).

5.1.5 Learning from the Vignettes

The presence of thanatology concepts in the participant’s practice and the engagement of the thanatological theories in patient interactions were present. What shines through in
these stories is how the participant actively chooses to have open discussions with their patients about their prognosis and ask more questions. They ensured that patients were as informed as possible to make choices moving forward from their appointments. From those pro-active actions, the primary thanatology theories present were anticipatory grief and assumptive beliefs. Participants provided support by sharing and providing as much information as possible in an effort for the patients to have as much information as possible to make decisions for their lives.

While the participants’ stories do not explicitly name thanatological theories, they do reflect an integration of some of the critical principles of thanatology. These stories show how patients and their caregivers are seen and heard. Given the challenging diagnoses and prognoses, patient outcomes matter to the participants considerably. Healthcare providers will do what they can with the time they have to transition their patients and caregivers through the various treatment options available in their remaining healthcare journey. One participant explicitly emphasized in both interviews that when patients or their caregivers choose to suspend active medical treatments and accept what palliative care can offer to them, the patient and their family are never alone; the healthcare team is beside them (P14, September 1 & October 4, 2022).

The participants said that the more aware and prepared patients and caregivers are before entering a hospital or medical emergency, the more they know about their advance care plans, the less traumatic decision making might be. This is why they mentioned how patients’ health literacy would be helpful for themselves and their caregivers. A lack of awareness or understanding of the patient’s prognosis was also frequent with participants when seeing patient charts. Along with decision making, choices of treatments came up. Inevitably, patients were always offered treatments but were not always offered a choice not to accept an active treatment. This is where, when appropriate, participants introduced palliative care to patients. They introduced palliative care in a way that patients understood that some options included more holistic forms of care were available. Participants also shared experiences of other healthcare providers not understanding that palliative care is not just for a patient's imminent death.
5.2 Thanatological Analysis

In this section, guided by a series of questions, I will further provide my analysis from the thanatological lens. As you will see, many of these themes are present in my narratives as an amalgamation of the data.

I would have talked to my participants for hours if time permitted. Their personal and professional theoretical perspectives were always a part of their patient conversations. As I considered summarizing everything I had learned from my participants, I returned to review their comments and my research memos. I posed a few guiding questions as I revisited my notes to organize my thinking.

**How do we move this learning forward?**

Participant 15 posed the question:

> How is it that students are prepared? How do we enable our learners to be good at this kind of thing or to recognize that it is a thing that they have an opportunity to become good at? You know, all the way down to making explicit...they don't know what they don't know, kind of thing. And I don't know, it was a lament for me that there are these barriers to learners getting the opportunities that they realistically need in order to become good because you can't read it out of a textbook...it's an experiential learning. And so, I would want for there to be as many opportunities as possible for people to get as much experiential learning as possible so that we can have as many good people doing good work as possible. And then there's barriers to that…

Participant 8 imagined a technological solution that could bring the knowledge of all interactions together in a more unified way:

> I really wish that we all had an electronic system that all is integrated. And if you had a code status, say you had an advanced care discussion with your primary care provider, it's on your file. If you have this at your nursing home, it's all in your file. I really wish that was out there a lot more because even you have the discussion this time, the next time you come into hospital, it won't be automatically flagged is that was your discussion last time. You have to search back through the files to see what did you talk about last time.
Overall, participants identified the need for integrated, explicit education of both healthcare providers and patients and that the conversations and education need to start early:

But I think that, yes, it needs to start early, and it needs to be normalized, and I think it needs to be a part of every single specialty because it is a part of every single specialty, with the exception of maybe pathology and radiology and ophthalmology would be less often, that kind of thing (P05).

What do you see when you look at the reflections as a whole?

The participants have invested their entire professional practice and draw on parts of their personal life when having end-of-life conversations with patients. As Participant 16 said: “Every conversation needs to be tailored toward the human being in front of you. It's not like a checklist or blueprint that we should follow. So, I'm trying to listen and get an idea of what's the best approach.” The findings had two responsibilities: the healthcare provider, and the patient and caregiver. The participants were already invested and having quality end-of-life conversations with their patients, that had worked for years to build their conversation skills. I saw the effort they had made to make sure their patient was getting as much information during the time they were together. Participant 14 suggested that they may have come in with more of a checkbox mentality:

And I just have to do this because it's part of all the 30 steps I have to do to admit a patient, whereas now I take a bit more time with it. I think language matters a lot, and I found something that works for me. But listen. Listening as either a learner or another team member, somehow someone else leads an end-of-life or a potential palliative care discussion; you learn a lot from that. Both things that I think people say or language that they use that I pick up on I think is good. And more often, language and approaches that I think are not good for families to understand or are not making it clear and even sometimes harmful.

Others were more direct and confident in what they needed to do. Participant 13 described it this way:

I don't think I'm fearless, I just think that's what we do. What are you supposed to talk about? … they're coming to you with their cancer… And what else are you
supposed to talk about? Truth. Just this is what you got. And this is what we can do for you or can't do.

Patient and caregiver preparedness in health crises was infrequent with the participants despite the same available online educational literature on how to have these end-of-life conversations. Participants recognized that the language that they used mattered and that they may have been trying to soften the reality:

So, I think people are, that don’t maybe have the knowledge or are concerned about pronouncing things and being wrong. And they probably see that as a moral harm. So rather than get into the weeds of it, they just use colloquialisms…where you've got a mass or a bump or a lump or tumour even, is sometimes used in a more benign way of saying, you've got cancer. (P09)

Participants spent a lot of their clinical time educating patients and caregivers on information,

I'm having to educate and teach families about it in a very short period of time to figure out what their family member or they themselves want…I think I spend a lot more time having these conversations and trying to make patients comfortable and their families comfortable with this. (P05)

Participants said that having patients and caregivers who already had advance care planning or goals of care conversations made their time together more collaborative and less emotionally charged because everyone understood the healthcare plan. For example, Participant 2 summed it up in this way:

I think having more exposure and practice with goals of care discussions earlier on and learning how to how we need to frame them and approach them, I don't think that's done necessarily well from earlier on. And I know the curriculum can be challenging because there's only so much you have to fit into a finite amount of time. But I just don't think we get enough training with it, and we're all expected to really lead these important discussions from very early on in our careers and how you approach a goals of care discussion will drastically affect the outcome of that meeting. So, it's really, really important.
Some participants mentioned they had patients who would not talk about it and used the term death denial, which was challenging for everyone. For example, participant 17 noted that cultural differences could play a role:

Where you run into difficulties is when the relative comes from abroad or hasn't seen their loved one forever. They may be less accepting of what conversations happened in the past. So, it depends on how involved the family members are and even for patients, it depends on how involved they are in their care. If they've been very involved in discussing their goals of care, wanting to discuss them, that gives a very clear idea of what they want and there was very little discussion or debate once they get very sick and it's imminent that they are going to pass away.

**How has participating in the research discussions led to some insight?**

Those participants who came back for a second interview mentioned that when speaking and reflecting on their process, reading about it through the transcript, and speaking further about it in a second interview, they were surprised at how often they had end-of-life conversations. In some ways, more surprising for them was realizing how they learned to have these conversations based on their merit. Many indicated that learning how to have end-of-life conversations is not something you can learn in a three-hour lecture. With experience, they seek meaning on behalf of their patients:

I think a lot of times what happens that's really unfortunate, is these are really important discussions, and they often occur with the least well-educated people. We sometimes send the medical student in there to go get a code status and document that. And then the medical student goes in, not having a real good sense of what is this person's prognosis, what are the treatment options, what are the chances if we were to ventilate this 85-year-old with pneumonia. (P04)

Honing one’s ability to have end-of-life conversations in a way that honours the patient takes time to observe others having those conversations and the experience of leading those conversations and learning from the patient. Before our interviews, they already saw the importance of bringing learners into family meetings to observe. However, they also recognized the importance of bringing learners into family meetings to observe and normalize the process in a more formalized process as part of their training.

Participant 18 came to insights through an additional pathway:
The things that really have made it change…patients teach you so much…and research definitely has made me change… I personally got sick… And that was a real insight for me into patient-focused listening to patients and just being present with them…and also being a patient teaches you a lot about listening to patients. And I think that made a big difference for me. Huge difference in absolutely how I practice after that.

**What does this say about a patient’s health literacy?**

The experiences participants shared with patients they were always mindful of seeing the patient as a human first and foremost. They were aware of the patient by asking questions and whom they brought with them. If they did not bring someone to their appointment, they asked the patient if there was anyone they wanted to call during the appointment to make sure they had support during their health. Further knowledge mobilization on palliative care early in a patient’s health was apparent in participants’ reflections as they offered it primarily as in-patients. Some participants stated that this is needed not only for the public but for healthcare providers as well. The readiness of substitute decision makers also played into the need for families to have these conversations prior to a medical crisis.

There's a lot of people who will not talk about these things and I've had it before where I've got the family member there and the family member sitting there shaking their head; they won’t engage in this conversation; the patient will not engage. And I try to explain to them, I know you don't want to engage, but we may end up doing things to you that you don't want or, if we may end up making decisions harder for your family ultimately, where your family has to then try to decide what happens to you without any of your input, which is harder on them. So, you try, but there's some people who, death is not something you talk about, and they will not engage. (P06)

There was also a growing recognition of those patients who were showing up at appointments with no support:

I’ve been able to reflect more deeply on how important the family structure is to people and be even maybe a bit more attuned as well. And to try to identify, to notice patients more that are coming to me without that support. So, patients who
may come to their visit alone, it's been, I guess, a renewed sense, having spent a lot of time with my own family over the last six months, just to remind myself that it is really an important thing to address and just to name and kind of offer space for that patient to talk about, why is there nobody with you at your visit? Who would you normally want here? I can call anybody and invite them into the visit with us by telephone. So maybe, if anything, I think that I've thought about that maybe a little bit more lately. (P11)

SDMs are a large part of the patient’s decision making if they cannot speak for themselves, and the healthcare provider relies on the SDM to learn more about who the patient is a person to help with their healthcare plan. This is why everyone needs to think of these considerations and talk to someone about it, so the SDM does not carry the weight of the decision making. Participant 19 agrees:

Even if the patient is able to make the decisions themselves, I want that family in the room, co-making that decision so that when things get hairy later, the family has been involved with that decision making from the beginning.

Participant 20 also wanted to ensure that we do a better job of educating SDMs:

It becomes much more challenging because family has a great deal of difficulty in removing themselves from the significant emotion of the fact that their loved one's dying and that they don't want that and thinking what their loved one would want and reframing it, not what do you think should happen, but what do they want?

Considering these participants were self-taught through years of experiential learning, they felt learners should take less time to learn these skills. They learned to be confident when asking more questions, giving options, and giving the patient the power of information.

Participant 9 described this as

...pretty neat work. It doesn't get talked about enough. And I think the more we do, the more we learn and understand, the better we'll be able to do it. Will it ever be as sexy in Emerge as putting in a chest tube and opening a chest, for some people probably not, but [its] just as important.
5.3 Thanatological Analysis Summary

My analysis of the information gathered from the questions and data made it apparent that the participants strongly desired to improve patient care. I am grateful for the chance to have spoken with twenty healthcare providers and gain insight into their experiences. Their commitment to their patients is genuinely admirable, and I was honoured to share their stories in a manner that emphasizes the significance of their work. I felt this was a real privilege to have the opportunity to categorize their experiences and give their procedures structure and purpose.
Chapter 6

“Courage gives us a voice and compassion gives us an ear. Without both, there is no opportunity for empathy and connection”.

Brené Brown, 2007

6 Introduction

In this final chapter, I will share the implications participants shared in their experiences and recommendations. Across the scope of the data, I interpreted some interesting thanatological concepts with a thanatology approach. This engaged group of healthcare providers naturally came to these thanatological concepts through their experiences. Still, it was very clear from that data that it takes a long time and a lot of effort. People in the field of thanatology are theorizing about this and researching as these concepts have moved beyond Elizabeth Kubler-Ross’s stages theory from the 1960s. Yet, stage theory is often the only concept people have been introduced to and explicitly reference.

The healthcare providers in this study provided rich data about navigating the healthcare system and their awareness of their challenges as they practice within a flawed system. The disruption occurred as participants spoke about their patients within all stages of their health trajectories. When participants spoke about the conversations with patients and caregivers, they described an integrated care pathway where death is part of the living cycle, which implicitly involves dying and death. Through the participant's experience and reflection on their practice, they included death in the patient’s pathway. In the previous chapters, the findings and results engaged in theory-building through iterative coding from 21 categories into categories: the paradigm of the healthcare provider, the disruptor, prognosis, goals of care and end-of-life, palliative care, a good death, and an integrated healthcare pathway that includes death.

Harvey Chochinov (2022) spoke to a standard rationale of decision-making and care of the patient with “The Golden Rule - do unto others as you would have them do unto you” (p. 1). This means the healthcare provider may choose a specific treatment based on what they want or do if they were the patient. All participants responded in some way about
the importance of transparent conversations because, if it were someone they cared about, they would want the same care for them. However, these participants did not consider the Golden Rule their only moral compass. Numerous participants spoke about the importance of knowing their patients as a human and understanding what is important to them and what they value. This was in line with what Chochinov considers the Platinum Rule (2022) of patient care: “doing unto patients as they would want done unto themselves” (p. 2). From the start of the interviews, it was clear that, as participants shared their experiences, they applied principles from thanatology theory without knowing they were using them. Two participants were aware of some thanatological ideas: one from hearing about Elizabeth Kubler-Ross’s stages and another from taking a thanatology course in their undergrad. But for most participants, there was very little or no formal education on how to have these challenging conversations. For most participants, experiential learning was their only teacher in the absence of formal education. The fact that so many participants were engaged and were doing their best (e.g., not putting a band-aid on the gap in communication and moving patients along to the following healthcare provider) speaks to the kind of person who volunteers to participate in a study like this. I recognized that these participants wanted to help make a change and share their realities in this underdeveloped research area. My interest in this healthcare population was not to generalize but to learn from these participants and how so much of their learning about difficult conversations has been left to chance.

6.1 The Paradigm of the Healthcare Provider

Physicians, surgeons, residents, and medical students must adhere to a Code of Ethics and Professionalism set out by the Canadian Medical Association to support virtues and commitments while respecting their professional responsibilities (The Canadian Medical Association, 2018). The Canadian Nurses Association also has an aspirational and regulatory Code of Ethics for Registered Nurses (The Canadian Nurses Association, 2017). Both sets of codes exhibited what the healthcare providers must demonstrate with the multiple roles they assume: the expert, the advocate, and the caregiver. While we never talked about regulatory codes, I heard from participants about their experiences of how these codes do not include the social, economic, or policy pressures that impact how
healthcare is delivered to patients. However, healthcare providers are responsible for achieving positive health outcomes.

Participants were also responsible for being leaders and team players, honing their ethical expertise and technical skills while still making time to communicate empathically with their patients and their caregivers. Is it realistic for healthcare to ask for a single healthcare provider to accomplish all these expectations? What is considered a success for the patient, and what is regarded as a success for the healthcare provider? What happens when their day appears outside this constructed patient-centred care archetype? Is death still considered a failure? For these participants, the answer was understanding what success meant for the patient so the healthcare provider could advocate for them. Asking questions and giving the patient choices about having a treatment or not having a treatment does not mean they are giving up on them; it is about what success looks like for the patient. The healthcare provider helps manage that.

6.1.1 The Disruptor

The notion of a disruptor became visible early in the interview process. I found that participants were enacting the role of disruptor when sharing their patient care experiences. Participants shared that there was a lot of good news with their patients, but the bad news conversations sometimes took a toll but informed them how to have them better. Some of these conversations were telling patients bad news on their health trajectory, experiencing COVID-19 as a healthcare provider, witnessing the trauma from patients and caregivers being quarantined, telling a patient they are not taking curative chemo, they cannot do anything more for them while not wanting to lessen hope for patients and many more. Some participants described empathizing with their patients but understood that they did not cause the disease. Some participants compartmentalize and liken it to “a layer of soot you would have from the factory that you wash off when you get home after work” (P10, August 5, 2022). All the participants noted a different culture of medicine they practice: “There are options for care, not just big treatments” (P03, June 22, 2022). Participant 2 shared an introspective viewpoint: “I have a fundamental philosophical belief that the end-of-life is still life and that for a lot of people, they still
have developmental end-of-life goals to achieve during that phase” (July 12, 2022). They still have life to live, and they are living up until the moment that they die.

Almost half of the participants experienced someone they cared about going through the present medical culture of maintaining the patient’s life and treating them. Participants who had first-hand experience with loved ones at their end-of-life tried to step back in their roles as providers and instead be caregivers to their loved ones with a life-limiting disease. Their loved ones were not always given the direct prognosis or context for their life-limiting disease. In some cases, the participants had to fill in the blanks for their loved ones: “Yeah, it is difficult, you don't want to be the doctor when it's your own dad, really you want to just be a son and be there for him and not directing his care, 100%” (P17, October 28, 2022). Each participant who experienced the death of a loved one was compelled to create a different pathway that included more conversations and options surrounding treatments. Their experiences helped change the language around cure, care and quality of life.

Participants shared their experiences of working within a flawed system, where curative interventions or active treatments were emphasized more than the patient's well-being holistically. When being brought into a patient’s care, no matter where their patient was in their health trajectory, participants could interrupt their former linear sequence of care to pause at an opportune moment by asking the patient: What did they know about their disease? What did they value? What did they want? Asking patients these questions could happen from diagnosis to the middle of treatment to a juncture where palliative care could and should be introduced. However, participants often shared how they might be the third or fourth person seeing the patient, and the patient would still not understand the seriousness of their illness. In these situations, all participants wished these conversations would have happened earlier. The participants’ responses usually led me to further probing, asking what patients' reactions are when they bring up palliative care support. The answer was that patients usually associated palliative care with imminent death and were unfamiliar with the central roles of pain and symptom management. What was more surprising was hearing that other healthcare providers were unsure when to bring up end-
of-life conversations or referrals for palliative care. That may be why many participants were the third or fourth providers with prognosis news to offer their unaware patients.

The range of participants differed in specialty, years and scope of practice, and education. The common denominator was that all were deeply engaged, experienced, confident, and willing to communicate with patients and caregivers. This is when the participants would read the notes of other healthcare providers and choose to disrupt the linear curative pathway of the patient. In this decision-making by the healthcare provider, their experience in practice provided the curiosity to initiate an emotional conversation with the patient and their caregivers rather than pass the responsibility on to the following healthcare provider. Participants recognized early as medical students or residents that they did not see their jobs finished when they could not cure. They also learned through observation what they would do differently if not in a junior position. They already recognized the flaws in a system where the cure was the focus and death, the failure.

The term ‘curious’ was noted when considering how participants pursued these more difficult conversations. As I reflected more deeply on the interviews, the more relevant term was courageous. The act of further pursuit into uncomfortable conversations that could evoke emotion and silence in patients takes a willing healthcare provider who will follow through with the entire conversation. That takes courage to lead.

Some of the disruptors were in the form of simply asking the patient: “What do you know about your disease?” (P06), “Do you want to discuss your prognosis?” (P13), and “What’s a good day”? (P09). Patients who were offered surgery or further active treatments would have a choice for “a palliative approach or a non-surgical approach, or if they don’t want any treatment, then this may happen, or that may happen” (P12). When it came to decision making, participants were often asked what they would do if it were their loved one: “I really struggle with that question. I do try to tell people … I can't answer them that way, but if they've given me a lot of information about who their loved one is as a person and what's important to them, I will try to guide them based on what they've already shared with me” (P03), “I never would answer that. The question has to be flipped. What do they want? What did they think? And sometimes it's a short loop
from, ‘Oh, we never talked about it. But my mom and I had that conversation a lot. My mom watched my dad die in ICU, and she hated it. And she knew that that wasn’t a good quality of life’ … And then I can say, ‘is that then expressing her wishes, do you think?’” (P09).

When one participant notices new patients brought in overnight and reads their chart, they will often go in and ask the patient: “…can we have a re-discussion? Explain to me what you heard yesterday. What is your understanding of what they went over and see if I can clarify to help you guys with anything” (P08). Many participants were constantly reflecting on the conversations they had. Participant 20 said: “…it’s amazing how these conversations go. You are always learning from them…sometimes I can even ask the patients, ‘How’d that go? Did I answer your questions? Was I ever confusing in any way or any way that you felt I didn’t understand what was going on with you?’” It was the pressing on in dialogue that created engagement in the conversations.

In these spaces, the participants made time for the patients and caregivers to learn more about their values and wishes. As the developer of Dignity Therapy, Dr. Harvey Chochinov (2020) asks patients, “What do I need to know about you as a person to take the best care of you possible?” (p. 1295). This question can be asked at any time in a patient’s health trajectory, which helps the collaboration between the patient and healthcare providers. What kept coming up in the interviews were the linear goals of care pathway for diagnosis, treatment, and cure versus goals of care that include the dying, the death, and the natural completion of the living cycle.

6.1.2 Disruption

The theoretical perspectives can be characterized in two ways: 1) While participants work within the present healthcare pathway that struggles with death as a part of the living cycle, they forged 2) a new integrated pathway that includes death within the living cycle. The participants shared patient stories of how that interrupted the present healthcare pathway and invited their patients to include death in their living cycle.
6.1.3 Prognosis

Over 34 interviews, I listened to participants' accounts of patient health trajectory stories that included a new prognosis, non-curable disease, sudden deaths, patients nearing the end-of-life, and everything in between. According to the participants, some patients were aware of their prognosis and were planning for what it meant in their lives, while others seemed unaware or had not processed their prognosis completely. As a result, participants admitted that they were often the third or fourth person talking about a life-limiting prognosis:

Often, I'm not the first person that sees these people. So, everybody else is passing the baton, and nobody's told them. I've had patients come to me and say, you're the only one. They've seen a medical oncologist, they've seen their family doctor, radiation oncologist. And they turn to me and say, “you're the only one talking like that”. And I sit there, what? You know, I shouldn't be the first one you're hearing this from. (P13, August 17, 2022)

When participants would read the notes in the patient's chart from other providers, the notes were not always clear. One case noted they were on a palliative pathway, but the patient believed their disease was curable. In the effort to gain an understanding of what the patient understood before disclosing their prognosis, participants often led with the following:

…what do you know of your disease? What are you hoping to get out of this? And this is what I foresee with this illness. And so, what do you think you would like knowing that? Do you think you would want to have very invasive things that put you on life support type machines, on ventilators? (P06, May 20, 2022)

Every participant said how important mentorship and observing healthcare providers’ conversations earlier in their careers were to their current practice. This is how they learned.

I've seen some where I think, wow, that was a really good way of explaining it. The family really understood, they were really appreciative or when I come back later, the family will tell me how the way that that physician explained it to them really made sense. You know, they really appreciated the way they took the time
and talked to them. So, I’ve had good mentoring and poor mentoring. (P08, July 5, 2022)

When it came to prognosis, all participants felt it was their duty and responsibility to inform the patients compassionately, as it is the patient’s right to know so they could plan for the remainder of their life. Even when curative treatments were unavailable or inappropriate, the healthcare provider saw the patient as a person. They were still living even if they had a life-limiting disease or were actively dying. There was something more they could be doing, and caring for the patient was not finished.

6.1.4 Goals of Care and End-of-Life

Although they have different purposes, the description of goals of care and end-of-life conversations are sometimes discussed within the same conversations with patients. As explained by Participant 11:

I think there is some overlap; goals of care is a conversation that happens for all admitted to hospital, end-of-life care is when someone is more unwell often in our environment, although with palliative care it can likely be as preparing for that down the road. (August 10, 2022)

When asked how participants learned to have these meaningful and direct conversations, all shared that there was minimal training in their medical education and sometimes there was no training.

I think having more exposure and practice with goals of care discussions earlier on and learning how to how we need to frame them and approach them; I don’t think that’s done necessarily well from earlier on. And I know the curriculum can be challenging because there’s only so much you have to fit into a finite amount of time. But I just don’t think we get enough training with it, and we’re all expected to really lead these important discussions from very early on in our careers and how you approach a goals of care discussion and will drastically affect the outcome of that meeting. So, it’s really, really important. (P03, June 22, 2022)

Some had participated in courses through professional development, but most of their learning was experiential. Participants expressed their use of reflection and how
rewarding it was to have these critical conversations because the patient and their caregivers never forget this. As a result, healthcare providers must speak in a way that demonstrates that they understand the patient's values and beliefs. Patients developing trust and seeing their doctors as human beings while discussing treatment options were critical elements in these conversations. The need for mentorship emerged as a key finding, as Participant 20 described:

...some patients need more guidance than others to help them reach their decision. And you have to be insightful about what's important to them in their life. Before you can really approach this outcome-oriented discussion … and that is what needs to be included with learners, and there needs to be mentoring and coaching. (October 18, 2022).

Participant 5 states: “I think that we need to observe more of these conversations for our learners. I think that we need to have our junior learners watch some, and then do some of them, be with them when they do them” (June 10, 2022). Participants felt that direct language was the best way to have these conversations. However, some participants mentioned that euphemisms were necessary if the patient or their caregivers struggled with the language of death or dying.

Participants also emphasized the role that caregivers played in their ability to have open and honest discussions:

Sometimes it's been great in that, “no, mom has made it very clear there is no way she wants any part of that”. And that makes it really easy; I just say, “thank you. I will be back and talk with you longer”. And then I make sure that the whole room knows where we're going and how we're going to be proceeding in terms of palliating this patient… symptom relief and all of that and looking after that. Then I can have a good conversation with the family. And those ones are nice, ones to say what a gift your mother gave you to have talked about that, to be able to in this, this really difficult time not have to worry about that part of it. But you knew what she wanted. I can do it. I will make it happen. And sort of take that away from them. And we know where we're going, and we can get things going easy and that's the best-case scenario. (P09, July 11, 2022)
However, when they were able to be open about the prognosis and the full range of options for patients (including ending curative treatments), patients and their families often responded with relief:

I get more thank you’s from dead people and their families than I ever do from anyone whose life I saved. So, it's always the people who had a comfortable death and dying process that the family, there's all a lot of fear and sort of worry: am I going to be short of breath? Am I going to be in pain? And if you can make that the best possible experience, they're very much more appreciative than somebody whose potentially life you saved, because there's a lot of fear, anxiety and concern about death and dying. (P04, June 9, 2022)

### 6.1.5 Palliative Care

The term palliative care is a tricky word for some patients and healthcare providers as it has been understood that the patient is dying imminently. Therefore, it is only sometimes suggested until the patient's end-of-days. Ideally, palliative care would be offered when a life-limiting illness is diagnosed, but unfortunately, waiting too long can also mean it is too late for patients to access it. One participant described an interaction with a patient:

I know I need to do this, but he said, “The word just makes me sad.” And I said, “I know”, and that's because around this word, palliative care, it's a death sentence to many people. And that's how we sort of have been brought up to understand palliative care. (P07, June 7, 2022)

Some participants have used other words, like symptom management or comfort care, to ease the language for the patients. However, for one participant, changing the name still creates a death denial:

The reality is we don't get any further in having it less of a death-fearing society if we just try and extract death from conversations or from titles because, at some point, everybody is going to die. And it's a reality of our medical work that we can't prevent all deaths. (P02, July 12, 2022)

During the interviews, it was evident that the participants knew how palliative care could help the patient and their caregivers. Initiating the process of referring patients and seeking assistance from palliative care doctors and increasing the confidence that they
can palliate their patients is likely: “...to ensure that somebody's death is meaningful and is private and their symptoms are managed well” (P04, June 9, 2022). In similar participant stories, understanding how palliative care can support patients was at times avoided by both patients and providers, especially for non-malignant illnesses:

…non-malignant palliative care tends to still have very poor equity. So, most patients with non-malignant illnesses don't have access to palliative care. And as a learner, I had much, much, much, much, much more exposure to malignant conversations about goals of care and treatment plans with patients with cancer than with patients without cancer. And so, it was a lot of learning on the job. (P02, July 12, 2022)

However, some participants reported that what palliative care meant in their environment was different than it may have been in surrounding communities:

I guess our definition of what the palliative care team has to offer this is in the community, is different and so maybe their mandate is different than what I think I need from them or that I think they can do for the family (P07, September 12, 2022).

Many participants encountered patient’s healthcare records (charts) that indicated the patient was considered palliative when the patients understood they were being treated with cure as the central goal. Whether the patient had been told of their prognosis and had not fully processed it or if their provider was avoiding the conversation was ambiguous. I asked the question, who should be disclosing the information to patients? Participants suggested that perhaps without surety of a diagnosis, a provider may feel it would cause harm to the patient. However, other participants noted that acknowledging there is a concern is where they must first disclose this to the patient:

But I think, really whoever the most responsible physician is for that, for the disease that's going to lead to their death, I think that person bears a responsibility to be frank with people. And if they can't sort of walk people through what the transition to end-of-life or what the end-of-life process looks like, either because they don't know, or they're too busy or they're not comfortable, whatever. I think there should be a clear pathway for them to say; I don't have any more therapy for you, I don't think there is any more therapy for you, this is moving towards
terminal and palliative care. And here's some resources for you to hear (P14, October 4, 2022)

6.2 An Integrated Healthcare Pathway – The Living-Dying Cycle

The Canadian healthcare system currently includes the objectives of diagnosing, treating, and curing illness. Death as an outcome of that trajectory is considered a failure to achieve the treatment objectives (Tucker, 2009). The training of healthcare professionals aligns with this objective. However, all healthcare professionals understand that death is part of the everyday living cycle, and there are times when, despite everyone’s best efforts, there are no curative treatment options and no hope for a cure. Because there has not been space for a more integrated pathway through healthcare that includes dying and support for dying well, no mandated curriculum or training was developed that aligns with that reality. These research results call for a more realistic, integrated healthcare system that recognizes death as an inevitable destination for everyone as they journey through life. Explicitly naming and including the destination as part of healthcare would create space to properly train, prepare, and support all healthcare providers to honour all stages of life's pathway – to death.

The interviews represented a small portion of healthcare providers who deal with patients from diagnosis, prognosis, goals of care, end-of-life, and palliative conversations. Beyond the roles of patient care within the present healthcare pathway and through participant experiences, they have created their own patient care guidelines that include death as an eventual outcome. The participants are not passing on the opportunities to speak directly to their patient’s health and by suggesting supports they have made themselves aware of. A patient’s health literacy (P02, July 12, 2022) also came up in the interviews. How does that affect a patient’s collaboration with their healthcare providers? What can their families do to help prepare them for any change in health outcomes? With longer wait times to see patients, participants said that it makes a big difference in time and emotional energy when patients and caregivers are prepared with an understanding of some of the terms and an advance care plan. The care of one’s health must be embraced and include all the conversations that cannot be outsourced to Hospice or have the patient
sent home without someone providing them with further information. Death needs the same attention, focus, and care presumed for the living cycle, which is why an integrated healthcare pathway includes death in the living cycle. Considering how many participants have these life-changing conversations with patients in every work shift, the only participants with palliative care rotations in residency were those specializing in palliative care. Other participants learned through observing mentors and in family meetings, but the majority learned through their own experiences. When I asked a participant about any resources for medical students or residents, they said:

First and foremost, I suggest that anybody who has a medical license should have to spend time in palliative care. I think it's just mind-blowing that we know that people die, that is a universal aspect of our care. Maybe the exception to that is radiology, but people who have received a medical license and have patient-forward roles and inpatient-forward specialties. And if your patients are at risk of dying, I really feel that people should be exposed to palliative care. I don't think there's a good tool [or] course that people learn how to attend to people and the patients in their families in the clinical setting that provides what people need, what trainees need in order to be able to have the lived experience of doing it and seeing it done. And I think that's really challenging. (P02, July 12, 2022)

These participants, on their own, try to make up for this kind of deficit in their training and the shortcomings in how the system is designed for their patients. They are individually trying to do these things based on what they may have learned, what they may have seen from a role model, or what they may have gathered from their own life experience. Leaving it up to chance is concerning. It would be beneficial to have a comprehensive healthcare pathway that incorporates a curriculum and policies tailored to the entire life cycle. This would ensure that all healthcare providers have the necessary skills and knowledge to provide the best care possible for their patients.

The twenty participants in this study had much to say about how their experiences taught them to have conversations about death and dying. They also highlighted their desire to share their knowledge with junior learners and colleagues so they could make a difference in patient care. The participants collaborated on theory building through their
experiences, and many participants had similar experiences despite having different specialties.

Many participants said talking to patients and caregivers about a life-limiting prognosis or end-of-life was uncomfortable. Healthcare providers should have longer conversations with patients to ensure they feel heard and understood, instead of just going through a checklist. This means understanding who the person is and speaking to them about possible treatment options or the lack of options in their health trajectory. As a result, they can have as much information as possible to make an informed decision. Participants suggested that younger learners must lean into that discomfort by exposing themselves to goals of care and end-of-life discussions early to learn how to frame and approach uncomfortable conversations. This early access to learning can help them throughout their careers by caring for the whole person. When I interviewed my last participant, they shared with me how they have these conversations with patients and reflected how many people do not want to talk about their death, but the importance of facing this reality:

> But it’s such an interesting interaction to have and have a meta-view of people’s responses and in how they engage with that. There’s the Harry Potter reference from the final book, The Deathly Hallows, where they talk about the invisibility cloak…there’s the three hallows, and the one is the super powerful wand, the elder wand. And that person uses it for nefarious purposes, and death finds them, and then there’s the one who wants the stone, and I think the stone is the one that sort of gives you eternal life…and they use it for nefarious purposes, and death finds them. And then there’s the invisibility cloak and that one, the person just uses it to evade death, and they just do their life. And then, at the end of it all, they take off the cloak…and he says they greet death as a friend. And that's my mindset about it when it comes to you, [death] it is a friend, and it's time, but you have to lay all the groundwork to be in that headspace. You have to be investing in your relationships to realize that relationships are paramount to a successful life. (P20, October 28, 2022)

Dr. Balfour Mount’s (1993) early research and practice saw the need for whole-person care in healthcare providers treating a person more than only their disease (p. 28). When
having challenging conversations, the patient must know their life has meaning from their healthcare provider.

### 6.2.1 The Good Death

Participants in different specialties had similar experiences with junior medical professionals. They would check boxes on an internal list of important topics to cover, such as resuscitation, when asking patients about their goals of care instead of going over what resuscitation might do to their bodies and their outcome. Participants used words like “good” death, “bad” death, and palliative care. I also explored the different meanings as I returned to participants' descriptions of these words. A few participants articulated the desire to give patients a good death. However, all participants described the importance of creating an atmosphere for patients and their caregivers to receive privacy and support.

The experience of my grandparents’ peaceful deaths, with family circling them, did not include an understanding of the efforts made by healthcare providers to help ensure it was as comfortable as possible. For example, I was unaware then that the sedation provided to my grandparents was used partly to ease and perhaps quiet the usual noises and gasps of a body shutting down to create a “good death” that left such an impression on me. My understanding grew after speaking with the participants who have witnessed many deaths. Participant 2 reflected that “a good death” has morphed into a Westernized “one-size-fits-all model” of what death looks like:

> A good death is such an interesting concept because… it tends to also be a really Western concept… And so, their end of life is informed by what they value. I find a lot of times trying to achieve this, a good death, I find leads to a one size fits all model of how we prescribe and how we manage active dying. That I just find a bit paternalistic sometimes in, making everyone look peaceful and sedated. For me, my practice is much more giving them the type of death that would be consistent with what their wishes and values are and their priorities … I have a fundamental philosophical belief that the end of life is still life and that for a lot of people they still have developmental end of life goals to achieve during that phase. And if I
can treat symptoms while minimizing sedation to keep someone as alert and wakeful to be able to achieve that, especially if that's what they want, then that tends to be my approach to managing that important phase of life. (July 12, 2023)

Participant 8 approaches the conversation by asking the family if they have witnessed a death to understand what they have experienced (or not) to mitigate fears and expectations. For example, some family members expressed frightening experiences:

…the person looked like they were suffocating…drowning, they were in a lot of pain. That's usually the descriptors the family uses when they're concerned about a bad death… I did have a conversation with the physician once…when family do describe bad or good death when we're trying to cover up some of those symptoms, it really is for the family…secretions can be okay. A person's not drowning, but the family seeing that and so they want that to stop…we gave more medications. Still, maybe even the patient isn't in pain and not showing signs of pain and that those secretions are okay, but for family that are sitting there watching…sometimes some of these symptomatic things that we do treat are for a family to feel like this was a good death. (P08, July 5, 2022)

Moreover, another participant described it as ugly:

And then, depending on the cancer…every once in a while, not often, it'll be an ugly death because it's fungating out of the pelvis or something like that…you have this tumour growing into your rectum, into your bladder. You might end up with ostomies and tubes to keep that going…the pressure…is causing all sorts of problems. Swollen legs and pain and it's a miserable death. (P13, August 17, 2022)

Healthcare providers must initiate conversations with patients and their caregivers about their end-of-life goals and wishes and palliative care support. Doing so can show their support and respect for their patients throughout their living cycle pathway. Starting this conversation to ensure patients' needs and desires are met in their final days is never too early.
6.3 Thanatology, Medicine, and Patient-Caregiver-Centric care

Participants practiced another pathway of healthcare. Their knowledge was conceptualized through their experiences in practice due to the lack of formalized healthcare death education across all disciplines. As the participants went through medical school and into their professional designation, they saw the importance of personal perspective informing their professional practice to engage with their patients while disrupting the suggested linear health pathway. Healthcare providers must have a broader understanding of a patient’s diagnosis and prognosis. They need to start by asking their patient what is important to them, but without a healthcare provider understanding why it is important to engage and be present with their patient, the patient and caregivers will sense this gap in care.

While enacting principles and practices aligned with thanatological theories, participants minimized the gap and provided more patient-caregiver-centric care. The participants were implicitly drawing on thanatological concepts in their practice of care, such as anticipatory grief and assumptive beliefs. Still, they may not be aware of the implications of the patient's experience. The participants noted that breaking bad news to patients was a challenging part of the job, but they felt it was their patient's right to know, which is in line with giving as much information as possible so they could plan for their next steps. Even though how patients received bad news was not explicitly referenced in the data, it was intrinsically present throughout the data, and this was an essential part of their practice in treating the whole patient. The participants learned from their patients how to have better conversations from their experiences and enacted change from that. What reactions after the news from the patient and their caregivers the healthcare provider cannot predict. However, some of the thanatology theories most prevalent in the data would benefit the healthcare providers with background information to be better prepared and aware of different losses. This basic understanding is to help support the patient and their caregivers and for healthcare providers to recognize when they may need to bring in more support. Is it essential for healthcare providers to be aware that how they talk about
diagnosis, prognosis, and end-of-life conversations affects how patients and their caregivers process this information for the rest of their lives. Participant 10 contemplated that perhaps,

... patient-centred teaching as opposed to patient-centred education...having an element of a family member if they're willing to come and talk about what they like or don't like out of all of these...we get all these formulas of breaking bad news, give a warning shot and wait and then do this...keep asking the questions and give them time. And there's all these strategies which are very valuable...one piece that's probably missing is the whole component of having a patient, potentially a patient family member...involved in when we heard this is what we needed...that would probably be very valuable. (October 11, 2022)

Participant 10 talked about patient-centred teaching and wanting to learn more about how these conversations are landing with patients. Thanatology literature reports on how these conversations are being received, as thanatology is the reaction, voice, and call to how people are treated when there is a loss in their lives.

### 6.4 Recommendations

When learning how participants had these end-of-life conversations, they learned extemporaneously and were not directly exposed to theories from thanatology. However, they have developed an understanding of these theories through their experiences. They may not have explicitly talked about anticipatory loss or assumptive beliefs; still, they recognized the principles of anticipatory loss and assumptive beliefs in how they enacted patient-centric care. Many spoke about the challenge of learning it through experience, the experience of doing, way less so than the experience of personal life experience. But the experience of having these conversations and feeling that they are important.

As a student of curriculum, I know that when students are introduced to information – whether theoretical or practical, deep learning is often consolidated and strengthened when they have an opportunity to apply it across various contexts. This is why many students feel that they are learning once they are in residency and in practice. Both are necessary. Introducing knowledge, ideas and language to medical students helps set them
up with what they will need to draw on once they are in practice. Similarly, practice will continue to refine and revise their existing theoretical knowledge. The reciprocity of theory-informed practice and practice-informing theory helps the professional be mindful of the ‘theories-in-use’ and reflexivity that leads to their ongoing professional growth. Thinking about where this research might have some application from a medical education lens, may be through some core conceptualizations that thanatology has advanced but need to be taught explicitly in medical schools, residency programs, or continuing professional development (CPD). Medical schools might want to collaborate with faculty from departments of Thanatology to look at their curriculum and ask what core concepts might be relevant. My participants suggested that they did not get any explicit teaching about these concepts, and while some of them seemed to come to do practices that aligned with a thanatological approach, it was left to chance; a good mentor, the right experiences, at the right time, or their desire to independently seek new learning that brought them to that point. Introducing the language and concepts would remove the ‘chance’ that they would get this learning and ensure they had it much earlier. In residency programs where people may be responsible for end-of-life conversations, core concepts could be introduced to the faculty and their residency program directors. For practicing healthcare providers taking on more end-of-life conversations, thanatology may have a role to support in practice professionals. CPD is a strategy that is often used, and thanatology could share some of those understandings and help healthcare providers recognize that they may have some intuitive understandings of these, but that grappling with the theories may provide deeper, richer insights that may allow them to support families better.

At the Government and policy level, and from a population health standpoint, there may be opportunities for better education about the population and for Funders as they recognize the importance of supporting people to take the time needed to do this important work. These preparatory conversations would be helpful to have before a medical visit, as the participants did say that they sometimes feel they cannot have a deeper conversation given time constraints. Therefore, these introductory conversations with their primary healthcare providers should have their own billing codes, considering there are different billing codes for counselling, so they do exist to do it.
Finally, participants were disruptors by stepping away from the linear pathway that seems to be happening in healthcare. This disrupting action resonates with the existing literature, suggesting that their experiences are not unique and that many feel that way, especially those in the palliative care community.

6.5 Summary

Although I found the presence of thanatological theories in this research, it became clear that healthcare providers would benefit from early and explicit education in this area. While participants may not have known the theory, it was visible in their desires, intentions, and actions of caring for their patients and caregivers. All participants enacted thanatological practice from years of observation and experiential learning. First and foremost, they were reflective and conscientious in their life as humans before they enacted the consideration they bring to patients and caregivers. They saw their patients in front of them as a human with life to lead and not as a checklist. Participants were always aware of their words, body language, and responses to the patient and caregiver’s questions. They understand that it will be remembered, repeated and have some effect on their patient and caregivers beyond that conversation. Precisely in the way that Robert Buckman (1992) shared the patient experience when receiving bad news:

> The task of breaking bad news is a testing ground for the entire range of our professional skills and abilities. If we do it badly, the patients or family members may never forgive us; if we do it well, they will never forget us.

(pp. 208-209)

The participants were mindful of the challenges the people were facing. They understood the importance of their conversation and were dedicated to their role. The healthcare provider's main objective was to comprehend what matters most to the patient and how they can work with them on their health trajectory.
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Appendices

Appendix 1: Ethics Approval - Lawson Final Approval Notice

LAWSON FINAL APPROVAL NOTICE

LAWSON APPROVAL NUMBER: R-22-101

PROJECT TITLE: Physician, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

PRINCIPAL INVESTIGATOR: Kathy Hibbert

LAWSON APPROVAL DATE: 1/03/2022

ReDA ID: 11910

Overall Study Status: Active

Please be advised that the above project was reviewed by Lawson Administration and the project was approved.

"COVID-19: Please note that Lawson is continuing to review and approve research studies. However, this does not mean the study can be implemented during the COVID-19 pandemic. Principal Investigators, in consultation with their program leader or Chair/Chief, should use their judgment and consult Lawson’s research directive and guidelines to determine the appropriateness of starting the study. Compliance with hospital, Lawson, and government public health directives and participant and research team safety supersede Lawson Approval."

Please provide your Lawson Approval Number (R#) to the appropriate contact(s) in supporting departments (eg. Lab Services, Diagnostic Imaging, etc.) to inform them that your study is starting. The Lawson Approval Number must be provided each time services are requested.

Dr. David Hill
V.P. Research
Lawson Health Research Institute
Appendix 2: Ethics Approval – HSREB & WREM

Dear Dr. Kathryn Hibbert

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.

Documents Approved:

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No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.
Appendix 3: Ethics Approval – WREM – 1st Amendment

Date: 7 April 2022
To: Dr. Kathryn Hibbert
Project ID: 120178

Study Title: Physician, resident, and nurse practitioner’s experiences with patients about end-of-life conversations
Application Type: HSREB Amendment Form
Review Type: Delegated
Meeting Date / Full Board Reporting Date: 26/Apr/2022
Date Approval Issued: 07/Apr/2022
REB Approval Expiry Date: 01/Mar/2023

Dear Dr. Kathryn Hibbert,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

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REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00009040.

Please do not hesitate to contact us if you have any questions.

Sincerely,
[Redacted]
behalf of Dr. Philip Jones, HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix 4: Ethics Approval – WREM – 2nd Amendment

Date: 15 July 2022
To: Dr. Kathryn Hibbert
Project ID: 120178
Review Reference: 2022-120178-68747
Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations
Application Type: HSREB Amendment Form
Review Type: Delegated
Meeting Date / Full Board Reporting Date: 09/Aug/2022
Date Approval Issued: 15/Jul/2022 09:38
REB Approval Expiry Date: 01/Mar/2023

Dear Dr. Kathryn Hibbert,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

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REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guidelines (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000340.
Appendix 5: Ethics Approval – WREM – Continuing

Date: 10 February 2023
To: Dr. Kathryn Hibbert
Project ID: 120178
Review Reference: 2023-120178-76158
Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations
Application Type: Continuing Ethics Review (CER) Form
Review Type: Delegated
REB Meeting Report Date: 21/Feb/2023
Date Approval Issued: 10/Feb/2023 17:41
REB Approval Expiry Date: 01/Mar/2024

Dear Dr. Kathryn Hibbert,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP), Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Electronically signed by:

[Signature]

Reason: [Signature] of Dr. P. Jones, HSREB Chair 10/Feb/2023 17:41

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix 6: Protocol

Protocol #120178

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Research Team:

Principal Investigator (PI):

Dr. Kathy Hibbert, Ph.D. (KH), is a Professor and Associate Dean of Teacher Education in the Department of Education at Western University. For this study, she will be the primary supervisor assisting with overall study management and development, data collection, data analysis, and dissemination of results.

Faculty of Education, Western University
XXXX Western Road, London, ON, Canada N6G 1G7
e. XXXXXXX@uwo.ca

Co-Investigator:

Jill Dombroski, BA Honors in Women’s Studies and Thanatology, MA Education, (JD), is a Ph.D. candidate in the Curriculum program in the Faculty of Education. This work is being completed as part of her Ph.D. Thesis. JD will be involved in all aspects of this project, including study conceptualization, development and refinement of study materials, ethics support, data collection, analysis, and the presentation of research findings.

e. XXXXXXX@uwo.ca

Lay Summary

Given the lack of knowledge mobilization on death and dying conversations in medical education literature (1), it is unclear if physicians are aware of alternative theoretical frameworks and research that may support their patients and caregivers. However, awareness of new ideas is insufficient. As Downar (1) argues, “undermined by the ‘hidden curriculum’ in medical education; interventions must be accompanied by continuing education and faculty development to create lasting change in physician behaviour” (1). Taking into consideration how grief is not spoken about at length in general medical training programs (2), how participants make sense of their experiences and organize themselves during these conversations with patients will help identify how thanatology has some promising options to support better conversations around end-of-life.

Background and Rationale for Study

Leading discussions with patients about the reality of an end-of-life prognosis constitutes a challenging conversation. Further complicating an already challenging conversation is the reality that many health care practitioners lack sufficient training in holding this
conversation and may have had little or no exposure to training around Advance Care Planning (ACP) or Medical Assistance in Dying (MAiD), which may make leading such discussions more challenging. What might inform physicians’ capacity to engage with patients in these end-of-life discussions are thanatology teachings (3-7).

Death and dying is a complex phenomenon, and the process for engaging in meaningful dialogue with patients and their families who are struggling with end-of-life support requires a broader understanding than what is presented in the still dominant work introduced by Elizabeth Kübler-Ross (8). Literature from the fields of thanatology and palliative care have advanced researchers’ understandings of Kubler-Ross' early theory, yet these advancements in learning do not appear to be taken up specific to medical education literature.

However, further exploration and attention are needed to advance work on this topic and improve end-of-life communication. Educating people about death, dying, and bereavement not only comes in a formal classroom to fulfil competencies (9) but often in more informal or unplanned ways through interactions with family, friends, and social media (10). Corr et al., (10) believe there are four dimensions related to teaching death, dying, and bereavement education that includes: “what people know, how they feel, how they behave, and what they value” (10). Practically speaking, teaching death education requires active participation for the student to reflect, be vulnerable, the willingness to see resiliency in loss, and the ability to move through that to be available for those who may need them (11).

Recent advancements in thanatology literature (death systems, culture, grief, and bereavement) practices and training could offer physicians meaningful ways of thinking that could develop the end-of-life support they provide to patients.

**Research Objectives and Research Questions**

This project aims to co-construct and support developing new training or preparation in this area of death and dying conversations for training physicians. Understanding how physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners have these conversations with or without prior experiences or training on death and dying conversations, will allow the ability to share their practice experiences by ultimately improving the quality of end-of-life conversations they have with their patients.

**Research Questions**

Specific research question(s) include:

1) What are the theoretical perspectives and personal or professional experiences physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners draw on during end-of-life conversations?

2) In what ways have these changed over time as a result of the introduction of MAiD in Canada?

3) How might theories from thanatology specifically contribute to training or preparation in this area?

**Methodology and Methods: Research Design**

This qualitative study will use Constructivist Grounded Theory (CGT) to guide our data collection and analyses. Constructivism allows us to collect and value multiple, equally valid realities, and CGT provides a set of clear guidelines that will enable us to build
explanatory frameworks from the experiences shared by participants (12). The details of each data collection stage below note our interest in creating a framework for understanding the participant's experience with their patients. CGT is a helpful approach to meet our research objectives.

**Research Sites**
As detailed below, individual interviews and focus groups will be conducted virtually via video conferencing software Western Corporate ZOOM in the interest of maintaining physical distancing measures. Thus, while the study team will be based at Western University, research activities involving interactions with research participants who are employees of the London Health Sciences Centre (LHSC), or community-based, will be performed through online media. Given the uncertainty regarding the COVID-19 situation and the duration of protective measures, the method of a focus group or interview (electronic) will respect the physical distancing guidelines determined by the University, LHSC and the government in order to maintain the safety of all involved. Study data collected will be stored within a secure drive folder on the secure Western University Network.

**Study Population, Sampling, and Recruitment**

**Inclusion Criteria**
We will include:

- **Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners:** who are able to read and communicate in English.
- **Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners:** who work within the London Health Sciences Center (LHSC) or who may be community-based.
- **Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners:** who regularly speak to and hold end-of-life conversations with patients who are seriously or terminally ill.

**Exclusion Criteria**
We will exclude:

- **Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners:** who work within the London Health Sciences Center (LHSC) or who may be community-based, treat pediatric patients (age >16).
- **Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners:** who do not regularly speak to and hold end-of-life conversations with patients who are seriously or terminally ill.
- **Physicians, senior residents (PGY3 and above), and nurse practitioners:** who cannot read and communicate in English.

**Sampling**
We will engage in purposive sampling (13). Key informants who are known colleagues of the research team will be asked to identify colleagues whom they believe regularly hold and take part in end-of-life conversations and may provide valuable insights around holding these important conversations.

**Recruitment**
Physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners who work within LHSC or who may be community-based.
Members of the research team will contact via email (Appendix F) clinicians who have expressed an interest in helping support study recruitment to members of the research team as key informants. Key informants, who are known colleagues of the research team, will recruit participants through email (physicians, surgeons, residents (PGY3 and above), and nurse practitioners) who regularly hold end-of-life conversations and those they feel could provide important insights about holding these conversations. Key informants will email (Appendix F) the identified physicians, surgeons, residents (PGY3 and above), and nurse practitioners on behalf of the research team to inform them that the research team is conducting a research study that may be of interest and provide further study details and provide them with a letter of information (LOI) (Appendix A). After receiving the information about the study, the physician, surgeons, residents (PGY3 and above), and nurse practitioners will be informed at the time that they are under no obligation to participate in the study, and their decision will have no bearing on their position or standing within LHSC or their community-based practice. They can decide whether or not they would like to participate and are free to contact members of the research team directly. Two reminder emails (Appendix G) may be sent out every two weeks if recruitment is low.

Withdrawal of Study (By Research Team)

The research team members will elect to withdraw participants from the study if concerns emerge around a participant’s ability to provide informed consent, concerns with participants’ ability to engage in an interview process appropriately, or if participants experience any observable distress during the study duration that prompts safety concerns. In the event of these circumstances, members of the research team or the clinicians will have contact information for counselling support services available (Appendix H) and will provide the participant with the opportunity to debrief.

Benefits

While it is possible that there may be no direct benefit to participation, we think this is highly unlikely. The most likely benefit of this study is that information learned from this study may lead to improving the education of physicians or other healthcare providers who engage in end-of-life conversations with patients to improve our collective ability to ‘die with dignity’. Another possible benefit is that clinicians may feel better prepared to have these conversations with patients and substitute decision makers through these conversations.

Costs

There will be no costs incurred as a result of participating in this study.

Compensation

You will not be compensated for your participation in this research.

Risks

There is minimal risk for participating in this study. Participants are free to share only the information they choose to with the research team, and they may discontinue participation at any time. There is also the risk of a privacy breach.
There is minimal risk to participation for physicians, surgeons, residents (PGY3 and above), and nurse practitioners. They are free to choose what they share with the study investigator and research team. They may reflect on difficult situations they have encountered that could trigger a variety of emotions. They may discontinue their participation at any time, and support or counselling resource contact information can be provided to them (Appendix H). Because of the nature of focus groups, privacy breaches are also a possibility. Although the research team will make every effort to ensure participants respect the confidentiality of the group and the information shared, unfortunately, we will not be able to ensure this after the focus group ends. The opportunity to debrief any adverse events that occur during the interviews will be made available to participants if needed.

Consent Process

Individual Interviews

Before collecting any data, individuals who have expressed interest in participating in the study will be sent a Letter of Information (LOI) (Appendix A) via email and will be given time to review the document and have any questions answered. Phase 1 - Prior to the start of the scheduled interviews (Appendix C), the research team will complete a verbal consent document (Appendix B) in consultation with the participants. The verbal consent document and interview will be completed simultaneously to document the verbal consent given in the interviews and serve as physical documentation for the consent process for the PI. Verbal consent will also be captured on the interview recording for further documentation. Phase 2 - Prior to the start of the scheduled interviews (Appendix D), the research team will complete a verbal consent document (Appendix B) in consultation with the participants. The verbal consent document and interview will be completed simultaneously to document the verbal consent given in the interviews and serve as physical documentation for the consent process for the PI. Verbal consent will also be captured on the interview recording for further documentation.

Focus Groups

Phase 3 – Prior to the start of the virtual focus group interview (Appendix E), the research team will complete a verbal consent document (Appendix B) in consultation with the participants. The verbal consent document and interview will be completed simultaneously to document the verbal consent given in the interviews and serve as physical documentation for the consent process for the PI. Verbal consent will also be captured on the interview recording for further documentation.

Data Collection

Interviews

Interviews will be conducted through Western Corporate Zoom in order to comply with appropriate physical distancing measures. Data collected in this phase of the study will consist of transcripts that will be video and audio-recorded using the Western Corporate Zoom recording feature. Since Western Corporate Zoom will only record audio and video simultaneously, participants will be given the option to turn their video off during the
interview, and the video file will be permanently destroyed immediately upon completion of the interview.

The primary data collection method will be a semi-structured in-depth interview (Appendix C). At a time mutually agreed upon by the research team and participant, two interviews will take place with each participant. After the transcription and review of the first transcript, a second interview (Appendix D) will be scheduled to explore any evolving theories further and expand upon participants’ previous answers, which will allow for a deeper collaborative analysis and ensure ample opportunity to reach saturation.

Based on prior studies, we anticipate that our recruitment aims of 20-30 participants in total (ten physicians, ten senior residents (PGY3 and above), and ten nurse practitioners).

**Focus Groups**
After completing all participant interviews, participants will also have the choice to participate in a focus group (Appendix E) to watch and discuss three short video clips from the Canadian Virtual Hospice gallery. Watching these videos will allow for further data collection by participants who may work in a different department but have similar conversations (14).

Focus Groups will be conducted through Western Corporate Zoom in order to comply with appropriate physical distancing measures. Data collected in this phase of the study will consist of transcripts that will be video and audio-recorded using the Western Corporate Zoom recording feature. Since Western Corporate Zoom will only record audio and video simultaneously, participants will be given the option to turn their video off during the focus group, and the video file will be permanently destroyed immediately upon completion of the focus group.

Each group interview will consist of three to five participants as recommended in previous studies (15) and last approximately 60-90 minutes. Identifying information such as their name and institution will be removed from the transcripts collected. A de-identified study ID number will be linked to your data to protect individual participants’ anonymity.

**Data Analysis**
Interview and focus group recordings will be transcribed verbatim, de-identified, and imported into NVivo 12 for coding. We will analyze interview transcripts and written reflections in an iterative process through four increasingly interpretive stages (12):

1) Initial Coding
The first two to three transcripts will be read line-by-line and coded independently by members of the research team with the goal of describing participants’ perspectives through gerunds (words ending in “-ing”). This is to ensure that preliminary findings are “grounded” to the data (12).

2) Focused Coding
Preliminary themes that arise from initial coding will be used to code subsequent transcripts. This stage is more interpretive, and the research team will discuss these preliminary themes frequently and determine a finalized list of themes by consensus. Throughout, sensitizing concepts from the literature on thanatology and end-of-life will be used to inform both interpretation of the data and the subsequent types of data that will be pursued in future interviews.
3) Theoretical Coding
Themes arising by consensus from focused coding will be used to re-code the entirety of the data set.

4) Theoretical Sampling
Theoretical Sampling will be used to go back to previous interviewed participants for further clarification and refinement of ideas to elaborate and saturate key concepts (12). JD and KH will be involved in data analyses.

Rigour
Rigour will be ensured through the use of constant comparison (as new data is collected, prior data will be reanalyzed in light of the new data and new coding identified), investigator triangulation (the team consists of a mix of clinicians and non-clinicians) and memoing to reflect both on the process of analysis and their own perspectives and how these may be influencing the research. Additionally, data will be collected until theoretical sufficiency is achieved, ensuring that discordant findings are used to inform future data collection as the research proceeds. Theoretical saturation is achieved by using the process of constant comparative analysis; going back and forth between the data, sharing the data with participants as co-researcher, that some of the categories may change due to the interactions throughout the analysis, but theoretical saturation is reached once the new data no longer is creating further insight into the present categories (16; 12).

Withdrawal of Study
Participants can choose to withdraw from the study at any time. If they decide to withdraw from the study, they have the right to request the withdrawal of information collected about them at any time through email or telephone. If participants wish to have their information removed, they can let the researcher know. While their study data may be destroyed if the participant withdraws from the study, given the iterative nature of this research, the researcher team may not be able to remove participant data totally.

NOTE: Once the study has been published, we will not be able to withdraw information.

Confidentiality and Data Storage
Given the uncertainty of the COVID-19 situation, paper copies of the verbal consent form will be filled out by JD, scanned and uploaded to the secure Western OneDrive. The written copy will then be destroyed. A master list linking participants alphanumeric code to their identity, audio recordings, and transcripts will be stored securely within Western’s secure OneDrive.

Outside the research team, a transcription program (Trint) will be used to transcribe the interview and focus group data. Audio recordings securely stored on Western’s secure OneDrive will be uploaded to Trint for transcription. For data transfer and storage, Trint uses HTTPS (using TLS 1.2) for secure data upload, export and transfer. Data is encrypted at-rest using AES 256. Physically, Trint stores the data in data centers owned and operated by Amazon Web Services (AWS) in the us-east-1 (N. Virginia) region. All data is encrypted at-rest using the industry standard AES-256 algorithm. These data centers deliver the very highest levels of physical and infrastructure security. https://info.trint.com/hubfs/Security-at-Trint.pdf?tid=17d7c18727f475-033439881032e28-3fd2684b-15f900-17d7c18728011f4. All files will be permanently deleted through an email request to Trint. Trint is GDPR compliant, and all will be erased within the legally prescribed timeframe (30 days).
Any identifiable information (E.g., participant name, institution, etc.) will be removed from the transcripts and de-identified with an alphanumeric code by JD. In the master list, alphanumeric codes will be linked to participant data to protect the anonymity of participants. The management of the master list will be delegated to JD for the duration of the study. At the conclusion of the study, the master list will remain in Western’s Secure OneDrive.

Computer files, including interview recordings, raw transcripts, and de-identified transcripts will be stored on the secure password-protected Western’s secure OneDrive in separate folders from one another. The raw transcripts and audio files will be destroyed once they are no longer needed.

The research team will keep any personal information in a secure and confidential location for 15 years (as per Lawson Health Research Institute policy).
Appendix 7: Letter of Information (A)

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Principal Investigator (PI):

Dr. Kathy Hibbert, Ph.D. (KH), is a Professor and Associate Dean of Teacher Education in the Department of Education at Western University. For this study, she will be the primary supervisor assisting with overall study management and development, data collection, data analysis, and dissemination of results.
Faculty of Education, Western University
XXXXXX Western Road, London, ON, Canada N6G 1G7
e. XXXXXX@uwo.ca

Co-Investigator:

Jill Dombroski, BA Honors in Women’s Studies and Thanatology, MA Education, (JD), is a Ph.D. candidate in the Curriculum program in the Faculty of Education. This work is being completed as part of her Ph.D. Thesis. JD will be involved in all aspects of this project, including study conceptualization, development and refinement of study materials, ethics support, data collection, analysis, and the presentation of research findings.
e. XXXXXX@uwo.ca

Introduction

You are being invited to participate in this research study because you are a physician, surgeon, senior resident (PGY 3 and above), or nurse practitioner working within the London Health Sciences Center (LHSC), or who may be community-based, with or without prior experiences or training on death and dying to share end-of-life conversations you are having with your adult patients.

This letter contains information to help you decide if you wish to participate. Please feel free to ask further questions if any study part is unclear.

Background/Purpose

Leading discussions with patients about the reality of an end-of-life prognosis constitutes a challenging conversation. Further complicating an already challenging conversation is the reality that many health care practitioners lack sufficient training in holding this conversation and may have had little or no exposure to training around Advance Care Planning (ACP) or Medical Assistance in Dying (MAiD), which may make leading such discussions more challenging. What might inform physicians’ capacity to engage with patients in these end-of-life discussions are thanatology teachings.
Death and dying is a complex phenomenon, and the process for engaging in meaningful dialogue with patients and their families who are struggling with end-of-life support requires a broader understanding than what is presented in the still dominant work introduced by Elizabeth Kübler-Ross. Literature from the fields of thanatology and palliative care have advanced researchers’ understandings of Kübler-Ross’ early theory, yet these advancements in learning do not appear to be taken up specific to medical education literature. However, further exploration and attention are needed to advance work on this topic and improve end-of-life communication. Educating people about death, dying, and bereavement not only comes in a formal classroom to fulfil competencies but often in more informal or unplanned ways through interactions with family, friends, and social media. Corr et al. believe there are four dimensions related to teaching death, dying, and bereavement education that includes: “what people know, how they feel, how they behave, and what they value”. Practically speaking, teaching death education requires active participation for the student to reflect, be vulnerable, the willingness to see resiliency in loss, and the ability to move through that to be available for those who may need them.

The objective of this study aims to co-construct and support developing new training or preparation in this area of death and dying conversations for training physicians. Understanding how physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners have these conversations will allow them to share their practice experiences by ultimately improving the quality of end-of-life conversations they have with their patients.

**Research Questions**

Specific research question(s) include:

1) What are the theoretical perspectives and personal or professional experiences physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners draw on during end-of-life conversations?

2) In what ways have these changed over time as a result of the introduction of MAiD in Canada?

3) How might theories from thanatology specifically contribute to training or preparation in this area?

**Study Procedures**

You are being asked to participate in two individual interviews, and the opportunity to join a focus group with other participants and colleagues within the same healthcare field. All dialogue aims to discuss your approach when speaking to patients who are seriously or terminally ill in end-of-life decision-making conversations.
You are invited to participate in all phases at a date and time convenient for you. However, you can decide after each interview whether you would like to continue participating in the next phase(s) or not.

Semi-structured interviews will be used with approximately 20-30 physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners, with each interview lasting approximately 45 – 90 minutes. Interviews will be audio and video recorded using Western Corporate Zoom and transcribed verbatim by a professional transcription service (Trint). Since Western Corporate Zoom will only record audio and video simultaneously, participants will have the option to turn their video off during the interview. The video file will be permanently destroyed immediately upon completion of the interview.

If you choose to participate in all interviews and the focus group, verbal consent will be captured prior to each recording. You will be asked to reflect on and provide details about how you prepare for end-of-life conversations with patients.

These are the three progressive phases of this study:

1. Interview #1 - Individual interviews through Western Corporate Zoom will be conducted and recorded for approximately 45 – 90 minutes.

   a. After your first interview has been completed and transcribed, I will email you from my Western email address to your LHSC or work email address and return the transcripts to reflect, comment, change, or elaborate when we meet for our second interview.

2. Interview #2 - Individual interviews through Western Corporate Zoom will be conducted and recorded for approximately 45 – 90 minutes. We will go over your reflections from your previous interview and expand on those discussions.

3. Focus Group - Western Corporate Zoom will be conducted and recorded for approximately 60 – 90 minutes. After all the second individual interviews are complete, I will invite all participants to join and engage with a focus group of professionals in the same field. I will share three short video clips from the Canadian Virtual Hospice gallery. We will watch them together and then discuss each clip.

Based on the data collected, the research team may contact you to ask follow-up or clarification questions outside of the interview sessions with your permission.

**Voluntary Participation**

Your participation in this project is voluntary. The alternative to this project is not to participate. If you do not wish to be audio recorded, you cannot participate in this project. The decision of whether or not to participate will not impact employment or any other relationship with LHSC/Western or your community-based practice.
Withdrawal of Study

Participants can choose to withdraw from the study at any time. If they decide to withdraw from the study, they have the right to request the withdrawal of information collected about them at any time through email or telephone. If participants wish to have their information removed, they can let the researcher know. While their study data may be destroyed if the participant withdraws from the study, given the iterative nature of this research, the researcher team may not be able to remove participant data totally.

NOTE: Once the study has been published, we will not be able to withdraw information.

Risks

There is minimal risk to participation. You are free to choose what you share with the study investigator and research team. You may reflect on difficult situations you have encountered that could trigger a variety of emotions. You may discontinue your participation at any time, and support or counselling resource contact information can be provided to you.

Because of the nature of focus groups, privacy breaches are a possibility. Although the research team will make every effort to ensure participants respect the confidentiality of the group and the information shared, unfortunately, they will not be able to ensure this after the focus group ends. The opportunity to debrief any adverse events that occur during the interviews will be made available to participants if needed.

Benefits

While it is possible that there may be no direct benefit to participation, we think this is highly unlikely. The most likely benefit of this study is that information learned from this study may lead to improve the education of physicians or other healthcare providers who engage in end-of-life conversations with patients, to improve our collective ability to ‘die with dignity’. Another possible benefit is that through these conversations, clinicians may feel better prepared to have these conversations with patients and substitute decision makers.

Confidentiality

Given the uncertainty of the COVID-19 situation, paper copies of the verbal consent form will be filled out by JD, scanned and uploaded to the secure Western OneDrive. The written copy will then be destroyed. A master list linking participants alphanumeric code to their identity, audio recordings, and transcripts will be stored securely within Western’s secure OneDrive.

Outside the research team, a transcription program (Trint) will be used to transcribe the interview and focus group data. Audio recordings securely stored on Western’s secure OneDrive will be uploaded to Trint for transcription. For data transfer and storage, Trint
uses HTTPS (using TLS 1.2) for secure data upload, export and transfer. Data is encrypted at-rest using AES 256. Physically, Trint stores your data in data centers owned and operated by Amazon Web Services (AWS) in the us-east-1 (N. Virginia) region. All data is encrypted at-rest using the industry standard AES-256 algorithm. These data centers deliver the very highest levels of physical and infrastructure security. https://info.trint.com/hubfs/Security-at-Trint.pdf?tid=17d7c18727f475-033439881032e28-3f62684b-15f900-17d7c18728011f4. All files will be permanently deleted through an email request to Trint. Trint is GDPR compliant, and all will be erased within the legally prescribed timeframe (30 days).

The Quality Assurance and Education Officers from Lawson Health Research Institute (Lawson) may audit this research study for quality assurance purposes. Representatives of Western University’s Health Sciences Research Ethics Board and Lawson’s QAEP may require access to your study-related records to monitor the conduct of the research.

Identifying information such as your name and other personal identifiers will be removed from collected data and replaced with an alphanumeric code that will be linked to your data to protect individual participants’ anonymity. The management of the master list will be delegated to JD for the duration of the study. At the conclusion of the study, the master list will remain on Western’s secure OneDrive.

If the results of the study are published, your name will not be used.

Please be advised that although the researchers will take every precaution to maintain the confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus groups to others.

Costs

There will be no costs incurred as a result of participating in this study.

Compensation

You will not be compensated for your participation in this research.

Rights as a Participant

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate, you have the right not to answer individual questions or to withdraw from the study at any time. If you choose not to participate or leave the study at any time, it will not affect your position.

You do not waive any legal right by consenting to this study.
Questions about the Study

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844-720-9816, email: ethics@uwo.ca. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss will be kept confidential.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact the Patient Relations Office at LHSC at (519) 685-8500 ext. 52036.

You may also contact the Principal Investigator, Dr. Kathy Hibbert at XXX.XXX.XXXX (xXXXXX) or XXXXXX@uwo.ca if you have any questions regarding the study.

If you have questions or are interested in participating in this study, please feel free to contact Jill Dombroski at XXXXXX@uwo.ca for further assistance.
Appendix 8: Verbal Consent Form (B)

Appendix B: VERBAL CONSENT FORM

Study Title: Physician, surgeon, senior resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Date and Time of Interview: ______________________________

Please state your name for me BEFORE I start recording: ________

Any questions from participant before verbal consent obtained? ________

Participant has received Letter of Information (LOI) and been given enough time to review. ________

The participant was offered the opportunity to ask questions and discuss the information found in the LOI. ________

Do you have any questions that have not been addressed? ________

Do you provide verbal consent and agree to participate in this research study? ________

Do you agree with being audio and video recorded in this interview? ________

Date and Time of Verbal Consent: ______________________________

Consent Documented by (Please Print): ______________________________

Signature of Person Obtaining Verbal Consent: ______________________________

Participant Alphanumeric Code: ______________

Version 3: July 12, 2022
Appendix 9: Interview Guide (Phase 1) (C)

Appendix C: Interview Guide (Phase 1)

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Interview Process and Questions:

1) Complete Verbal Consent Documentation with Participant.

2) Preamble: Thank you for agreeing to participate in this interview today. I want to remind you that your participation in this project is voluntary and that you may choose to end your participation at any time. I will also remind you that this interview will be audio and video recorded to help with our analysis and that you have the option to turn off your video if you wish. I also want you to know you have the choice not to answer or skip any questions asked. My supervisor Kathy Hibbert, the transcription company Trint, and myself, Jill Dombroski, will have access to the recordings.

3) Start recording.

4) State date and time of interview for recording.

5) Verify that the Verbal Consent Process has been completed and documented with the participant on the recording.

6) Please describe a little bit about your clinical practice.
   a) How often are you involved or included with patients and their families around the issues of death and dying?
   b) In the past few weeks, have you had an encounter with a patient and their family related to death and dying?
   c) (If they have) Of those, is there one that you feel represents the typical type of conversation you have with patients and families?
   d) (If they have) Were there any challenges in the conversations?
   e) Can you tell me what was challenging about it?
   f) How did you handle it?
   g) Are there any variations that are different from the conversation you have with each patient?

7) How many years have you been in practice?
   a) How has your style changed?
   b) Are there any pivotal moments or things that happened in your life or education that helped to make those changes or instigated those changes?
   c) If you're comfortable, may I ask if you have had any personal experience as a family member or with the loss of someone you care about?
   d) In what way do you think that has impacted how you have these conversations, or in what way has that not impacted?

8) Looking back over your career, at what points in your training did you have preparation to support your competency in this area?
   a) Did you read personally to prepare, or have you taken courses on this subject later in your career?
9) In what ways are your conversations different from those of your colleagues.
   a. Is there anything unique about how you have these conversations compared to others?
   b. Can you point out some of the key features you think are essential in these conversations?

10) Thinking back throughout your training from medical student to now, what do you recall about your training?
   a. How about things like literature, films, podcasts or something like that? Has any of that influenced you?
   b. May I ask about any experiences in your family where you were personally or possibly involved with someone you cared about?

11) Have your workplace preparation and study habits changed over time?
   a. If so, how?
   b. When you first started as a resident, what was that like?
   c. Is your approach now different from when you were a medical student? If so, how?

12) Thinking back on your training, if you could go back and guide medical students or resident training, what would you suggest they need to include that they may not be currently having as you think about the next generation of clinicians being trained?
   a. What types of gaps in their training do you think there are, and what might be important?
   b. As you think about your own training if it was possible to direct you to a resource, what would you want that resource to have, what would you want to know more about that you currently don't know about that but to make you more effective.
   c. Is there anything that you would find helpful to continue to help you to develop these skills?
   d. As you think about training the next generation, what do you think they need that they are not currently getting?

Thank you for your participation!
Appendix 10: Interview Guide (Phase 2) (D)

Appendix D: Interview Guide (Phase 2)

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Interview Process and Questions:

1) Complete Verbal Consent Documentation with Participant.

2) Preamble: Thank you for agreeing to participate in this interview today. I want to remind you that your participation in this project is voluntary and that you may choose to end your participation at any time. I will also remind you that this interview will be audio and video recorded to help with our analysis, and that you have the option to turn off your video if you wish. I also want you to know you have the option to not answer or skip any questions asked. My supervisor Kathy Hibbert, the transcription company Trint, and myself, Jill Dombroski, will have access to the recordings.

3) Start recording.

4) State date and time of interview for recording.

5) Verify that Verbal Consent Process has been completed and documented with participant on recording.

6) Since our last meeting, I have sent the transcript of our conversation and invited you to check for any inaccuracies, to expand upon anything you wished to after reflection, and to remove anything that you were uncomfortable sharing.
   a) Was there anything you wanted to change, remove, or expand?

7) I presented a summary of some of the initial findings that have been identified across participants.
   a) Did those findings resonate, or surprise you in any way and if so, how?

8) Is there something else you think I should know to understand your process or experience of speaking to your patients?

9) Is there anything you would like to ask me?

Thank you for your participation!
Appendix 11: Focus Group Guidelines (Phase 3) (E)

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Interview Process and Questions:

1) Ensure the consent process has been completed with all participants.

2) Preamble: Thank you for agreeing to participate in this focus group today. I want to remind you that your participation in this project is voluntary and that you may choose to end your participation at any time. I will also remind you that this focus group will be recorded to help with our analysis and that you have the option to turn off your video if you wish. I also want you to know you have the option not to answer or skip any questions asked. My supervisor Kathy Hibbert, the transcription company Trint, and myself, Jill Dombroski, will have access to the recordings.

3) Start recording.

4) State date, time researchers present, and participants present for the recording.

5) Today, I would like to share 3 short video clips from the Canadian Virtual Hospice gallery. We will watch them together and then discuss each clip.
   a) The first one is titled “Reflections on Living and Dying”. It is about 10-minutes long and is a story shared by Dr. Balfour Mount, widely known as Canada’s father of palliative care:
   
   
   b) What comes to mind as you think about what Dr. Mount had to say? [What was new information? What had you heard before? (And where?)]

6) The second much shorter video, presented by Dr. Kenneth Doka, addresses ‘Anticipatory Mourning’.
   a) In what ways does grief show up in your patients?

7) The last clip, with Dr. Kenneth Doka (3:40), discusses ‘Health Care Provider Grief’.
   a) What is your response to what he has to say?

b) How have you been able to experience and contain your grief for your patients?

8) Is there anything anyone would like to ask me?
Thank you for your participation!
Appendix 12: Recruitment Email to Key Informant & Recruitment Invitation to participate in a research study (F)

**Subject Line:** Invitation to participate in a research related to physician, surgeon, senior resident (PGY 3 and above), and nurse practitioner’s experiences with patients about end-of-life conversations

**Study Title:** Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Hello,

My name is Jill Dombroski, and I am a Ph.D. candidate in the Faculty of Education in the curriculum stream, and my supervisor is Dr. Kathy Hibbert. I am looking for your help as a Key Informant on recruitment for my doctoral thesis research. More specifically, I am looking for your help in recruiting appropriate participants for my study.

You are being emailed because you work within the London Health Sciences Center (LHSC) or community-based, and I am hoping you can help in the recruitment of physicians, surgeons, residents (PGY 3 and above), and nurse practitioners who regularly hold end-of-life conversations with adult patients and those you feel, in particular, could provide essential insights about holding these conversations.

The objective of this study is to gain new insights into the current practice of holding end-of-life conversations with the ultimate goal of identifying opportunities for improving training. Interviewing experienced physicians, surgeons, senior residents (PGY 3 and above), and nurse practitioners who have these conversations will allow me to gain those insights.

Below is a recruitment e-mail that I am hoping you can send on my behalf to potential participants. I have also included an attached Letter of Information (Appendix A). If it would be helpful, I would be happy to also meet with you to discuss in more detail exactly the type of participant I am hoping you could reach out to. If recruitment is low after the first email has been sent, two reminder emails may be sent out to you every two weeks.

If this is something you are willing to support me with or if you would like more information on this study, please contact me at XXXXX@uwo.ca or Dr. Kathy Hibbert at XXXXXX@uwo.ca.

Kindly,

Jill Dombroski

**Note:** As a Key Informant, please do not send the study team a list of potential participants or their contact information as any interested participants will contact the study team directly.
Email Instructions for recruitment: Please copy the subject line and body of the email into a new email to send to appropriate participants for my study. Please make sure the Letter of Information (LOI) (Appendix A) is attached to the email.

Subject Line: Invitation to participate in research related to physician, surgeon, senior resident (PGY3 and above), and nurse practitioner’s experiences with patients about end-of-life conversations

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Hello,

My name is Jill Dombroski, and I am a Ph.D. candidate in the Faculty of Education in the curriculum stream, and my supervisor is Dr. Kathy Hibbert, and you are being invited to participate in a research study as part of my doctoral thesis.

You are being invited in particular because you work within the London Health Sciences Center (LHSC) or maybe community-based as a physician, senior resident (PGY3 and above), or nurse practitioner and hold regular end-of-life conversations with adult patients. You are under no obligation to participate in the study, and your decision will have no bearing on your position or standing within LHSC or your community-based practice.

The objective of this study is to gain new insights into the current practice of holding end-of-life conversations with the ultimate goal of identifying opportunities for improving training. Interviewing experienced physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners who have these conversations will allow me to gain those insights.

For full study details, I invite you to review the Letter of Information (LOI) attached to this email. If you would like more information on this study or to volunteer yourself for participation after you have had a chance to review the (LOI) attached to this email, please contact Jill Dombroski at XXXXXX@uwo.ca directly and do not respond to this email.

You may receive an invitation to participate two more times over the next four weeks, so please disregard this email if we have already been in contact or you wish not to participate.

Thank you,

Jill Dombroski

<table>
<thead>
<tr>
<th>Research Student</th>
<th>Principal Investigator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jill Dombroski, Doctoral Candidate, <a href="mailto:XXXXXX@uwo.ca">XXXXXX@uwo.ca</a></td>
<td>Dr. Kathy Hibbert, PhD., <a href="mailto:XXXXXX@uwo.ca">XXXXXX@uwo.ca</a></td>
</tr>
</tbody>
</table>
Appendix 13: Reminder Recruitment Email to Key Informant & Recruitment

Invitation to participate in a research study (G)

Subject Line: Reminder Invitation to participate in a research related to physician, surgeon, senior resident (PGY 3 and above), and nurse practitioner’s experiences with patients about end-of-life conversations

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Dear ________________,

An email was sent to you ________ ago and I wanted to send you a quick reminder about my study.

My name is Jill Dombroski, and I am a Ph.D. candidate in the Faculty of Education in the curriculum stream, and my supervisor is Dr. Kathy Hibbert. I am looking for your help as a Key Informant on recruitment for my doctoral thesis research. More specifically, I am looking for your help in recruiting appropriate participants for my study.

You are being emailed because you work within the London Health Sciences Center (LHSC) or community-based, and I am hoping you can help in the recruitment of physicians, surgeons, residents (PGY 3 and above), and nurse practitioners who regularly hold end-of-life conversations with adult patients and those you feel, in particular, could provide essential insights about holding these conversations.

The objective of this study is to gain new insights into the current practice of holding end-of-life conversations with the ultimate goal of identifying opportunities for improving training. Interviewing experienced physicians, surgeons, senior residents (PGY 3 and above), and nurse practitioners who have these conversations will allow me to gain those insights.

Below is a recruitment e-mail that I am hoping you can send on my behalf to potential participants. I have also included an attached Letter of Information (Appendix A). If it would be helpful, I would be happy to also meet with you to discuss in more detail exactly the type of participant I am hoping you could reach out to. If recruitment is low after this second email has been sent, one more reminder email may be sent to you.

If this is something you are willing to support me with or if you would like more information on this study, please contact me at XXXXXX@uwo.ca or Dr. Kathy Hibbert at XXXXXXX@uwo.ca.

Kindly,

Jill Dombroski
Note: As a Key Informant, please do not send the study team a list of potential participants or their contact information as any interested participants will contact the study team directly.

Email Instructions for recruitment: Please copy the subject line and body of the email into a new email to send to appropriate participants for my study. Please make sure the Letter of Information (LOI) (Appendix A) is attached to the email.

Subject Line: Invitation to participate in research related to physician, surgeon, senior resident (PGY3-5), and nurse practitioner’s experiences with patients about end-of-life conversations

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Hello,
An email was sent to you ________ ago and I wanted to send you a quick reminder about my study.
My name is Jill Dombroski, and I am a Ph.D. candidate in the Faculty of Education in the curriculum stream, and my supervisor is Dr. Kathy Hibbert, and you are being invited to participate in a research study as part of my doctoral thesis.
You are being invited in particular because you work within the London Health Sciences Center (LHSC) or maybe community-based as a physician, surgeon, senior resident (PGY3 and above), or nurse practitioner who hold regular end-of-life conversations with adult patients. You are under no obligation to participate in the study, and your decision will have no bearing on your position or standing within LHSC or your community-based practice.
The objective of this study is to gain new insights into the current practice of holding end-of-life conversations with the ultimate goal of identifying opportunities for improving training. Interviewing experienced physicians, surgeons, senior residents (PGY3 and above), and nurse practitioners who have these conversations will allow me to gain those insights.
For full study details, I invite you to review the Letter of Information (LOI) attached to this email. If you would like more information on this study or to volunteer yourself for participation after you have had a chance to review the (LOI) attached to this email, please contact Jill Dombroski at XXXXXX@uwo.ca directly and do not respond to this email.
You may receive an invitation to participate one more time over the next two weeks, so please disregard if we have already been in contact or you wish not to participate.
Thank you,

Jill Dombroski
Research Student

Dr. Kathy Hibbert, PhD.,
Principal Investigator

| Jill Dombroski, Doctoral Candidate, XXXXXX@uwo.ca |
| Dr. Kathy Hibbert, PhD., XXXXXX@uwo.ca |
Appendix 14: Support Services (H)

Appendix H: Support Services

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Some questions about death and dying may trigger psychological distress as you recall past events or behaviours. The research team will be respectful of your wishes and will stop the study if they feel you are not comfortable with the conversations.

The hospital also offers other resources (Spiritual Care Services Tel: (519) 685-8500. Pager - 14692) for spiritual, cultural and religious requests around the issues discussed in the study. This support is available 24/7.

Other support services could include but are not limited to:

1. London Distress Centre
   (519) 667-6711
   www.londondistresscentre.com

2. St Joseph’s Hospice of London
   (519) 438-2102
   http://www.sjhospicelondon.com

3. Daya Counselling Centre
   (519) 434-0077
   www.dayacounselling.on.ca

4. Family Services of Thames Valley
   (519) 433-0183
   www.familyservicethamesvalley.com

5. Bereaved Families of Ontario (for individuals who have had a loss of a child or sibling) (519)-686-1573
   http://www.bereavedfamilies.net

6. South West Health Line
   www.southwesthealthline.ca
   Search word: end of life care or bereavement

7. What Needs to be Done When a Loved One Dies
   www.southwesthealthline.ca/docs/38dies.htm

8. Southwest Community Care Access Centre
   http://healthcareathome.ca/southwest/en

9. Your Family Doctor may also be a helpful resource in your own community.
Appendix 15: Reference list for Rational (I)

Appendix I: Email to current participants to inform them of amendments in the ongoing research study

Subject Line: Amendment change to Jill Dombroski’s research study you are participating in.

Study Title: Physician, surgeon, resident, and nurse practitioner’s experiences with patients about end-of-life conversations

Hello ________________.

I wanted to let you know that I have amended my research study to broaden my inclusion criteria. I have included surgeons on the guest list and expanded it beyond LHSC employees who are part of my participant criteria but invited these same healthcare professionals that work in community-based practices.

This does not affect your interview and contribution to this research study. Still, I thought I would reach out if you had other colleagues who may have been interested in participating in this study but did not meet the previous inclusion criteria.

Attached is a Letter of Information, Appendix A, for you to forward to any colleagues you think may be interested, and they can contact me directly.

Thank you again for your time, and I look forward to our next meeting to review the transcript of our first interview.

Kindly,

Jill Dombroski

<table>
<thead>
<tr>
<th>Research Student</th>
<th>Principal Investigator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jill Dombroski, Doctoral Candidate, <a href="mailto:XXXXXX@uwo.ca">XXXXXX@uwo.ca</a></td>
<td>Dr. Kathy Hibbert, PhD., <a href="mailto:XXXXXX@uwo.ca">XXXXXX@uwo.ca</a></td>
</tr>
</tbody>
</table>
Appendix J: Reference list for Protocol

References:


Version 1: December 10, 2021

Curriculum Vitae
Jill Dombroski

EDUCATION:
PhD Western University Education - Curriculum 2023
MA Western University Education - Curriculum 2017
HBA Western University Thanatology and Women’s Studies 2015
RMT Edmonton, Alberta Remedial, sport, and pregnancy massage 1993

RELEVANT WORK EXPERIENCE:

2022 - 2023 Coordinator: Writing Commons, Western University, London, Ontario
• A weekly Writing Commons to help English Language Learners and graduate students with their writing, research, feedback, and communications process in person or online nationally/globally, and assist students with in-class presentations.

2019 - 2023 Instructor and Researcher: Dr. Perry Klein, Western University, London, Ontario
• Liaising with classroom teachers; administering writing activities and oral narrative language assessments to elementary students; observing classroom writing activities; analyzing writing samples; assisting with data analysis using SPSS; assisting with conference presentation and article preparation.

2019 - 2020 Coordinator: Writing Commons, Western University, London, Ontario
• A weekly Writing Commons to help English Language Learners and graduate students with their writing, research, feedback, and communications process in person or online nationally/globally. Assist students on in-class presentations and also for 3M competitions (2 ESL students made it to the finals). Monthly guest speakers, 5-week dedicated writing morning, “WriteOn”, for students and faculty to participate.

2020 Academic Coaching in Writing for International Master’s program, Western University, London, Ontario
• Provide drop-in and online academic coaching for international students. This includes supporting students with finding good research sources, managing citations, using APA format, planning and organizing ideas for assignments, putting concepts into your own words, paraphrasing ideas to be concise and professional, and modelling group discussion strategies.

2018 - 2019 Researcher at Centre for Education Research and Innovation, Western University, London, Ontario
• Support the research activities for qualitative projects in adherence to ethics protocols and guidelines; assist in disseminating research results arising from these projects and perform qualitative data collection, analysis, and assisting in writing the paper.

2015 - 2016 Researcher: Dr. Perry Klein, Western University, London, Ontario
• Liaising with classroom teachers; administering writing activities and quizzes to elementary students; observing writing activities in classrooms; analyzing writing samples; assisting with data analysis using SPSS; assisting with conference presentation and article preparation.

2002 - 2005 Massage Therapy Instructor: Metro Community College, Edmonton, AB.

1993 - 2005 Owner & Operator: It’s Nice 2 B Kneaded (Massage Therapy), Edmonton, AB.
PUBLICATIONS: (09)


PEER-REVIEWED CONFERENCE PRESENTATIONS: (16)


**Dombroski, J.** (2022). Good Grief – Supporting students’ loss(es) in the classroom: In-service training and professional development of death and dying education for Learners of all ages. Online Presentation. The University of the West Indies, Cave Hill Campus, Barbados, West Indies. May 2022


Dombroski, J. (2022). Good Grief – Supporting students’ loss(es) in the classroom: Professional development of death and dying education. Wefla-Secan 2022, University of Holguin, Cuba, April 2022

Dombroski, J. (2022). Physician’s Experiences with Patients about End-of-Life Conversations Association of Death Education and Counseling (ADEC) 2022, St. Louis, MO, USA, April 2022


Dombroski, J. (2021). Expanding the concept of ‘care’: A narrative study exploring lessons from end-of-life patients to inform ‘Medical Assistance in Dying’. Online presentation and discussion, Wefla-Secan 2021, University of Holguin, Cuba, April 2021


Dombroski, J. (2018). What is a good death? With the advent of Bill C-14, 'Medical Assistance in Dying,' medical professionals need to understand their own assumptions and expectations about death and dying in order to better educate and support their patients. Round-table discussion with interactive visual methodology for data collection in a future study to inform curricula for death and dying in medical education. April 2018


CERTIFICATES AND TRAINING

Association of Death Education and Counseling, Conference Training Columbus OH, U.S.A. 2023
Association of Death Education and Counseling, Conference Training St. Louis, MO, U.S.A. 2022
Association of Death Education and Counseling, Conference Training Virtual 2021
Bereavement of Ontario Network Conference, Conference Training Virtual 2021 – present
Own Your Future, School of Graduate and Postdoctoral Studies, Western University 2017 – present
The Teaching Assistant Training Program (TATP), Western University 2016
Association of Death Education and Counseling, San Antonio, TX, U.S.A. 2015
Worker Health and Safety Awareness Training, Western University, London ON 2013 – present
Applied Suicide Intervention Skills Training (ASIST), King’s University College, London, ON 2014

SERVICE and PROFESSIONAL AFFILIATIONS:

American Educational Research Association (AERA), Peer Review for Conference Abstracts 2023
Lecture to Bachelor of Education Students, Brock University, 2023
Lecture to Bachelor of Education Students, Western University 2022 – present
Association for Death Education and Counselling (ADEC), Peer Review for Conference Abstracts 2022
Canadian Society for the Study of Education - Education Grad Students' Association - (CSSE - EGSA), Peer Review for Conference Abstracts 2022
ADEC – Association of Death Education and Counseling – SanP 2015 – present
CWCA/ACCR – The Canadian Writing Centres Association / L’Association Canadienne des centres de rédaction 2020 - present
AERA – American Educational Research Association 2019 - present
LLRC – Language and Literacy Research of Canada 2017 - present
CSSE – Canadian Society for the Study of Education, Student member at large 2017 - present
CBS – Canadian Bioethics Society – Student Membership 2016 – present
CAME – Canadian Association for Medical Education – Student Membership 2016 – present
BON – Bereavement of Ontario Network – Student Membership 2014 – present
BON – Bereavement of Ontario Network – Member at Large - Board of Directors 2014 – 2015
SAGE Student Coordinator for Mature Students at Western University 2014 – 2015
Mature Student Representative for the Women's Studies, Western University 2012 – 2015

HONORS AND AWARDS:

2023  Student Scholarship for the Association of Death Education and Counseling (ADEC), Columbus, OH, USA.
2022  Outstanding Poster Abstract Presentation. Centre for Education Research and Innovation (CERI) Research Symposium. Western University
2022  Top 26 Inspiring Minds – Showcasing Western’s Graduate Research, Scholarship and Creative Activity.
2022  Student Scholarship for the Association of Death Education and Counseling (ADEC), St. Louis, MO., USA.
2021  Student Scholarship for the Association of Death Education and Counseling (ADEC)
2020  Student Scholarship (Dr. John Morgan Memorial Award) Bereavement Ontario Network Conference
2016  Runner-up - The Robert Macmillan Graduate Award in Educational Leadership, Western University Faculty of Education
2015  Undergraduate Paper Award and Student Scholarship (Mary E. Brown Memorial Award) for the Association of Death Education and Counseling (ADEC), San Antonio, TX, U.S.A.
2015  Mature Student Award for Western University, The Student Success Centre, London ON
2014  Student Scholarship (Dr. John Morgan Memorial Award) Bereavement Ontario Network Conference, Orillia, ON
2013  Letter of Accomplishment in Individual and Group Leadership Recognition for “Creating a Society project” (Sociology 1020), Western University, London ON