# When Relations Matter Most: Death and Dying Personifications and Experiences from the Perspectives of Recreation Therapists

by

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## AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## ABSTRACT

Over the past 200 years, death has been heavily medicalized within Global North healthcare settings, no longer positioned as naturally occurring but as a failure of medicine. In modern society, death is hidden between the four walls of our hospitals and care facilities, resulting in healthcare workers developing a closer, more persistent relationship to death than the general public. This phenomenon was emphasized by the COVID-19 pandemic, causing healthcare workers' overexposure to death. The silencing of death creates barriers to care and emphasizes the need for comprehensive death education and better support for healthcare professionals when experiencing death in their workplaces.

Guided by phenomenology and expanding personification theory, this study aims to capture the unique experiences and perspectives of death from a healthcare professional group often overlooked in the literature, recreation therapists, by exploring the following questions: 1) How is death understood and experienced by recreation therapists? 2) How is death personified by practicing recreation therapists? What do these personifications tell us about understandings and experiences of death? 3) How might personifications of death and the experiences of death shared by recreation therapists inform us on what recreation therapists need to support their experiences of death and dying? How might death education benefit recreation therapists?

This study recruited nine recreation therapists across Canada to participate in a two-step data collection process. Step one used arts-based research methods to capture participants' personifications of death utilizing collaging and painting. Step two involved four small group virtual research conversations. The research conversations provided opportunities to share and explore the artistic personifications of death outlined in step one and delve deeply into the experiences of death for recreation therapists. A phenomenological analysis process was used to analyze and interpret both the personifications of death and the transcripts of the research conversations.

This project demonstrates the entanglement of beauty and darkness in the experience of death and dying from the perspectives of recreation therapists. The findings highlight the impact of relational approaches in end-of-life care and reveal the need for more support to combat burnout and expand the role of recreation therapists in caring for the dying. This project highlighted the participants' navigation of the emotional and relational challenges of death in healthcare, with artistic personifications reflecting the tension between solace and finality. There is a shared hope for greater support in environments that lack adequate resources, emphasizing the need for systemic change in end-of-life care.

This research integrates recreation therapy into the conversation on death and dying, highlighting the essential role of recreation therapists at the end-of-life. Methodologically, it contributes by combining phenomenology and personification to explore the essence of experience through visual art. The findings offer practical implications for recreation therapists, healthcare organizations, and educators in supporting staff and incorporating recreation therapy centered death education.

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## DEDICATION

*This master's thesis is dedicated to all those who have shaped my relationship with death. Each person, pet, and experience has impacted my life and my practice as a recreation therapist.*

*I dedicate this*

*To Jason Shelton.*

*To all the individuals who have allowed me into their lives through their participation in recreation therapy, creating art, memories, and legacy projects with you has empowered me to create change in end-of-life processes.*

*To Michael Harrison.*

*To Finn Howison*

*To Patrick Delaney.*

*To the pets that comforted me through grief and hard times, Tober, Oscar, and Booger*

*And finally, to the person who inspired me to be a carer and become a recreation therapist, my Grandmother Dorothy Delaney. Thank you for teaching me unconditional love and allowing me space to reciprocate the care you gave to me.*

*I love and miss you all,*

*Erin Delaney*

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## Chapter One: Meeting Death

What is it like to experience death? Many of us are never present at the time of death, only encountering the aftermath. The only experiences we can refer to are those that happen on the periphery. We experience death from our peripherals through the loss of another. How I experience death reflects the dozens of encounters I've had with it, including the loss of a friend as a teen, my grandmother's death to COVID-19, my cousin and friends' recent suicides, and the deaths of the patient's I work with.

Death seems to have a way of 'killing' any conversation. The silence of death was one of the first things I noticed as a teen. It was in the experience of losing a close family friend I tuned into my parent's discomfort. This was not an isolated experience, with the silence following me into the workplace as a recreation therapist. Entering healthcare, I became aware that I would face death more often than the general public. With this realization, I tuned into the effects we saw during the pandemic, the reality and presence of death. Starting my first recreation therapy/therapeutic recreation[1] job on a long-term ventilation (LTV) unit without death education felt like entering a battlefield without a sword. Instead of 'going to war' empty-handed I chose to take a Death Doula Certification. This course taught me the implications healthcare workers may face in silencing death.

[1] I intentionally use Recreation Therapy/Therapeutic Recreation to highlight the tensions between the profession of recreation therapy and therapeutic recreation. Often grounded in the medical model, recreation therapy is recognized in medical spaces and is the preferred title of practicing professionals in these spaces. Critiques of the medicalization of leisure have called for a re-imagining of therapeutic recreation practice by emphasizing core aspects of leisure, such as freedom and self-determination, and the importance of leisure and recreation for life enrichment and quality of life.

It became clear to me that the lack of death education for allied healthcare providers, specifically recreation therapists, was problematic. The silencing of death directly impacts service delivery, the creation of relationships, the ability to cope with patient deaths, and the health and well-being of recreation therapists. To address these concerns, I drew on phenomenology and expanded notions of personification and utilized arts-based methods to understand the experiences of death and dying for recreation therapists. An aim of this research was to create a foundation for advocating for the need for death education and better supports for recreation therapists and identifying what that death education and those supports should include.

**Interest Statement**

I became interested in the topic of death throughout my experiences of loss in childhood, realizing that the adults around me were hesitant to talk about death. In childhood, I believed that my parents knew everything, but death was one topic they could never explain to my satisfaction. However, the answer didn't seem to come easy to anyone. I was surprised to realize that even in healthcare, not many wanted to discuss loss, grief, or the legacy of the people we supported. The first space I engaged in an open conversation about death was in the first death café I attended.

A death café is an organized event where people discuss death. Death Café is a not-for-profit organization which hosts organized conversations about death. The goal of Death Café is to "increased awareness of death with a view to helping people make the most of their (finite) lives" (Death Café, n.d.). Developed by Jon Underwood and Sue Barsky, Death Café has been running since 2011, hosting thousands of events worldwide. Each conversation has no agenda, making the interactions fruitful. In one conversation, we spoke heavily about spirituality. Interestingly, everyone there that day identified as agnostic or atheist. Death seems to have a

voice in religion but not in our everyday interactions. Death cafés give death a voice while neutralizing its power.

After attending several death cafés, I pitched the idea to my colleague in Spiritual Care to host our own at the hospital. Our events would host 7-12 people in an unstructured conversation around death, allowing the group to direct the topic. Our role was to be present, prompt, and debrief. Our events aimed to 'bring life into the conversation of death,' a way to give fears, concerns, questions, and experiences of death a voice. I was able to see the importance and benefits of open conversations about death.

**The Problem**

As I mentioned above, death has been and continues to be, silenced. The silencing of death within society in the Global North has plagued all members, leading us to ignore thoughts on mortality. The silencing of death is connected to the taboo and fear surrounding death. Herman Feifel wrote an article titled 'The Taboo on Death' in 1963, attempting to reflect on the problems of Global North attitudes toward death within research. Feifel described how not engaging with death ensures it remains a minor part of our existence or can be ignored altogether. Feifel's work has been expanded by others who have explored the connections between the taboo of death and culture. Walter (1991) more directly examined the taboo nature of death by exploring how it is taboo and whether death is hidden from individuals rather than silenced. Walter (1991) emphasized that we need to examine the influence of:

1. distrust in ritual;
2. the implication of low death rates starting in 1945;
3. medical and media institutions creating the narrative around death;
4. incompatible lenses of death;

5. The duality of death being both denied and accepted; and
6. questioning the difference between the threat of death in culture and the individual.

Raymond L.M. Lee (2008) revisited the death taboo, stating that though the death taboo has shifted, we still live in the taboo's wake. In evaluating death as a taboo, it is important to explore the origins of the word taboo. In Polynesia, tabu describes the 'forbidden' or a rule of etiquette issued by a chief. In the book "Taboo Words and Language: An Overview," Allan (2018) reflected on Captain James Cook's first voyage of 1768-71 in Tahiti. In Cook's 1777 journal, he wrote that taboo signifies the forbidden (Allan, 2018). In 21st-century English, the word taboo refers to the forbidden by custom rather than law (Walter, 1991). The permanence of death as a taboo in a technologically advanced, secular Global North society may explain the fear-based taboo on death. Burridge and Benczes (2019) described the many fears held about death, including "the fear of the loss of loved ones; fear of the corruption and disintegration of the body; fear of the very finality of death; fear of what follows at the end-of-life, and the fear of malevolent spirits among the souls of the dead" (p. 62).

Is it that death is taboo? With modernity and the growth of scientific and medical knowledge over the past 150 years, most deaths occur in a care facility (e.g., hospital, aged care homes, etc.), which has hidden death from the general public, depersonalizing it (Adair, 2021; Kang, 2021). In these facilities, where death has largely been medicalized, death is no longer seen as naturally occurring but as a failure of doctors and medical officials (Walter, 1991). The medicalization of death supports Blauner's (1966) thesis that "death within modern society is not 'forbidden but hidden'" (Walter, 1991, p. 301) to protect us from the fear of exposure to a human corpse. Through the medicalization of death, societies in the Global North have created a means to 'hide' death from those outside of medical institutions. The forbidden nature of death is rooted

in and perpetuates stigma surrounding the experience of death, dying and bereavement. Death has become something that we hide rather than embrace, and experience has a part of life, often leading to the social avoidance of people experiencing death and dying (Kang, 2021).

Within modern Global North societies, our relationship to death is often indirect and rarely experienced personally, apart from healthcare professionals who have taken on the burden in protecting the public from death (Blauner, 1966). Since WW1, our mourning rituals and relationships to mortality have shifted from the personal to the social. The medicalization of death views death as a social problem that isolates and marginalizes death; dying is a failure and a social embarrassment (Walter, 1993).

Since death is hidden from society between the four walls of our hospitals and care homes, healthcare workers have a closer, more persistent relationship to death than the general public. This phenomenon was emphasized during the COVID-19 pandemic, with most deaths occurring within LTC and hospital settings, resulting in an 'overexposure' to deaths by healthcare workers (Hernandez-Fernandez & Meneses-Falcon, 2022). It may be presumed that being exposed to death regularly would assist in desensitizing our emotions. However, the results of Wilson and Kirshbaum's (2011) literature review of 73 articles on the effects of patient death on nursing staff highlighted a conflict with this assumption. This article notes that professionals have had an extremely difficult time coping with the high mortality rates, leading to emotional and physical consequences.

Hernandez-Fernandez and Meneses-Falcon (2022) note, "One should not forget that the healthcare and social services professionals have been socialized through the same processes as the population they serve" (p. 10). It is also true that healthcare workers often have the same level of death education as the general public. The lack of death education relates to the

medicalization of death, where death is hidden from society, but for healthcare workers, death is very present.

Until the 1990s, there was scarce information outside of medicine, psychiatry, and philosophy journals surrounding death concepts (Powar, 2015). More recently, with calls to action for more humane end-of-life care, palliative care has become a rapidly growing field (Hughes & Smith, 2014). However, even though palliative care addresses death more directly, significant barriers have been noted, including the lack of healthcare workers willing to work in that field, lack of appropriate training in end-of-life specific to death, and lack of funding for research on end-of-life (Hughes & Smith, 2014).

Death education within medical schools has shifted since the 1970s to offer some education focused on death and dying (Wass, 2004). Beginning in the 1990s, nearly all medical, nursing, pharmaceutical, and social work students were offered education on death integrated into the basic curriculum (Wass, 2004). For example, within Canadian Nursing Baccalaureate education, death education is now expected to be integrated into all nursing courses. However, it has been found that courses *specific* to death are more effective in decreasing the death anxiety of students (Degner, 1985). Wilson et al. (2011) noted a similar trend in Canada seeing death education introduced as an integrated part of the nursing curriculum. In an evaluation of death education conducted in 29 of 35 Canadian nursing schools, all were providing education but with little advancement from the 2004 curriculum. Wilson et al. (2011) called for greater advocacy for death education in Canada to assist nursing students to gain a stronger foundation for practice with gaps in education evident in the level of "theoretical and clinical preparedness" (p. 4). Unfortunately, members of allied health teams (e.g., Occupational Therapy, Physiotherapy, and Recreation Therapy), receive little to no education surrounding death, grief, and bereavement.

Research on the impacts of death education suggests that appropriate education specific to death can benefit healthcare professionals. Durlak and Reisenberg (1991) looked at the impact of death education and found that education programs are successful in changing participant attitudes about death but may not be effective in changing participants' feelings about death. The authors state this conclusion could result from teaching methods lacking theoretical and conceptual grounds, concluding that more evaluation of the student experience is needed (Durlak & Reisenberg, 1991). Durlak (1994) expanded their initial research to integrate experiential exercises for participants to confront their feelings about death. More specifically, workshops incorporating role-playing, death awareness, and grief activities were introduced. A more recent study by Wallace et al. (2019) utilized Durlak's findings to create an interdisciplinary course to transform students' attitudes and anxieties towards death and loss. The study identified promising results in student's attitudes, fear, avoidance, and anxiety toward death. The study, however, identified that more attention was needed for students who had experiences of loss, which led some students to struggle with course materials (Wallace et al., 2019). This study prefaced the importance of exposing students to death education prior to interacting on the frontlines, especially for students with a history of traumatic loss.

**Statement of Purpose and Objectives**

I believe the silencing of death and lack of opportunities to talk openly about death, especially for healthcare professionals, is an enormous problem. Opening ourselves and letting death speak may bring more *life* into the conversation. From my experiences participating in death cafés, this seems to be true. Like the narrator in 'The Book Thief' by Markus Zusak, death cafés gives death a voice. After each café, I've left grateful for the opportunity to have discussed death openly without judgment.

Given evidence surrounding the positive impact of death education, it is essential to understand how recreation therapists understand and experience death. This information might inform future education in the recreation therapy/therapeutic recreation curriculum and professional development. In understanding recreation therapists' experiences with death and dying broadly, we can start to fill the gap in the literature on where practitioners may benefit from implementing death education in Canada. More specifically, my research aimed to explore how recreation therapists understand and experience death. My research addressed the following research objectives:

- to create a safe space for recreation therapists to talk openly about their understandings and experiences of death.
- to create and explore expanded personifications of death held by recreation therapists and what they might illuminate about experiences of death; and
- to use this information to make recommendations to inform death education in recreation therapy/therapeutic recreation programs.

The research questions guiding this study included:

- How is death understood and experienced by recreation therapists?
- How is death personified by practicing recreation therapists? What do these expanded personifications tell us about understandings and experiences of death?
- How might expanded personifications of death and the experiences of death shared by recreation therapists inform us on what recreation therapists need to support their experiences of death and dying? How might death education benefit recreation therapists?

To address these objectives, I drew on phenomenology to investigate the 'essences' of death from the lens of recreation therapists. I also drew on personification theory to inform my methodology, which looked at experiences from multi-sensory modalities that are communicated through the spiritual, visible, invisible, concrete, and abstract to challenge and highlight opinion, belief, and 'fact' (Breen, 2021). An expanded approach to personification provided a unique opportunity for participants to imaginatively engage with their understandings and experiences of death. In past studies, personification has been explored primarily through quantitative research methods such as surveys. Using qualitative arts-based methods, I hoped to provide a platform where recreation therapists could openly share, reflect on, and discuss their individual experiences of death and dying, to begin to break the silence around death and dying in recreation therapy/therapeutic recreation. Using arts-based methods, expanded personifications were created through painting and collaging, which reflected a physical representation of death that was then used in my analysis process.

Within the next chapter, I elaborate on the conceptual lenses used to illuminate the experience of death which informed my research. I explore how phenomenology, in tandem with personification, were used to explore and describe the essences of death from the perspectives of recreation therapists. In the third chapter, I review other relevant literature important in contextualizing my research, including death and leisure, grief, and recreation therapy and death. In the fourth chapter, I describe the methodology and methods aligned with my conceptual lenses I used to address my research objectives and questions, including methods for recruitment, data collection, and analysis as well as the ethical issues that were important for me to consider throughout this project. My findings are presented in three separate chapters. Chapter five explores how recreation therapists navigate the emotional and relational terrain of death in

healthcare. This chapter describes the experiences of death from the perspective of the nine recreation therapists who participated in the study. Chapter six explores each of their expanded personifications in-depth which illuminated the essence(s) of death. This chapter looks at the complex entanglement of solace and finality in their personifications. The participants expanded participants' personifications demonstrated that their experiences and relationships to death were not linear, but a balance of beauty and darkness demonstrated through images of nature, colour, elements of care and dignity, and their personal experiences with loss in their personal and professional lives. The last findings chapter, chapter seven, explores the hope for and cultivation of support in unsupportive environments. In this chapter, participants outlined their hopes for death and dying support in the future as well as the existing supports, people, and mindsets they cultivate to combat burnout, emotional exhaustion, and death anxiety in their work. The final chapter, chapter eight, looks at the hopeful promise for the future of recreation therapy/therapeutic recreation in regard to death and dying. This chapter explores the impact of the study, the significance of the research, and the limitations and potential inspirations for future research.

## Chapter Two - My Conceptual Lens

My research was informed by both phenomenology and personification theories. Acknowledging and understanding the guiding theories that informed my research is necessary to ensure language is consistent with the chosen methodologies and methods. Theory, as identified by Berbary and Boles (2014), is “ideas with which to think about content, methodology, and analysis” (p.404). I chose phenomenology as one of the guiding theories because I wanted to centre my research on experiences of death. The following section explores different approaches to phenomenology research and describes interpretive phenomenology as the primary conceptual lens for this study. This section also summarizes past research where phenomenology has been used to explore death experiences.

The second theory I drew on to inform this work is personification theory. I chose to utilize this theory because it can be used to convey extreme emotion. It gives consciousness to an experience (Paxson, 2010). Similarly to how we connect with literary characters or cartoons, personification shows the embodiment of the experience. These human qualities and emotions can help analyze our understandings, relationships, and connections to specific experiences. In the second half of the chapter, I dive into personification theory, exploring studies using personification. To conclude the section, I describe the interplay of phenomenology and personification and why I felt both were important to informing my research.

### Phenomenology

What is phenomenology? Phenomenology is the study of the essence, defined by Webster's Dictionary as "the quality or qualities that make a thing what it is" (Merriam-Webster, n.d. a). Experience is the focus of phenomenological research, which can be understood as our consciousness, a making of the facticity through physical objects, values, emotions, activities,

and feelings (Merleau-Ponty & Smith, 1962). As Daly (2007) states, phenomenology looks at "the way people are geared into their everyday lifeworld (*Lebenswelt)"* (p. 94). More specifically, phenomenology is concerned with the taken-for-granted of our everyday realities. The role of phenomenological research is to understand these everyday experiences in the world from the perspectives of the research participants. I am engaging with phenomenology as a way to understand experiences of death and dying for recreation therapists.

Originating in the early 20th century and accredited to Edmund Husserl, phenomenologists sought a philosophy that equally valued individuals' subjective and objective experiences (Kafle, 2011). Husserl believed that phenomenology needed to be deeply rooted in epistemology to ask the expository question of "what it is for us to be conscious of anything" and "what it is for us to know?" (Barua, 2007, p. 2). Phenomenology is impossible to separate from epistemology as it links both the subjective and the objective to understand how individuals assign meaning to the "objects of their consciousness" (Daly, 2007, p. 94). Within Husserl's conceptualization, he believed that any experience could be the subject of study, pushing research beyond the objective of our senses and into the subjective of our thoughts, memories, imagination, and emotions (Neubauer et al., 2019). Within Husserl's phenomenology, he believed that individuals needed to use the process of reduction or bracketing, which aims to suspend assumptions to see the phenomena or life world clearly (Laverty, 2003). The 'lifeworld' can be understood by Husserl as a pre-reflective experience, how we understand phenomena without categorization or conceptualization of taken-for-granted experiences (Husserl, 1970). In contrast to ideas of bracketing and reduction techniques, phenomenology has appeared in many disciplines and traditions which take on a variety of labels, including reflective phenomenology,

transcendental, dialogic, empirical, existential, hermeneutic, interpretative, and social (Daly, 2007). I chose to take a hermeneutic or interpretive phenomenological approach to this research.

**Interpretive Phenomenology**

Heidegger's hermeneutic phenomenology (also referred to as interpretive phenomenology) is similar to Husserl's theory, looking at the human experience as lived by focusing on the taken-for-granted as a means of understanding (Laverty, 2003). The two philosophers disagree, however, in the extent to which consciousness can or cannot be separated from the world's historical, cultural, and situational positioning. Heidegger (1962/1997) believed that nothing could be engaged without understanding a person's background, believing we cannot stand away from the historicity of our experiences. For this reason, in my introduction, I needed to explain my story of meeting and engaging with death. Through this and other experiences that happened at a particular time and place in the world, they shaped my understanding of death in particular ways, motivating me to understand the experiences of others. In hermeneutic or interpretive phenomenology, it is important to state my position as the person seeking to understand (Gadamer, 1960/1976). To contextualize my research, I must include my ongoing personal experiences and reflections on the topic, including art, poetry, and stories experienced outside the research context that reflect and have helped shape my understanding of those experiences. I will continue to do this, when relevant, throughout this thesis.

Phenomenology is a uniquely positioned theoretical and conceptual lens that focuses on participants' lived experiences in the world, best suited for exploring complex phenomena (Reiners, 2012). Phenomenology focuses on describing rather than analyzing or explaining, prioritizing the individual essence(s) of things by understanding that everything we know about

the world is from our perspective. Phenomenology emphasizes that everything would be meaningless without these experiences with/in the world (Merleau-Ponty & Smith, 1962). Phenomenology makes us thoughtfully aware of the consequential, inconsequential, and significant in the taken-for-granted by simply asking, "What is this or that experience like?" (van Manen, 1984, p. 36). According to van Manen (1997), lived experiences and the many ways they can be understood account for the complexities of the lifeworld. To understand these complexities, we must look at van Manen's (1997) four fundamental existential themes within the lifeworld: spatiality, corporeality, temporality, and relationality.

1) Spatiality (lived space) refers to our experiences of space and how different spaces make us feel.
2) Temporality or (lived time) refers to our experiences of time and the way time passes within different spaces or situations. Temporality is about conceptualizing past, present, and future dimensions—directly connecting to our memories and aspirations.
3) Corporality or (lived body) refers to our experiences of our physical bodies or embodiment. We can reveal, conceal, and guard our experiences through our physical bodies.
4) Relationality or (lived human relation) refers to how we connect, maintain, and create space with others. This relationality connects directly to our impressions, feelings, and connections to relationships, highlighting a sense of purpose and meaning in a social context.

Within these four fundamental existential themes, it is important to note that though each is differentiated, they cannot be separated from the actor; they work together to shape our experiences in the world from moment to moment. Phenomenology aims to provide a holistic

description of experience, including what the experience is and how it is experienced (Neubauer et al., 2019). It is the continuous search for what it means to be human, attuning to the modern and timely experience of now. van Manen (2017a) stated,

> *"Phenomenology, if practiced well, enthralls us with insights into the enigma of life as we experience it—the world as it gives and reveals itself to the wondering gaze— thus asking us to be forever attentive to the fascinating varieties and subtleties of primal lived experience and consciousness in all its remarkable complexities, fathomless depths, rich details, startling disturbances, and luring charms" (p. 779).*

I interpret this to mean that the power of our experiences is the gateway to understanding human existence and its complexities. As phenomenological researchers, we need to educate ourselves on the fundamental direction of the importance of lived experiences; in so doing, researchers need to illuminate their own experiences. As van Manen (1984) stated, "My own life experience is immediately accessible to me in a way that no one else's experience is" (p. 51). Within my research, this means remaining reflexive about my own experiences that brought the experience of death to my attention, knowing that my experience is unique to me but can also reflect the experiences of my peers as well as illuminate differences in these experiences.

**Phenomenology and Death**

Death was first brought into the pre-ontological understanding of being through Heidegger's project "Being and Time" (1962/1997) to develop a philosophy of being. While attempting to explain a person's wholeness, Heidegger believed there was one phenomenon that could not be ignored, the phenomena of death. Heidegger believed that death does not come at the end-of-life but constitutes a person's life as lived (Pindle, 2023). In exploring the phenomena

of death, Heidegger was concerned with how the phenomenon enters and is experienced in everyday life. Specifically, Heidegger was concerned with how individuals respond to their death in their everyday behaviours, believing that "the fact of everydayness is characterized by fleeing in the face of death or covering up the fact of death" (Pindle, 2023, p.77). We are always aware of death and people die every day; we see it in the news, in our television shows, in video games, in our tangible life experiences, shaping death into a public occurrence rather than an experience of our potential. Heidegger believed that we have lost ourselves in the 'they,' which covers up our fears and attempts to cover our mortality by leaving death to be managed by other people outside of our homes. In 17th-century Puritan parents restricted displays of affection to protect from the problem of rampant death in infancy (Stannard, 1977). In our modern society, death is shielded by medicalization and the biomedical model, which reduces the human experience to one's biological function and physical body (Pindle, 2023).

I am looking at phenomenology to understand the experience of recreation therapists in relation to death. E. Mansell Pattinson (1977) looked at the phenomenon of 'covering up death,' which states that people cannot look at their mortality for long as a means to survive. I understand this phenomenon similarly to our relationship with the sun; we know it is there and appreciate it, but we cannot look directly at it or risk our safety. E. Mansell Pattinson believed this phenomenon is especially true for those who regularly engage in conversation, images, and relationships with dying persons (Pindle, 2023). Pattison identified a few attitudes in societies towards death: death-denying, death-desiring, and death-accepting. Pindle (2023) stated that death denying is the most common attitude in modern society. The repercussions of death-denying appear in the cracks of societies, in our rituals, religions, medical practices and treatment of grieving. In the phenomenon of death, we can see that the gaps in our teachings of

death create a polarizing effect, where death is denied by the general public or desensitized in the medical environment (Pindle, 2023). Pindle (2023) stated, “[doctors] are no more enlightened than others, and emotionally they respond to death in the same ways as others” (p.82).

### *Phenomenological Research Focused on Death*

Phenomenology is frequently used to inform research concerning healthcare workers' experiences, including nursing (Norlyk et al, 2023; Shorey & Ng, 2022; Benner, 1984; Benner, 1992; Morrison, 1994), occupational therapy (Aldridge et al, 2023; Finlay, 1999), and therapist professional identity (Tryssenaar, 1999). According to Gadamer (1960/1976), it is important to recognize the shared relations between people with divergent lifeworlds, such as healthcare providers and the people we support, which can be understood through interpretive dialogue (Wise, 2021). Within my research, I chose to focus on van Manen's methodological approach to phenomenology as it allows flexibility, where the focus is for participants to care and produce meaning cooperatively with the researcher. In taking on this approach to phenomenology, I connected to the foundations set by Heidegger’s hermeneutic phenomenology and Gadamer’s extension, which recognizes that “language-based, social interactions contribute to the creation of meaningful lives” (Wise, 2021, p. 153). I describe my methodological approach in detail in Chapter Four.

Phenomenological research has been used more specifically throughout healthcare to describe death experiences from the healthcare worker's perspective. This research has explored experiences of death in a number of different ways. For example, Zhou et al. (2022) conducted a phenomenological study to understand the experience of death from the perspective of student nurses. The authors outlined the study's cultural context, identifying that “in Chinese traditional culture, people regard death as taboo and ominous, and they usually avoid talking about it” (p.1).

In their research, phenomenology was used as a research method, guiding their interview questions. Their study identified that the fear and taboo of death impacted students' preparedness while entering clinical practice, leading students to think about death obsessively. In another study, Treggalles and Lowrie (2018) used interpretive phenomenology to develop insight into occupational therapists' perspectives in palliative care. This research highlighted four themes that describe experiences of palliative care: "*knowledge of self, giving permission for connections and feelings, filtering experience,* and *being present at work"* (p. 336). In another example, Sharif Nia et al. (2015) used descriptive phenomenology to explore experiences of death anxiety in 11 Iranian War Veterans. This study urged healthcare providers to be cognitive of the impact of death anxiety veterans may face by recognizing their attitudes towards death and dying and how they impact care. These researchers noted that religion was a crucial indicator in studying fears surrounding the afterlife and anxiety associated with personal choices. Similarly, Belanti et al. (2008) used phenomenology to conduct a cross-cultural exploration of near-death experiences. This study identified how culture was an influential factor that may explain specific features of near-death experiences. Belanti et al. (2008) stated, "The content and meaning of near-death experiences may also vary historically, depending upon the level of influence and involvement between religion and society" (p. 130). This study is an excellent example of why interpretive phenomenology is ideal in my research, as bracketing religious, cultural, and historical understandings could restrict the experiences of practitioners.

Despite the research focused on experiences of death by healthcare professionals, there remain gaps in our understanding and much more research is needed. Schulz-Quach (2018) concluded that phenomenological research surrounding death confrontation and awareness rarely comes from the healthcare professionals working in the field. They attributed the lack of

phenomenological understanding of the healthcare worker and their experiences to organizational demands. They explained that in the post-modern world following World War II, scholarly attempts at exploring the phenomenology of death remain "fragmented" (p. 303). Yet, understanding healthcare workers' experiences, especially around death and dying is important and distinctive because of healthcare workers' close relationship with the dying (Schulz-Quach, 2018). My research aimed to expand our phenomenological understandings on death experiences by focusing on a group of healthcare providers rarely considered in this research.

Phenomenology has proven helpful in understanding experiences of death, including how death is experienced by people working in the healthcare sector. Phenomenology holds promise for engaging with death because it highlights the range of experiences healthcare professionals have. Each profession is isolated depending on when you met with death (before, during, after) and where it occurs (Schulz-Quach, 2018). However, in my reading of how death has been taken up in the literature, I became intrigued with personification theory and how this approach might provide a unique way to understand experiences of death for recreation therapists. The current literature has yet to explore the phenomenological understanding of death from the perspectives of recreation therapists. Given the gap in the current literature, applying personification theory alongside existing approaches could help bridge that divide**.** Personification theory can offer unique insight into experience (Paxon, 1994). It was important for me to integrate personification into my study as it provided an important and unique opportunity for recreation therapists to explore their thoughts and feelings around death in a safe, and creative way. I will now discuss my second body of conceptual literature informing my research, personification theory.

## Personification

Personification, or *prosopopoeia,* is the rhetorical figure by which something not human is given a human identity (Paxon, 1994). Personification can be used as a descriptive communicative device operating from multiple sensory experiences which communicate the spiritual, visible, invisible, concrete, and abstract, and also challenge and highlight facts, opinions, and beliefs (Melion & Ramakers, 2016). As I began thinking about how I might approach my research, I was intrigued by personification theory and what it might contribute to my research. In this section, I describe personification theory and research on personifications of death. I then provide a brief critique and how this engagement with personification led me to expanding my approach to personification using arts-based methodologies.

Personification theory works from the ideas of hermeneutics that language binds our ability to share our thoughts; it gives power to the reader to see the participant's inner dialogue (Melion & Ramakers, 2016). Personification has been used to describe death through the language of art, poetry, and religious writings for centuries. Evidence of personification can be seen in religious texts such as the Old Testament, which represents death as evil, hostile, distressed, and apocalyptic (Tamm, 1996). The Greeks, however, did not ascribe to the same personification. In contrast, death was personified in many forms, including Moirai (the fates), the Keres (violent death), Hypnos (sleep) and Thanatos (death) (Vardal, 2019). Personification highlights our fears and hidden understandings and the temporality, spatiality, culture, and society we live in. During the time of the bubonic plague in 1347, death was painful and feared. It left people searching for answers, which prompted the poor and uneducated to turn to the Catholic Church for answers. This resulted in the vivid descriptions of heaven and hell that we still see today (Vardal, 2019). During the hundreds year period of 1450-1750, women were

targeted in witch hunts and trials, and death was commonly depicted as a woman who was inhuman, evil, and enjoyed the misery of others (Guthke, 1999). Within these examples, it is clear that personification and imagery are connected with our space in time and our relations to self, others, society, culture, time, and space. Using personification as a theory provides a lens for analysis to ask where personifications of death emerge from. Is it only rooted in relevant events, universal images, or personal factors (Kastenbaum & Herman, 1997)?

**Death Personification**

To answer this question, Kastenbaum and Herman (1997, p. 117-118) offered three tenants of death personification:

1) Human beings have the tendency to equate a human shape, qualities, ideas, and feelings to reveal nonhuman beings.

2) Personification connects directly with: a) culture and values, b) individual development, c) individual personality or coping, and d) situational contexts.

3) Personification has the potential for society to connect with death creatively by: a) objectifying a concept that is difficult to comprehend, b) expressing complex attitudes and emotions without language, c) differing communication styles which encourage individuals to speak of death-related feelings, d) absorbing overwhelming emotions experienced by trauma, and e) provide artifacts that can be reshaped collectively or independently.

In early death personification studies, Kastenbaum and Ainsberg (1972) conducted an exploratory study of death personification involving 240 college students, student nurses, and mortuary science students. In 1995, Kastenbaum and Herman replicated this earlier study with a sample of 447 general college students and nursing students. Tamm (1996) conducted a similar

study to understand how healthcare workers personify notions of life and death; their sample consisted of 47 people, including physicians, nurses, physiotherapists, hospital orderlies, library staff, and healthcare teachers. These studies found that male personifications of death are dominant, with a rise in feminine personifications among female respondents (Kastenbaum & Herman, 1997). Kastenbaum and Herman (1997) continued this line of work in a study that asked student groups, including geriatric nurses and aids, to imagine death as a character identified through fixed-choice responses presented through a survey. This research revealed that personifications are created through interactions of a) cultural traditions and values, b) individuals' level of development, c) individual personality and coping, and d) situational context.

### *Four Types of Death Personification*

Kastenbaum and colleagues' (1972) research contributed to the development of four types of death personification. These include:

1. ***The Macabre***: a disfigured, decaying, horrifying personification. This personification is often personified as male and extremely old. The closest image would be the Grim Reaper. Death is commonly personified this way in media in the Global North.
2. ***The Gentle Comforter***: often connected with father time or an older gentle person, personified as male, but there are also un-gendered or feminine typologies.
3. ***The Gay Deceiver***: this personification is sexier than the rest. It is younger, poised, sophisticated and attractive. This character embodies a worldly con-person.

4. ***The Automaton***: death is impersonal, unfeeling, and non-emotional; it is robotic and cold.

Following Kastenbaum and Ainsberg's (1972) study, research on the types of death personification continued sporadically. Lonetto (1982) researched the connection between death personification and death anxiety, finding some correlations between death personification and death anxiety. The connections suggested that those with the highest death anxiety personified death as a gay deceiver. Lonetto (1982) described the gay deceiver as connected to the "cognitive-affective component of death anxiety, i.e., fear of dying, appearing nervous when people discuss death, the frequency of death related thoughts and their effect and being troubled by thoughts of life after death and the future" (p. 407). Tamm (1996) studied Swedish healthcare workers' personification of life and death, finding that the majority of respondents, men (84%) and women (65%), saw death as an older man, wearing dark clothing, often in a rural location, with all respondent's stating death was solitary and never accompanied. In a more recent study, Kang (2021) used the four common types of death personification to ask what types of death are personified. This study also had participants envision six significant causes of death: 1) cancer, 2) old age, 3) car accident, 4) murder, 5) heart attack, and 6) other illnesses. Using the six causes of death and the four death personifications, the results indicated that the Macabre was associated with violent intentional death, the Gentle Comforter with old age, the Gay Deceiver with a heart attack or dying young, and the Automaton with cancer or death within the hospital.

I could not find any studies on death personification in the current literature that have included recreation therapists. This is problematic because recreation therapists often work in settings where people die, such as palliative care, hospital, home, and long-term care (LTC). Tamm (1996) stated that 25% of healthcare workers have a fear of death, though they come in

contact with it often, relative to the general public. Tamm highlighted that this should not be ignored as it "suggest[s] an unresolved problem in dealing with the phenomenon leading to complications in working life" (p.19). This quote further suggests that there is a lack of opportunity within healthcare to talk about death and how it is personified for healthcare professionals and highlights the possibilities of personification as a tool for educational purposes. Death is an imminent reality faced regularly within these spaces, yet recreation therapists have been left out of the conversation of death, grief, and bereavement. During the COVID-19 pandemic, healthcare workers noted higher burnout while dealing with higher fatalities, staff shortages, and budget cuts (Leo et al., 2021). Within these spaces, recreation therapists and therapeutic recreation students took more active roles at the end-of-life while living with complex bereavement. In understanding how recreation therapists personify death, we can understand how one experiences death on an individual level. Understanding how death is perceived and experienced is an important starting point in understanding how to better support these healthcare workers experiencing death in their jobs and the death education and other supports that might better prepare them for those jobs and experiences.

### *Artistic Personifications of Death*

Connecting death, art and personification is not new; death has been painted, photographed, danced, sung, and drawn throughout history. A famous representations of death are the 'Dance with Death motifs' or 'de Macabre la Danse" in Jean le Fecre's 1376 poem La repit de la mort. The first visual example is seen on (lost) wall paintings in Paris dating back to 1424-1425. The 'Dance of Death' (See Figure 1) is an allegorical confrontation of the living with death which aims to remind the observer of their mortality (Oosterwijk, 2004). Holbein's woodblock printing *The Dance of Death* was first published in

1538 and gained popularity quickly, supporting the moral lesson that death is a "great equalizer, putting all social stations on notice" (Ebstein & Self, 2017, p.132). The dance with death-theme has continued throughout centuries, highlighting that no matter your business or pleasure, it is difficult to find a topic more relevant to all than death.

**Figure 1: The Dance of Death', by Isaac Cruikshank (after George Woodward), published October 1808**



In many personified paintings of death, death is closely related to sex and leisure. One piece by an unknown artist portrayed in *Death, a Graveside Companion* entitled 'The Skeleton Tradition' shows an array of skeletons performing leisure activities (Ebstein & Self, 2017). Another, titled 'Cycle of Scenes of Living Skeletons,' painted by Paolo Vinccezo Bonomini, shows a military man, copper, husband and wife, and a self-portrait of a painter (Ebstein & Self, 2017). In the 1800's artists' renditions of death shifted to include the sensuality of death and death's connection to sex. Edward Munch's sketch 'Death and the Maidan' displays a woman

embracing and kissing death. Ebstein and Self (2017) offered two interpretations of this art piece: one “the triumph of life over death, or the ‘death’ implicit in sexuality” (p. 202). These medieval artistic personifications were amongst many personified renditions of how death is imagined and experienced.

As I continued to explore personifications, I was drawn to consider how personification could represent the modern experiences of death by recreation therapists. As I reflected on how art has been used to personify and make meaning of death, I thought about the possibilities of having participants’ personifications ‘come to life’ through visual art. Personification reaches beyond spoken or written words to create a distinct narrative between appearance and meaning. Through the personification of death, there is a potential to assist societies and individuals in engaging with challenging topics, by objectifying the concept, expressing feelings associated with the experience too difficult for words, serving as a communication tool, and providing artifacts (Kastenbaum & Herman, 1997). I will return to a discussion of my arts-based approach to personification in Chapter Four.

## Integrating Phenomenology and Personification

So, what is the alignment between phenomenology and personification theory? As mentioned earlier, phenomenology is the study of the essence of experiences in the world. Personification can be an important way of understanding and capturing the essence of experiences by providing “a visible representation of something abstract (as a quality)” (Merriam-Webster, n.d. b). Personification provides safe(r) opportunities for individuals to draw on and connect with real or imagined experiences of death and dying that might reflect and shape our understanding. Asking questions such as "what is it like to experience death?" and “what

does death look like?" opens space for recreation therapists to explore and discuss what their experiences mean to them and how they might be better supported.

In summary, I see exciting research possibilities of integrating phenomenology with personification. Within methodology, personification offers a balance of semiotic and phenomenological analysis focusing on the meaningful effects of presence. Melion and Ramakers (2016) stated that:

> …only when the image, natural or imagined, has been fully perceived, experienced, and analyzed on this sensual, bodily level does an interpretation in the traditional iconological (or hermeneutical sense) begin (p.8).

Personification allegory enables the researcher to tell and show a story; personification imaginatively enables the audience to see and feel the effects of experience or rhetoric. Shahar and Lerman (2013) indicated that personification is transformative, having the potential to change an external obstacle into something with purpose and meaning. Personification is a figure of speech that gives human qualities to objects, ideas, and abstractions. Using personification can work beyond rhetoric, providing opportunities to explore experiences, including death, through art.

Despite the potentials I saw in personification in terms of opening up unique spaces to intentionally explore understandings and experiences of death, I did have concerns with attaching human characteristics to death and the implications of that. One of my committee members asked some important questions that led me to reflect on: what are we leaving behind when we reduce death only to human experience? Are we only able to relate to something we make human? Are we only able to reckon with something that we interface with face-to-face? Why are we making a non-human experience limited to human faculties? I was interested in

seeing if recreation therapists would connect death with human qualities and/or would see and reflect death in alternative ways. This whole process led me to the use of arts-based methodologies. I put the conceptual ideas I have discussed in the Chapter to work in my methodology and methods described in Chapter Four. In my next Chapter, I describe how death has been broadly taken up in leisure studies and recreation therapy/therapeutic recreation.

## Chapter Three: Death in the Context of Leisure

In this literature review, I explore how death has been taken up and understood broadly within leisure studies and recreation therapy/therapeutic recreation more specifically. Leisure and death have multiple intersections within the literature. Most connections are not explored in-depth and demonstrate the need for further exploration. Some connections relate to leisure's role in mediating the risk of death, dark tourism, leisure in palliative care, and leisure to cope with death; I begin my discussion by reviewing these connections. I then explore how death has been taken up in the recreation therapy/therapeutic recreation literature and highlight the gaps. Examining how we understand death from a leisure perspective assisted in understanding how definitions and contexts are taken into recreation therapy/therapeutic recreation and healthcare settings. Finally, I explore the literature on death education and the benefits and challenges associated with death education or lack thereof. This chapter discusses death's role in leisure and how this translates into recreation therapy/therapeutic recreation practices.

### Death and Leisure

The relationship between leisure and death often explores how we use leisure to weather challenging times, looking to our hobbies and joyful experiences to mitigate or disguise our difficult experiences and emotions (Fox & McDermott, 2021). To understand the ways death is taken up in the leisure literature, I have organized the review into three categories:

1. Leisure Promoting Life Yet Predicting Death: this section explores how leisure has been positioned as a preventive measure for premature death (Lahti et al., 2014; Lan et al., 2006). Additionally, this category looks at how leisure can increase our risk of dying through risky leisure resulting in death (Creyer et al., 2003; Olivier, 2006; Berdychevsky, 2019; Taubman-Ben- Ari, 2004; Stone & Sharpely, 2013).

2. Leisure, Death, and Grief: this category focuses on the ways leisure has been used as a tool during grieving (Patterson, 1996).
3. Consumption of Death: this category explores how death is consumed through our leisure, such as through dark tourism pursuits (Ferrerira, 2023) and the pornography of death in our media consumption (Gorer, 1955; Tercier, 2013; Haider, 2010).

## Leisure Promoting Life Yet Predicting Death

Our leisure choices indicate our interests and identity and support our health (Anderson & Heyne, 2012). Much of the leisure literature focuses on leisure pursuits which are positive and enriching, but this is only part of the picture, with people worldwide participating in leisure activities that threaten the self or others. As stated by Stodolska and colleagues (2019), participation in deviant and "abnormal" leisure includes activities common among young adults. Within this section of the review, I describe the ways that leisure and death intersect through our leisure choices. Some research offered evidence that increased physical leisure decreases our risk of all-cause death, while other research suggests the latter, that leisure can define our death through the level of risk in our activities.

### *Leisure Promotes Life*

Leisure is typically portrayed positively with evidence supporting the role of leisure in buffering stressful events, providing escape, mediating mental illness (Takiguchi et al., 2023), and lowering the risk of all-cause death (Moore et al., 2012). In much of the literature, leisure is presented as a preventative measure to premature death. Thousands of articles correlate leisure time with lowering the risk of all-cause death. Often within these spaces, leisure is defined as physical activity, classified by the abbreviation LTPA (leisure time physical activity) (e.g., Shariful Islam et al., 2023; Moore, 2012). Within this definition, leisure takes on a specific form

focused on active leisure such as biking, hiking, and sport. This research highlights the correlation between LTPA and a significantly lower risk of all-cause death (Moore et al., 2012). Evidence indicating this correlation has led to investigations into the possibility of using leisure as medicine to cure illness and as a preventative measure to prolong life. For example, Pedersen and Saltin (2015) suggested that prescribing LTPA as therapy could be an important means of alleviating the symptoms of 26 chronic illnesses. Most research on leisure as prevention has been conducted through quantitative analysis using the biomedical model. Many published studies describe the role of leisure in maintaining a healthy physical life to avoid premature death and prolong life. This research tells us that our leisure choices influence our mortality risk.

### *Leisure Predicting Death*

Despite the predominant focus on the benefits of leisure for avoiding death, more recent research has also explored the negative side of leisure. In fact, until the 1990s, gang violence, substance use, dangerous sexual activity, and murder as leisure received little attention within the literature as leisure scholars and professionals focused on leisure as a social benefit to society (Rojek, 1999). Leisure, however, provides opportunities to participate in criminal activities, drug and substance use, and other risky behaviours, which increases risk of death (Stodolska et al., 2019). This type of leisure is often called ‘deviant leisure’ or ‘purple leisure’, which is defined as “behaviours that violate criminal and non-criminal moral norms” (Williams & Walker, 2006, p.195). When speaking on the intersection of leisure and death, it is also important to note that some people use leisure to harm themselves or others. There are countless reasons one may participate in ‘deviant leisure,’ including boredom, thrill-seeking, personal pleasure, and escape (Gunn & Cassie, 2006). Gunn and Cassie (2006) indicated it is important to understand that leisure activities are not inherently positive but may satisfy “criteria of deviance” (p. 48).

Researchers working in this area emphasize the significance of these ideas for leisure scholars to understand that deviant leisure exists and take note of its complexities and layers (Williams, 2009).

Like death, deviant behaviour has been pushed to the periphery, labelled as 'taboo.' However, it is important to note that not all deviant leisure assumes harm but can be a form of resisting ideologies and social norms which redefine boundaries and definitions (Williams, 2009). Deviant leisure resists moral norms through risk-taking, questioning social taboos, and considering sub-cultural contexts (Stodolska et al., 2019). For example, in the 21st century, sex clubs, BDSM (bondage discipline, dominance-submission), and kink have increased in popularity (Haywood, 2021). Since 2005, BDSM has been removed from the formal classifications of psychiatric illness, but participation remains a social taboo (Williams, 2009). Safety, protection, and consent are of high concern within sexual leisure spaces, but the risk to life through STIS (sexually transmitted infections) and risky play remains a possible threat to health (Haywood, 2021). Thus, participation in "deviant" leisure is not always bad, as it plays a role in resisting and challenging dominant ideologies and social norms while still posing an increased risk of death; the relationship between deviant leisure and death is a complex one.

Using the personification theory perspective, the perception of leisure's power to challenge or pursue death is best described in the personification of the gay deceiver. The gay deceiver, as understood by Kang (2021), is described as "death considered as morally punitive for self-indulgent behaviours such as unprotected sex or illicit drug use" (p. 491). The gay deceiver is an erotic perception of death, known for the Harlequin Complex, attractive and deceptive. Kastenbaum and Herman (1997) describe the gay deceiver as mysterious, egocentric, and sophisticated. Further, the gay deceiver is considered tempting and sexy, attracting their

victim with a good time before turning cold (Kastenbaum & Herman, 1997). Lonetto (1982) described the gay deceiver as "an attractive and beguiling figure" (p. 406) related to high cognitive-affective death anxiety. Cognitive-affective aspects of death anxiety correspond to the fear of dying and the high frequency of death-related thoughts.

**Leisure, Death & Grief**

In the literature, leisure has also been positioned as a source of comfort, distraction, and ritual during difficult times (Walter, 2007). Fox and McDermott (2021) asked the question about leisure's potential to address changes brought forth by COVID-19. Fox and McDermott (2021) suggested that if we view leisure differently, from the position of Pieper who believed leisure as an internal reality or a place to contemplate, there is more potential for leisure to address the human experience. Fox and McDermott (2021) further emphasised that leisure scholarship needs to see a shift to access the meaning and capacity of leisure through the "philosophizing individual" (p. 270).

The COVID-19 pandemic highlighted the vitality of leisure once our leisure spaces and connections outside the home closed their doors (Lashua et al., 2021). Though grief is prominently studied within psychology, grief is influenced by our culture and social structures (Lofland, 1985; Walter, 2007). Fox's (2021) article 'Leisure shows up for a wake' highlighted how ritual can play a powerful role in helping us cope with loss through a fictional vignette. In the pandemic, rituals surrounding death were forced to change through cyber funerals, long wait times for services, and lack of options. In times of overwhelming grief, uncertainty, and isolation, such as during the pandemic, leisure habits turned from leisure consumption to slow leisure, described as a time for introspection and creativity (Lashua et al., 2021). Walter (2007)

shared that it is within our leisure that we are given the time to explore and express our pain, fears, and grief.

After losing my grandmother to COVID-19 in early April 2020, I experienced this firsthand. After days of emptiness, grief, sadness, and regret, I questioned how to honour my grandmother. I looked to leisure as an escape from the pit of emotions left behind. To engage meaningfully in my grief, I connected to my grandmother's leisure practices of poetry to highlight her legacy, a piece I performed at her funeral. Kleiber and colleagues (2002) suggested that leisure can be utilized as an adjustment and coping strategy during negative life events, such as the death of a loved one. In these situations, leisure is presented as a tool for coping with loss. Findings indicate that those who participate actively in leisure pursuits, particularly social activities, experience higher levels of happiness and reduced stress (Janke et al., 2008a), especially during difficult times and challenging life transitions.

However, leisure and grief share a complicated relationship. Kleiber et al. (2002) stated that widowed women tend to disengage from socializing, sometimes believing they should not experience joy without their partner. Kleiber (2002 believes that coping with grief through leisure is complex because of the positive and negative ways in which people engage with leisure, whereby some individuals may participate in slow leisure (Andrews, 2006), while others participate in substance use (Woodford, 2022). The strategies most commonly used involve emotion-focused activities such as drug and alcohol use, video games, exercise, retail therapy, sex, or media consumption to reduce emotions connected to negative life event stressors (Kleiber et al., 2002).

One limitation of this research is that most of the research on grief is connected to widowhood in the older adult population. As we age, our leisure activities shift to accommodate

physical and mental capabilities (Janke et al., 2006). Standridge and colleagues' (2022) research on older adult widowed women found that though experiences are unique for each individual, there are visible common threads. The common threads included changing relationships, using leisure as distraction and reinvention, and using leisure to form a new reality (Standridge et al., 2022). The study found that women used leisure to reconstruct their identity by "embracing new leisure activities, new action patterns and new relationships" different from what they had experienced before the loss of their spouse (Standridge et al., 2022, p.85).

The COVID-19 pandemic led to additional literature surrounding loss and grief as more people experienced death at an accelerated rate (Weaver et al., 2022). As the news broadcasted the daily numbers of new deaths, hospitalizations, and cases, death became more visible than ever. For me, the numbers minimized the impact of loss seen throughout the pandemic. After losing my grandmother to COVID-19 and seeing the death tolls on the news, I was left disheartened that my grandmother's life was minimized to a number. Similar to others' experiences, I feared that my grandmother did not have a good death, experiencing her last breath surrounded by staff in hazmat suits and her family cautioned from entering the home. This was not an isolated experience and has since been identified as a barrier to coping. Weaver and colleagues' (2022) study of young adults' experiences of loss and grief during COVID-19 explored this experience specifically. Their research reflected leisure as a coping tool, supporting people with gaining control by grounding individuals and providing structure to an unprecedented time.

Looking at the pandemic, death, and grief, interesting personifications emerged. Common personifications representing the pandemic were those of healthcare and frontline workers donning superhero clothing (Saji et al., 2021). Research in this area explored the relationships

between personification and comics in times of crisis. Art was presented through the media during the pandemic, documenting our feelings through "conceptual metaphors of war, anthropomorphism, and superheroism … to represent the pandemic" (Saji et al., 2021, p. 138). Death personification was represented within Saji and colleagues' (2021) analysis through Bonil. Figure 2 depicts Xavier Bonilla's representation of the virus's relationship to death (See Figure 2). The image depicts death as a hooded figure donning an N-95 mask and the virus as an anthropomorphic pig-octopus combination to signify the "unreal nature of the virus" (p. 150). This image reflects many interactions, including the shift of power, the representation of geopolitical factors and xenophobia, and the dominance of the virus over human life. Within this image, the fear of losing a sense of control is also reflected (Saji et al., 2021); we see a depiction of something we fear (death), crowning a new enemy (COVID) that seemed impossible at times to beat. This image is an excellent example of how personification and art can help to interpret emotions and lived time and space without the restrictions of spoken language.

**Figure 2: Bonil Cartoon - Comics in the Time of a Pan(dem)ic: COVID-19, Graphic Medicine, and Metaphor. p. 151**



## The Consumption of Death

Death has a way of presenting itself within our leisure in ways that are sly and undetected. Gorer, back in 1955, described this phenomenon as the 'Pornography of Death', whereby a society banishes an experience to the sidelines. Groer believed that when we banish experiences, the forbidden finds a way of presenting itself through art and media in often graphic and violent representations (Tercier, 2013). We see death daily on the news, in video games which have been questioned for portraying violence and death, and art galleries presenting corpses for the pleasure of the masses to view. At the same time, society further pushes death to the periphery using euphemisms such as "passed away", "departed" and "gone" to reinforce our discomfort for and with death. It is here that "obscenity compels regression" (Tercier, 2013, p. 229). It is within the pornography of death that leisure and death interact through dark tourism and the consumption of death-related media.

### *Pornography of Death*

Death consumption for leisure has existed since ancient times, as demonstrated through the Roman gladiatorial games (Stone & Sharpley, 2013) and the popularity of public executions in 19th century London (Ferreira, 2023). We still consume death in modern society, but it typically takes shape through media. Today, our death consumption connects to our fascination with true crime (Frost, 2015). Interestingly, the fascination with true crime in the 20th century came in tandem with the shift in prudery when death among Anglo-Saxon societies became unmentionable (Groer, 1955). Most of the literature surrounding the consumption of death for pleasure has been studied outside of the leisure field, and thus most of the works presented in this section are drawn from anthropology and sociology texts.

As mentioned earlier, Groer (1955) coined the concept of the pornography of death in his self-titled article 'The Pornography of Death,' where the morbid representation in media and art is an embodiment of pornography. In his article, Groer claims that pornography representation became rampant as societies shifted topics further into prudery. We can see evidence of this in the pornography of sex (Tercier, 2013). Tercier (2013) extended Groer's (1955) theory of the pornography of death, particularly concerned with film media, to consider the modern phenomena of corpse photography within art galleries. Tercier explained that the pornography of death typically refers to media representation, which abstracts or presents death to an audience. They explained that when something is repressed or made taboo, it oozes into our society in uncensored forms. I believe this is rooted in our desire to understand while prescribing to a pre-dated taboo.

To explain the pornography of death further, Ruberg (2017) explored permadeath or permalife video games. Ruberg argued that both terms play out within video games through systemized conditions, determining whether a player lives or dies. The conditions of life and death within games regulate how a player approaches tasks, demonstrating mechanisms of life and death. For example, in the 'permadeath' game, which mimics real-life mechanics, you can only die once. This game structure affects how gamers experience or play the game. Ruberg (2017) stated that death in games communicates social meanings outside of the cyber world. Within video games, there are connections with the medicalization of death, where death is viewed as a failure. Ruberg (2017) argued that video games which use "extra lives" are connected to the healthcare practice of extending our life span through modern medicine.

Modern medicine is shaped by the view of death as a failure and by the commodification of death. This shift has weakened emotional and spiritual ties to death, moving it from the home

into institutional spaces marketed as caring environments. Death is now packaged and sold through media such as news, true crime, and video games. At the same time, the physical realities of death and grief are often stigmatized and managed by institutions like mortuaries. This removal of death from daily life reflects the influence of the death industry in shaping public discourse, framing death as abnormal and allowing society to avoid its emotional and social complexity.

The extension of life and removable of the relational experience of death through modern medicine has been evaluated by Kang (2021), who argued that the modern personification of death is represented by the Automaton. The Automaton takes on a robotic form, often represented as cold and faceless. Described by Kastenbaum and Ainsberg's (1972) study as "objective, unfeeling, automatic and soulless" (p.157), the automaton closely connects to modern death within a hospital (Kang, 2021). As the prudery of death is further enforced, we will continue to see reflections of death as impersonal, unnatural, and unemotive (Kang, 2021). Groer (1955) argued that if we do not take back natural death and re-admit our grief and mourning, and death is maintained as unmentionable in our polite society, we will "ensure the continuation of the 'horror comic"' (p.52).

### *Dark Tourism*

In addition to the connections between video games and death described above, the pornography of death and death consumption have connections to leisure in other ways. Mowatt (2009) described the spectacle of lynching of racialized bodies as violent acts of leisure. Another example of this is dark tourism or Thanatourism, which Lennon and Foley introduced into language in 1996. Dark tourism was designed to draw people to sites associated with death and disaster (Lennon & Foley, 2000). Death literature shows death has taken many forms outside of

medicine, including the continued consumption and participation in dark tourism, which "describes the relationship between tourism attractions and an interest in death and the macabre" (Dale & Robinson, 2011, p. 205). Dark tourism holds an interesting duality where some destinations are avoided for their darkness or connection with death, whereas others, such as London and Harlem, receive a flow of tourists seeking their dark histories (Lennon, 2017). To better understand dark tourism, Lennon (2017, p. 5) classified the phenomena into five "sites": 1) sites of death and disaster, 2) sites of mass or individual death, 3) sites of incarceration, 4) sites which represent or simulate death, and 5) sites of re-enactments or interpretations of death. While visiting Scotland, I participated in dark tourism through a 'Dark History Tour' of Edinburgh. The tour included three of the five classifications, through visitation of mass execution sites, prisons within castle walls, and a graveyard tour, which included a stomp at Adam Smith's grave in Canongate Churchyard (see Figure 3). Although a relatively 'new' formal classification of tourism, the dark and tragic, has attracted an audience since the rise of heritage tourism in the 1980s (Ferreira, 2023).

Regarding tourism and leisure research, dark tourism scholarship is in its infancy and needs more investigation and development. Possible explanations for this underdevelopment could connect to the taboo of death, cultural restrictions of the tourism sites, or the challenges within the marketing and management of dark tourism (Ferreira, 2023). With the limited evaluation of tourist motives for visiting, the simplest motive is curiosity, while Raine (2013) argued that spiritual or personal relationships may draw individuals to sites. Dark tourism may have been officially defined in the 1990s, but humans have been engaging in the spectacle of death for much longer.

**Figure 3: Canongate Churchyard, Royal Mile Edinburgh Scotland Adam Smith's Grave**



To summarize, the scholarly connections between leisure and death are in early development, with much of the literature focusing on leisure as a tool to avoid or hasten death and leisure's connection to grief and coping. Having said that, literature outside of leisure studies has contributed to this knowledgebase, particularly in relation to the consumption of death in media and leisure activities. However, I found no literature exploring leisure professionals' experiences or understandings of death. Fox (2021) argued that this may be an effect of the definition of leisure; rather than seeing death as a peripheral experience, it is important to centre "both life and death" in conceptualizations of leisure (p. 272). I now turn the discussion to exploring how death has been taken up specifically in recreation therapy/therapeutic recreation literature and the role of the recreation therapist in death and dying.

## Death and Recreation Therapy/Therapeutic Recreation

With the gap(s) in specialized training for recreation therapists, including the lack of training surrounding death before graduation highlighted by Prentice and Narushima's (2022) study, I turned to exploring the literature published in recreation therapy to investigate how, if at all, death is taken up in the recreation therapy/therapeutic recreation literature, highlighting the gaps. I started by looking to the *Therapeutic Recreation: Practice and Research* journal (TRPR), the Journal of Therapeutic Recreation Ontario, and the two primary therapeutic recreation journals in the United States, the *Therapeutic Recreation Journal* and the *Annual in Therapeutic Recreation*. Although it might be assumed that death would be taken up in the context of recreation therapy/therapeutic recreation (TR), particularly since many recreation therapists often work closely with older adults and people with chronic illnesses and/or complex co-morbidities, I was surprised at how little death is talked about or explored in this literature. When mentioned, death is predominately described in association with the number of deaths from a specific illness such as cancer (Martin et al., 2014;), COVID-19 (Loy et al., 2021), dementia (Skalko et al., 2013; Litchke et al., 2014; DeVries et al., 2019), or complications in later life (Piatt & Chiasson, 2016; Chen et al., 2018). When death is engaged with more directly, it is most often associated with how recreation therapy/therapeutic recreation can be utilized in palliative care. Far fewer studies have examined how recreation therapists can be supported during experiences of grieving (King, et al., 2016), interventions to address posttraumatic stress from war (Bennett et al., 2014; Craig et al., 2020), near-death experiences (Mikal-Flynn et al., 2018), or natural disasters (Kono & Burton, 2019). Among much of this literature, recreation therapy/therapeutic recreation is presented as a preventive option for lifestyle behaviours associated with premature death

(Anderson et al., 2016). A much smaller body of literature explores death education in the context of recreation therapy/therapeutic recreation.

**The Intersection of Recreation Therapy/Therapeutic Recreation and Death**

When death and dying are explored in the context of recreation therapy/therapeutic recreation, it is explored predominately in relation to palliative or hospice care facilities, and, even then, research in this area is limited and is all relatively recent. In my review of the *Therapeutic Recreation: Practice and Research* journal (TRPR), I found only five articles addressing death or end-of-life, all addressing palliative care. This included an article by Alexander-Gertz (2005) entitled "What Can We Learn About Caring for Palliative Patients? The Power of Therapeutic Recreation", an article by Charles (2020) entitled "The Effectiveness of Engaging Volunteers Virtually with Palliative Patients During COVID-19", an article by Athithan (2021) entitled "Literature Review on Therapeutic Recreation Practice in Palliative Care," an article by Teles (2021) entitled "Reconceptualizing the APIE model in Palliative Care" and Bayly and Stephans' (2004) article on collaborative programming between art and recreation therapy.

The role of the recreation therapist in these settings is as a respite from physical medical care, giving a vehicle for people who are dying to connect to reflection, peace, legacy, and experiences (Alexander-Gertz, 2005). Recreation therapists within these settings often work from a unique lens of care, nurturing opportunities for connection. Through this lens, recreation therapists encourage connection and promote comfort, reflection, and release (Alexander-Gertz, 2005), which creates opportunities for individuals to feel comfortable bringing death into the conversation. An example of research conducted in this area is Bayly and Stephans' (2004) study that brought art therapy together with recreation therapy at Toronto's Sunnybrook Veterans

Centre. The authors facilitated collaborative art programming in their study to explore residents' self-expression through leisure choices. In their analysis, death was brought up by several residents who expressed their fears, queries and insights surrounding death and dying through art. Some of these representations included a 'faded leaf', which elicited discussion surrounding death and dying through memories of lost family members (Bayly & Stephens, 2004). Other artwork reflected the loss of group members by creating memorializing art. Through these sessions, residents could "concretize their grief" (p.41) through representations that symbolically represented their friends. Bayly and Stephens (2004) connected this process to work by Borowsky-Junge (1999), who explained that memorializing the dead unifies the living and gives solace that they will not be forgotten.

Recreation therapy/therapeutic recreation also provides opportunities for individuals to connect with their wishes for the end-of-life, including their legacy. In embracing conversations around end-of-life, recreation therapists can understand people's wishes for a 'good death.' O'Keefe's (2005) work in the *Philosophy of Therapeutic Recreation* is a good example. O'Keefe reflected on their time working as a therapeutic recreationist in a palliative care setting, noting the wishes of a person they worked with for end-of-life care. These wishes included: 1) to embrace death without fear but fully acknowledge the loss; 2) to spend time creatively with her family in activities that would bring enjoyment, peace, and good memories for the whole family; and 3) to be physically comfortable with a satisfying level of alertness (p. 81). The conversation surrounding a 'good death' provided an opportunity for the recreation therapist to collaborate with this person and their family to create an activity encompassing their end-of-life wishes. The experience created was a collaborative videotape project with the person's family to reflect family joy, memories, reflection, and connecting to the inner self (O'Keefe, 2005).

The “good death” is a dynamic and complex concept that continues to evolve overtime. Cotteral and Duggleby (2016) provided an integrative literature review on attributes associated with a “good death”. An important aspect of a “good death” was the presence of control. Control showed up in different ways such as controlling aspects of dying, such as the timing and location of death. It also showed up in being able to manage unpleasant physical symptoms and the social dimensions of dying. For individuals approaching death, having control over these aspects is essential for accepting death, making informed choices, and preparing for the process of dying. However, Carr (2003) questioned the idea of a “good death" by asking, who is the good death for? Does the concept of a “good death” favour the needs of the dying person, their family, or the healthcare professionals? Who is served by a “good death” and what purpose does it serve? I continue to grapple with this concept.

**Death Education in Recreation Therapy/Therapeutic Recreation**

The literature surrounding death and recreation therapy/therapeutic recreation is sparse, with limited connection to practice, education, and programming opportunities. Stensrud (1993) attempted to fill this gap by highlighting leisure education's potential as a catalyst for death awareness practices for the people recreation therapists work with. The study brought together people receiving palliative care, family, and staff in a “non-threatening arena” (p.34) to explore and express feelings related to death, grief, legacy, and values. Stensrud (1993) argued that recreation therapists have one of the best opportunities to address death awareness because of their holistic visions for care, relationships with the people we work with, and expressive domains. They saw death awareness as an important area that could be integrated into pre-existing leisure education programs. In such programs, death can be centred as a part of life, with the intention to connect people to cherished moments of living and gain awareness of death's

presence. One activity they offered for practitioners to get started is the 'Lifeline Activity" (p. 37) where death is included in the participants timeline. This activity aims to position death as a part of life rather than the end-of-life. Stensrud (1993) states that the "journey into the unknown requires anticipating one's future, even perhaps, one's death" (pg. 37). Unfortunately, I could not find any evaluative research of this leisure education programming. In fact, I could not find any literature exploring death education for recreation therapy/therapeutic recreation. To me, this indicates that the key to integrating death awareness programming is educating recreation therapy/therapeutic recreation practitioners on meaningful end-of-life conversations, navigating personal experiences of death, and coming to terms with our mortality and grief before facilitation.

The gaps in death education are even more evident when looking at the foundations of recreation therapy/therapeutic recreation education. From a preliminary search of five Canadian recreation therapy/therapeutic recreation program course offerings, there are no compulsory courses surrounding death, dying, or end-of-life. The only courses related to these topics, if offered at all, are elective courses within Psychology or Gerontology. The Death and Dying courses include: Memorial University PSYC 3040—Contemporary Issues in the Psychology of Death and Dying; University of Waterloo PSYC 218—Psychology of Death and Dying; Brock University GERO 5P87—Death and Dying in Later Life; Dalhousie no course found; and Concordia University where Death and Dying are included in a Lifespan Development course.[2] The lack of death education is apparent in Canadian recreation therapy/therapeutic recreation

[2] This evaluation only includes courses centered around death and dying and does not include courses with units on death and dying. For example, the University of Waterloo does have a TR course with a unit on Palliative Care within the Therapeutic Recreation: Developmental and Emotional Disabilities course.

programs, and this gap is also evident within scholarly research on death education in recreation therapy/therapeutic recreation.

The aging population continues to grow in Canada, with an estimated 10.9 million older adults aged 65 and over by 2036 (Statistics Canada, 2016). As the aging population grows, so does the demand for LTC settings, including the call for additional staff (Ontario Long-term Care Commission, 2021). In Prentice and Narushima's (2022) cross-sectional survey of 487 Ontario LTC recreation staff, participants frequently noted the need for specialized courses surrounding death and dying to assist in coping with loss. Given the lack of death education in recreation therapy/therapeutic recreation curricula and the limited understanding of death and dying experiences among recreation therapists in the recreation therapy/therapeutic recreation literature, my research aimed to fill these gaps by exploring the experiences of death among recreation therapists. I hope that this information will inform future death education curricula centred around the needs of the recreation therapist in processing, communicating, and experiencing death, including the grief and loss experienced at these times.

## Chapter Four: Methodology and Methods Used to Explore Experiences of Death

This phenomenological study aimed to explore the experiences and meanings of death from the perspectives of recreation therapy practitioners, drawing on personification theory as a starting point for the exploration. More specifically, my research addressed the following research questions:

- How do recreation therapists describe experiences of death?
- How is death personified by practicing recreation therapists? What do these expanded personifications tell us about understandings and experiences of death?
- How might expanded personifications of death and the descriptions of experiences and meanings of death shared by recreation therapists inform what recreation therapists need to support their experiences of death and dying? How might death education benefit recreation therapists and the people they work with/support?

### Methodology

According to Berbary and Boles (2014), methodology gives a "rationale for methods" (p. 404). Consistent with the phenomenological theories of death grounding this research, I turned to van Manen's (2017a) interpretive phenomenology as the primary methodology. Max van Manen (2017b) understood the phenomenological gesture as a means to use language to describe the "raw moment[s] in lived experience" (p.812). van Manen (2017b) defines phenomenology as methodology that requires a continuous reconceptualization of both the idea and the data. From my understanding, this meant that I needed to remain flexible recognizing that the data and ideas might change throughout the research process. I attended to this throughout my work by writing reflexively about the changes in my understandings as they happened. Since phenomenology centres lived experiences, understood as our "consciousness of physical things, values, moods,

activities, and feelings" (Daly, 2007, p. 94), the data is not concerned with numeric values or codes but relies on examples. Examples within phenomenology are used to illustrate a story or general idea, which would then be developed into a theoretical conceptualization (van Manen, 2017b). Lived experiences can be further explored through the use of van Manen's articulation of the lifeworlds. The lifeworlds have been used to guide phenomenological methodology and understand lived experiences (Rich et al., 2013). I explored these in more detail in the next section.

**Phenomenology as Methodology**

Phenomenology recognizes the multitude of experiences individuals face in the world, including those understood through spirituality, family dynamics, culture, art, and education, for example (Daly, 2007). Van Manen (2007) states:

> *Phenomenology is a project of sober reflection on the lived experience of human existence - sober, in the sense that reflecting on experience must be thoughtful, and as much as possible, free from theoretical, prejudicial, and suppositional intoxications (p. 12).*

To encounter the "sober reflection," van Manen suggests a methodological structure through four procedural activities that inform research methods. van Manen does not believe these steps must be followed in a particular order and can all be analyzed simultaneously.

***Turning to the Nature of Lived Experience***

Max van Manen (2017b) defined turning to the nature of lived experiences as giving a connection of a person's lived relationship with the world. Within experiences, individuals carefully gather experiential data, better known as 'examples' (van Manen 2017b). I understood

turning to the nature of lived experience through examples as similar to gossip. Similar to sharing over a glass of wine or sitting in the office with colleagues after a challenging day, each person shares an example from their experience that reflects key information about the essence(s) of the day. It is within these moments of gossip that people can orient to a phenomenon. For me, orienting to the phenomena of death grew from sharing experiences of loss with my colleagues, leading to shared conversations in the death cafés. van Manen (1984) claimed, "It is always a project of someone: a real person, who, in the context of particular individual, social and historical life circumstances, sets out to make sense of a certain aspect of human existence" (p. 40). In this activity, the researcher orients their interest to the lived experiences of a particular phenomenon. While working in healthcare and experiencing the shared loss of the people I worked closely with, I was introduced to and oriented toward the experience of death. These experiences affected me heavily as I never felt there was an appropriate place for my grief. At work, there were minimal opportunities to pause and recollect because of the fast-paced environment. Additionally, it was difficult to bring the grief home in an attempt to balance work and life. These experiences prompted me to explore and reflect more on the nature of the lived experience of death through the facilitation of the death café groups in my work environment. It was during one specific death café held with the recreation therapy team where I realized my experiences were not isolated. One by one we discussed the hardest cases and experiences of death and how they could have been experienced differently. It was here that I realized that our lived experiences of death, although different in some ways, were compounded by the same feelings of isolation and disconnection.

Phenomenology aims to define the "essence" or "essences" of an experience. Essence is the qualities that make up an experience, whether it be shared emotion, sensation, action, or

reaction; the qualities paint a linguistic description of phenomena. Using arts-based methodologies, the participants in this research explored the phenomenon of death and dying through artmaking, specifically the creation of expanded personifications of death through collaging. Our goal in using arts-based practices is to use colours, shapes, images, and symbols to center the essentials of the experience.

Quantitative research has taken a different approach to understanding death and how it is represented using personification. These research approaches use standardized surveys as tools for building phenomenological research questions that centre the essence of a particular experience. For example, Kastenbaum and Ainsberg (1972) created the Death Personification Exercise (DPE), which asked participants to select an answer that best aligned with their perception of death as a person. Questions included: What colour eyes does death have? Red, blue, black, green. What gender is death? Male, female, unidentified. These questions are a starting point in orienting individuals – turning to – the phenomenon itself and the personification of death. These questions, however, need to be expanded to explore more deeply the diversity of understandings and experiences of death. I used personification as a means of orienting recreation therapists to the phenomenon of death and then building on these personifications to delve more deeply into understandings and experiences of death for these professionals through dialoguing with others. van Manen (1984) also provided guidance on how researchers might approach or structure phenomenological investigation; I turn to this next.

### *Existential Investigation of Experience as We Live It*

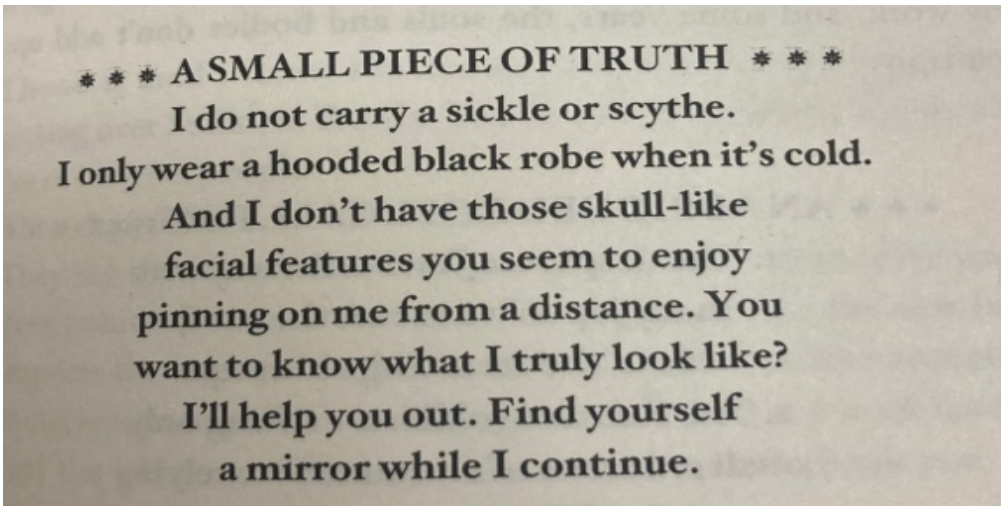
Within phenomenological research, existential investigation typically refers to the generation of data. However, van Manen (1984) believed this may imply that this phase is mechanical, where the investigator manipulates research data. In contrast, van Manen believed

this phase is centred around the researcher's educational development, where the researcher finds ways to understand the phenomenon better. A researcher can do this in a few different ways:

a) "Standing in the middle of life" (p. 50) or the importance of experiencing life can be achieved through extensive experiential understandings via interviews, observation, play, conversation, case studies, and participatory action research.

b) "Read[ing] widely and deeply" (p. 51) involves turning attention to detail in art and literature. This point of reference reflects that we sometimes learn more about human life through artistic rendition over scientific text. Within this, the researcher gains an interpretive understanding of lived experience through art, poetry, novels, and film. For example, while researching the personification of death, I revisited the famous novel *The Book Thief*, narrated by Death. Within the book, Death takes a moment to 'clear up' stereotypes of his appearance. I was struck by the 'humanity' of Death and his quest for recognition within this passage. It begs the reader to stop momentarily and reflect, reminding us that our death is uniquely our own (see Figure 4).

**Figure 4: The Book Thief** (Zusak, 2014, p.307)




One essential step in investigating phenomena is obtaining "experiential descriptions from others" (van Manen, 1984, p. 55). This can be done through individuals writing their

personal experiences as they lived them or speaking to them in conversation or interviews. While writing this thesis, I had conversations with neighbours, friends, and family about my research and why I believe it is important. Usually, the first reaction to the word death is strange, whereby my conversation partner is visibly uncomfortable but intrigued. In one conversation with my neighbour, he explained that his experience of death is a dark black box. To him, the experience of death is unknown and out of reach. Other methods to investigate have been to look through historical art to see how death has been perceived and represented throughout history. A book titled *Death: A Graveside Companion* shares a compilation of art presenting death throughout history as referenced in Chapter Two. Within the pages of this book, I was struck by how the relationship with death shifted depending on the historical events at the time. This shows the role that personification through art plays in describing how people have made meaning of death and death experiences. The personifications in the book give context to times throughout history where death was greeted differently. I also looked towards novels such as *Radical Acts of Love* by Janie Brown, which described her experiences with patients at the end-of-life. Each story ends with the passing of a palliative cancer patient, highlighting a different perspective, philosophy, and relationship with end-of-life. These conversations and representations in art and literature have informed my understanding of death by presenting it in different forms and providing the opportunity for me to orient to and reflect on the phenomenon. These experiences also inspired my use of arts-based methods with recreation therapists in this research to further inform my understanding of experiences of death as we live it.

### *Reflecting on Essential Themes*

Unlike other types of research, phenomenology distinguishes between what is experienced and the essence(s) of the experience. Reflecting on essential themes aims to ask,

"What is it that makes this lived experience what it is?" (p. 41). The goal is to bring the taken-for-granted and obscure into light and reflect on what it means to experience a particular phenomenon. It is about getting to the core of a particular experience. In some research, this step may be achieved through multiple interviews with participants, where the first interview is aimed at identifying essential themes connected to the phenomenon, while the follow-up interview(s) explores the essential themes more deeply. Here, the researcher and the participant work closely to go through data together and understand the foundations of what it is to experience the phenomenon. In the case of this research, reflecting on essential themes started with expanded personification through the use of the arts to explore an experience often ignored or silenced in the context of recreation therapy/therapeutic recreation. To do this, I created an art guide to assist participants in reflecting on the images, feelings, and experiences they associate with death by asking questions such as: "When you think of death, what images come to mind?" "What does death look like?" "What colours are associated with death/what are the colours of death?" and what surrounds death?" During the research conversations, I then supported participants in revisiting these images to build a robust group dialogue about the experience of death. Within the research conversation, participants were asked to draw on their personifications to explain the experience of death from their perspectives. The questions addressing their personifications included, for example: 1) What does your personification of death tell us about your meanings and/or experiences of death? 2) Tell me about the elements of your personifications, if any, that represent your experiences of death in recreation therapy. 3) Tell me about the experience of making your personification. Building on these personifications provided an opportunity to reflect on what makes the experience of death what it is for each person and the commonalities and differences between those descriptions of experiences.

### *Describing Through the Art of Writing and Rewriting*

van Manen (1990) stated that phenomenology is the application of *logos* to phenomena. Believing that separating language and thought is complex, van Manen relies on the word 'logos.' Gadamer (1960/1976) highlighted that rationality, language, speech, and thought are all contemporary definitions derived from the Greek word *logos*. It is through the process of writing and re-writing that allow "what is being talked about to be seen" (p. 41). Within this process, the researcher needs to attend to the spoken language through attention to detail. As the researcher, I needed to tap into the subtle changes in tones and body language of participants to orient to what things mean in that particular space. This stage of the process relates closely to the writing process, including: 1) attending to how language is spoken, 2) providing examples, 3) writing, and 4) rewriting, starting from the original orientation to the phenomenon (van Manen, 1984).

Attending to language involves listening to outside spoken language, attuning to the minor undertones, body language, and emphasis. In this process, van Manen (1990) highlighted, "An authentic speaker must be a true listener, able to attune to the deep tonalities of language that normally fall out of our accustomed range of hearing" (p. 64). This step was reflected in my research through the active interview process in the data collection. In this step, participants reflected their thoughts in spoken language and through metaphor, colour, images, and examples expressed in their expanded personifications. Having each session recorded and transcribed verbatim, along with my observations of each session and detailed field notes from the sessions, allowed me to revisit the subtleties in the participant's mannerisms, tones, and descriptions.

Examples relate to the "quality of phenomenological knowledge" (p. 64). Examples help to uncover the phenomena, drawing attention to the description of the essence(s). Within this second step of writing, it is in the varying of examples that the phenomenological themes are

revealed. For my research, the description and examples given to the experience of death through images, metaphor, understandings, and experiences are phenomenologically powerful. Understanding this, van Manen (1984) claimed that experience gives transparency and provides meaningful opportunities to see the essence(s), structures, and significance of lived experiences.

Writing relates to building the essence(s) of the phenomena. Within this step, van Manen (1984) offered a way to organize writing to highlight the essential essence(s) of the experience: 1) Thematically, 2) Analytically, 3) Explicatively, 4) Existentially, and 5) Exegetically. My research most aligns with organizing using the fourth method, 'Existentially.' This supported my approach to exploring death through existing themes of temporality, spatiality, corporeality, and relationality, as described in Chapter Two. Writing with existential themes means centering the experiences of recreation therapists and how they experience death differently in time, space and place, through their lived body, and through their relationality or relationships with others. In the next sections of this chapter, I describe in more specific detail how I achieved each of these phases of my phenomenological investigation of death for recreation therapists.

## Methods

### Sampling, Recruitment, and Research Participants

Within phenomenological research, it is important to select participants with lived experiences of the phenomenon, those willing to speak about their experiences, and participants diverse in their experiences and backgrounds to capture a more comprehensive understanding of experiences (Wojnar & Swanson, 2007). I utilized purposeful or purposive sampling to do this. The use of purposeful sampling as outlined by Patton (2002) selects participants who "offer useful manifestations of the phenomenon of interest" (p. 40). This method ensured I collected educated insights into the phenomenon, rather than generalized data from a large sample

population, to gain a deeper understanding (Patton, 2002). To recruit participants who were information-rich, I used snowball or chain sampling within the recruitment process. This entailed using my pre-existing networks through employment, student placements, and volunteering to identify information-rich members.

While working in recreation therapy, I worked with four different centres within Toronto to complete my student internship and cooperative learning and engage in full-time work. My advisor also had contacts with recreation therapists working in the hospital, mental health, long-term care, and community organizations across the country. These networks were drawn on in my recruitment process. In addition, participants were made aware of the study by utilizing the communication channels of Therapeutic Recreation Ontario (TRO) and through the use of recruitment posters shared through recreation therapy/therapeutic recreation programs and departments. For example, a colleague shared recruitment materials at the University of Dalhousie and another colleague shared materials at hospitals in the Ottawa region. I used these networks as a means of recruitment by sharing my email script (see Appendix B) and/or recruitment flyer (see Appendix C) with contacts within these settings.

Recreation therapists interested in participating in the project and/or wanting more information emailed me directly. Once potential participants contacted me, I shared my Letter of Information (see Appendix D) and Consent Form (see Appendix E) with them and arranged a meeting to address any questions or requests for additional information.

I recruited nine recreation therapists to participate in this study. In order to be included in the study, participants had to be over 18 years of age; be currently working in recreation therapy/therapeutic recreation as a recreation therapist, recreationist, activity aide, or other recreation role; have obtained a degree or diploma in recreation therapy/therapeutic recreation;

be currently working in a Canadian clinical or community healthcare setting (e.g., long-term care home, hospital, rehabilitation facility, hospice, retirement home, community home support program, etc.); and be open to speaking about death and dying. Seven of the participants identified themselves as cisgendered woman and two participants as cisgender men. This ratio is consistent with the gender proportions commonly found in the therapeutic recreation field (Therapeutic Recreation Specialist Demographics and Statistics, 2025). The age of participants ranged from 24-40 years old. Most participants were white, and the study included participants who identified as Greek (1), Finnish (2), Mennonite (1), non-specified (4), and Chinese Canadian (1). Most participants specified that they were not religious but spiritual. Two participants shared that they grew up within the Jehovah's Witness community but had since left.

Most of the participants had been working in recreation therapy for less than 10 years, with one participant having 18 years of experience working in recreation therapy/therapeutic recreation. The participants came from across Canada, with a total of five participants from Ontario, one from Alberta, two from Newfoundland, and one from Nova Scotia. I intentionally recruited recreation therapy staff working as front-line staff in diverse settings and with different populations. Four of the participants worked in a LTC setting at the time of the research, two were working in rehabilitation/reactivation, two were working in children's oncology, and one participant was working in a hospice setting. Having diverse perspectives helped illustrate the range of settings where recreation therapists are present and the different experiences of death in these settings.

**Getting to Know Participants and Building Rapport**

Once participants signed the consent form, I met with each of them independently over telephone to get to know each participant and collect information important to them to describe

themselves and their identity. Given the topic of this study, this was an essential process for building rapport and creating a safe(r) space for talking about experiences of death. During this meeting, participants were asked to describe themselves (detailed descriptions of each participant are provided in Appendix A). The use of this method to collect information about participants is aligned with the phenomenological structure of the study. It supports participants in describing aspects of their identity that are important to them and how they navigate the world. More specifically, participants were asked (see also Appendix I):

- Tell me about yourself. How would you describe yourself to someone else?
- What are aspects of your identity important to you (i.e., culture, race, ethnicity, leisure interests, geographical location, birthplace, religion, etc.)?
- Can you describe your experiences as a recreation therapist?
    - How long have you been a recreation therapist?
    - Where have you worked as a recreation therapist, and where do you currently work?
    - What does it mean to you to be a recreation therapist?

During this initial meeting with participants, I also asked participants how they would like to be identified in the research by having them choose their pseudonyms. At the end of this meeting, I described the subsequent phases of the project and answered any questions the participants had.

After the initial meeting, I sent instructions to complete Step One of the project and worked to arrange the small group research conversations at dates and times convenient for the participants. Finding dates that worked for all participants was challenging. It was difficult to balance their commitments at work, their varying time zones, and the length of time needed for the conversation. Using the digital platform Zoom was a helpful tool to facilitate the research

conversations as it allowed me to include practitioners across the country and accommodate their busy schedules. In the next section, I describe the data collection methods in detail.

**Data Collection**

Given the taboo nature of death in our society and the challenges associated with talking about death, I was interested in finding alternative ways to create safe/r spaces to explore understandings and experiences of death. As mentioned in Chapter Two, I was intrigued by the potential of personification but also saw limitations that came with just a focus on personification and attaching human qualities to representations of death. Expanding on the notion of personification, I became drawn to the possibilities of arts-based methods to illuminate experiences and understandings of death among recreation therapists. Personification can restrict the understanding of death to a human-centered perspective. I wanted to avoid this limitation and allow participants to engage with death as a multifaceted experience, recognizing that not everything needs to be human to be understood. This aligns with phenomenology, which seeks to capture the essence of lived experience in its fullness.

Arts-based research provides a creative, accessible, embodied, and unique lens for exploring lived experiences and meanings (McNiff, 1998). Such approaches support extending knowledge beyond the constraints of traditional language-based communication to unlock experiences that would otherwise be inexpressible (Barone & Eisner, 2011). That is, the arts offer communication that is accessible without the necessity of spoken word which opens communication of complex emotions and experiences without the confines of language. Arts-based research is where the arts and science intersect. Arts-based research methods open up qualitative research spaces, providing a specialized way to understand and represent what we experience in the world (Eisner, 1993; Leavy, 2020). Creative approaches also provide an entry

into new knowledge as both the participant and the researcher engage in a "process of de-familiarization" (Fleetwood-Smith, 2021, p.272). To me, the process of de-familiarization is related to how we identify and draw from reality and fiction to shape our understandings of the world (Fleetwood-Smith, 2021). Arts-based practices can utilize any art form, including but not limited to literary forms, visual art, multimedia forms, and multimethod forms (Leavy, 2020).

The arts have become an increasingly popular research tool since the 1980s (Eisner, 1981), used in a number of disciplines and fields, including healthcare. Creative approaches are increasingly being used to explore and share the experiences of health and illness, illuminating emotional insights that would not be possible without the arts. For example, Dupuis et al. (2016) used art-based methods to explore and resist experiences of stigma for people living with dementia. Velasco et al. (2014) used photography to illuminate the voices of children living on the street in Bolivia. Khanolainen et al. (2021) used graphic vignettes to explore student and teachers' perceptions of bullying in school. It is important to note that creative/arts-based research methods allow for 'slow science', built from reflection and the "aim of better understanding the subjective worlds" (Mannay, 2015, p. 104). Producing visual art does not come with an instant reward, it invites participants to linger with and tune into their perception. Creating art challenged me to connect deeply with the concept I was attempting to understand. In these moments, art created opportunities for reflection, offering us new understandings and perceptions.

**Expanding Personification through Visual Arts**

Visual arts, including drawing, painting, collaging, and photography have been used as creative data collection strategies to gain insight into the participant's world without using language (Broadbent, 2004). Artistic modalities allow participants to identify and draw on

feelings that may otherwise be untapped; this technique is typically non-directive, does not require concrete answers, and is primarily driven by the lens of the participant (Fraser & Sayah, 2011).

Artists are able to emote through their art, opening a world for the interpreter to infer. In my experience, arriving at an Art Gallery excites me, as the walls are filled with stories and experiences waiting to be interpreted. As I moved through my ideas for this research project, painting and collaging were some of the first methods that came to mind to express the complex experiences of death. The possibilities of using painting and collaging came from my work as a recreation therapist working with patients in a long-term ventilated (LTV) care unit. Within this space, I worked with patients with complex diagnoses from Muscular Dystrophy, Quadriplegia, Spina Bifida, and Amyotrophic Lateral Sclerosis (ALS). What I learned about artmaking with people with disabilities was that important stories, experiences, and meanings can be conveyed through colours, shapes, and images. From these interactions, I was inspired to create a project that was not only accessible to scholars but also to practitioners to connect with research and their experiences on different levels.

An additional factor that inspired the use of visual arts in this project was the potential of the arts to challenge discursive spaces which portray death as a cultural taboo and thus discussions of death to be avoided at all costs. The visual arts can effectively put death on display rather than 'hiding' it from our gaze, as a means to minimize its threat (Freud, 1917). I believe that, in silencing death, we are not tapping into our potential for authenticity within ourselves and our relationships with others; in highlighting death and making it visible, we can understand that death brings us closer to life. I wanted to use the arts to create a safe space to open up conversations about death and experiences of death for a group of people who have

often not had the opportunity to discuss these experiences. By incorporating arts-based methods, I provided a platform for participants to explore and express the diverse in multiple ways, including the human and non-human dimensions of death. This opened up space for a more expansive and nuanced understanding of death beyond human personification. For these reasons, I noted to participants that they were not expected to draw a human figure but qualities such as emotion, colour, seasons and images they associated with death and experiences of it. The results of expanding personification beyond human led to images of nature, symbols, memories and feelings that connected each participant to death; these will be explored in Chapter Six.

## Specific Procedures Used for Data Collection

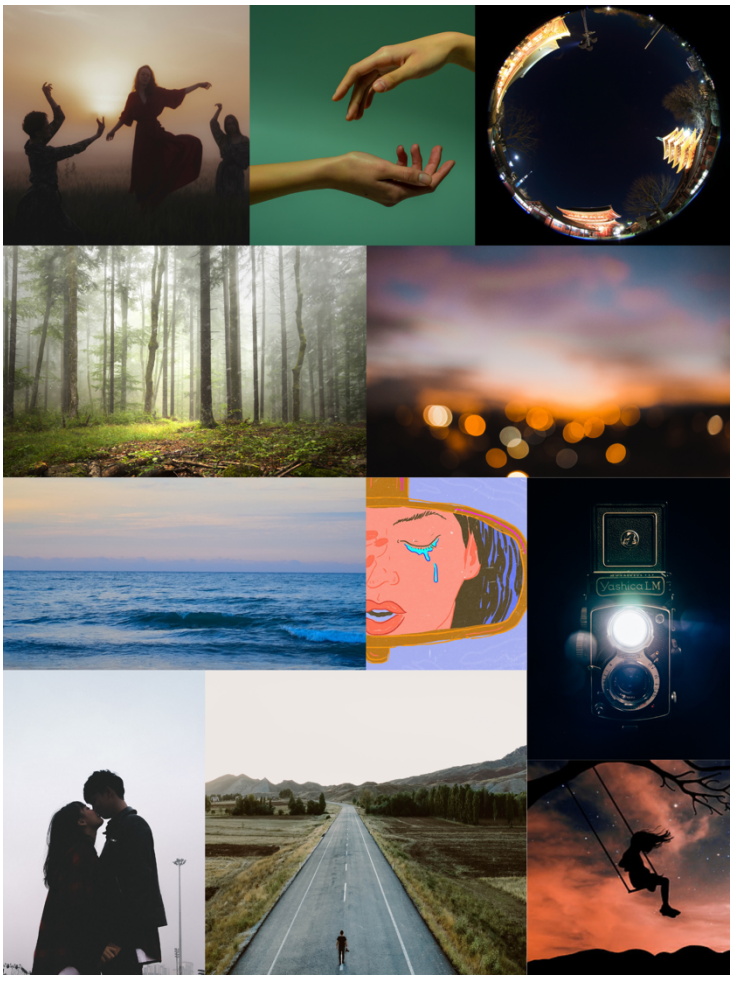
This study required a two-step data collection process. Step One included an arts-based activity that participants facilitated with the assistance of the art guide (see Appendix G). Step Two involved four small-group research conversations to accommodate the nine participants. I had two to three participants in each research conversation, providing an opportunity for intimate, open discussions about experiences and creating a robust dialogue.

### *Step One: Artistic Expanded Personifications of Death*

In Step One, participants were given an art guide for the arts-based component. The art guide provided a brief introduction to personification as a means of exploring meanings and experiences associated with death. It also emphasized that death does not need to be represented as a human figure in their personifications, urging participants to use any images or metaphors that represent personal experiences and meanings of death. My understanding of personification is that it does not have to be limited to images of a person but can contain human elements such as emotion, action, and behaviour related to the human experience (Melion & Ramakers, 2016).

As an example, one of my own personifications included two hands reaching for one another, barely touching, titled ‘Out of Reach,’ (see Figure 5). To me, this represented knowing I will never know death intimately until the time of my death; until then, I can only experience it through the periphery and in connection to my emotions after the death of another.

**Figure 5: Out of Reach by Erin Delaney**




The art guide invited participants to create a personification of death using the materials they felt most comfortable with. Methods could include drawing or painting, collaging using raw materials the participants had at their disposal, or online formats through Canva or Microsoft Word. The art guide also provided research prompts to reflect on as the participants created their personifications of death. The research prompts were informed by Kastenbaum and Ainsberg’s

(1972) study on personification and the Death Personification Exercise (DPE). This format was originally written for quantitative research analysis, including close-ended questioning focused on death as a person. I have adapted and added to these questions, which are open-ended and prompt personal images of experiences and meanings of death. Reflecting on these prompts, participants were asked to represent their interpretations visually. To incorporate the lifeworld existentials described in Chapter Two, I organized the art guide into four prompt sections. The prompts include:

***Temporality***

- What does death/the experience of death look like? What images come to mind? What does death look like?
- What is the proximity of death?
- What is the connection between death and time?
- What time do you associate with death?
- What season is associated with death?
- What age is death?

***Spatiality***

- What is the location of death?
- Where does death take place?
- What spaces/places do you associate with death?
- What surrounds death? What setting, background or scenery is associated with death?

***Corporeality***

- How do you feel death in the body?
- How is death experienced in the body?
- What parts of the body do you associate with death?
- What actions or behaviours are associated with death?
- What emotions are associated with death?
- How does death feel?
- What is the reaction to death?

***Relationality***

- What relationships are associate with death?
- Who is present at death?

***Other***

- What colours are associated with death/what are the colours of death?
- What textures represent death?
- What (if any) leisure does death participate in, or do you associate with death?

For Step One, I chose to use a self-directed method to allow participants the time and space to think through the research prompts without rigid time constraints or influence from others. This method supported participants to work with art modalities that suited their needs, preferences, and comfort levels. Understanding that I was interacting with time-crunched healthcare professionals, a self-directed approach supported participants in working independently when they were able, without having to take time away from work or meet within a specific time and location.

Participants had three weeks to complete their expanded personifications. All participants were able to complete their pieces in this timeframe. When completed, participants were asked to send a photocopy, photo, or physical copy of their art to me before the date of their small-group research conversation. The personifications were one of the data forms collected for the analysis and used for further exploration in Step Two.

### *Step Two: Exploring Experiences and Meanings of Death in Small-Group Research Conversations*

Step Two of my data collection process included small group research conversations with the participants. Some arts-based and liberatory researchers replace the language of interview/focus group with ‘research conversation’ in order to emphasize the relational, dialogical nature of these interactions (Harvey, 2015; Watson & Shulman, 2008). The research conversations shared and explored the artistic personifications of death outlined in Step One and

delved deeply into the experience of death for the recreation therapists in the context of recreation therapy/therapeutic recreation and healthcare. Each small group research conversation included two to three participants; I facilitated four conversations in total.

The research conversations were conducted virtually to make it easier for healthcare workers to participate. This allowed practitioners to participate from home or at work and minimize the pressure and resources needed to travel. Virtual research conversations provided benefits to both the participants and me. The virtual aspect allowed me to expand my geographical parameters and provide a more extensive variety in the research sample (Keen, et al., 2022). The virtual aspect also allowed participants flexibility in the scheduling of the research conversations. The benefits also extended into aspects surrounding data analysis, whereby the virtual platform offered increased transcript credibility/trustworthiness (Keen et al., 2022). Keen and Colleagues (2022) highlighted that the use of virtual platforms increases recording clarity because audio-files come directly from the video-call platform, compared to in-person interviews with traditional audio recorders.

I used research conversations to provide opportunities for the participants to be more active in the interviewing process. Within the research conversation format, I encouraged participants to talk with each other and to share similar and differing points of view. Throughout this process, I aimed to co-create the meaning of the experience of death and how it is reflected in their expanded personifications. To make this possible, I was guided by an active interviewing approach. Active interviewing within research conversations allows the researcher to activate the conversation and become a co-producer of information. As Holstein and Gubrium (1995) described, “the active interviewer does far more than dispassionate questioning; (they) activate narrative production” (p.39). They also emphasized:

> [B]oth parties in the interview are necessarily and unavoidably "active". Each is involved in meaning-making work. Meaning is not merely elicited by apt questioning nor transported through respondent replies; it is actively and communicatively assembled in the interview encounter. Respondents are not so much repositories of knowledge - treasures of information awaiting excavation - as they are constructors of knowledge in collaboration with interviewers (p. 4).

This approach allowed me, as the facilitator of the research conversations, to set parameters for the conversations while not restricting natural responses and storytelling.

Holstein and Gubrium (1995) outlined the ways in which the active interview process differs from a more structured interview, understanding that "*how* the meaning-making process unfolds in the interview is critical as apprehending *what* is substantively asked and conveyed" (p.68). I understood this statement as to mean there should be an equal emphasis on the interaction between researcher and participants to co-create knowledge throughout the interview. Active interviews provide opportunities for co-creation whereby the researcher is equally part of the interview through shared meaning-making. The second aspect is related to *what* or the issue which is explored collaboratively in the interview. With these two elements in tandem, the active interview process is enacted. Like interpretive dance, the researcher and participants work together to tell a story meaningful to them and create meaning. Holstein and Gubrium (2003) reflected on Garfinkle's earlier work in interpretive practices suggesting that meaning is not formulated as new. However, it is through ongoing conditions of time, space, and relations to others and the lived body that we orient to topics.

In order for me to delve more deeply into death and death experiences for recreation therapists, I created a research conversation guide (see Appendix F). Within phenomenological

interviewing, there are multiple methods used to investigate phenomenon. One method I used was contextualization. In this research, contextualization started with the personified art. That is, we used the participants' art pieces to contextualize our discussion and as a starting off or reference point for exploring the objects and images that provide meaning to the experience of death (Bevan, 2014). More specifically, after brief introductions (approximately 5-10 minutes) at the beginning of each research conversation, we spent approximately 45 minutes for participants to share their expanded personifications of death. We then explored more deeply where these personifications are rooted and what they tell us about personal understandings and experiences of death. All of the prompts used are presented in Appendix F but here I provide some examples. First, I used the following prompts to explore the meanings and experiences of death as reflected in the expanded personifications:

- What does your personification of death tell us about your meanings or experiences of death?
- What are the similarities and differences you are noticing in the personifications of death?
- What do you think has shaped or influenced your understandings or experiences of death as reflected in your personifications?

Contextualizing questions also allow participants to describe experiences through the storytelling of the events, spaces, actions, and activities surrounding the phenomena (Baven, 2014). After our exploration and discussion of the expanded personifications, we spent time exploring experiences of death more directly. Examples of contextualizing questions I used to do this included:

- Can you describe to me a time you experienced death in your roles as recreation therapists? What was that like?
- How has your understanding of death changed, if at all, since working as a recreation therapist?
- Tell me about what your role looks like at a patient/client's end-of-life? What does your role look like following a patient/client's death?
- How do you navigate the loss of a patient/client?
- In your jobs as recreation therapists/therapeutic recreationists, when have you felt supported in your experiences of death? How were you supported? In what ways did this change your experience of death?
- How could you be better supported in your work?
- How might death education have supported you when experiencing death? If death education were offered, what topics would be important to explore?

This discussion provided contextual factors that highlighted the elements of the death experience specific to recreation therapists.

The last 10 minutes of each research conversation focused on a debrief. Reflecting on the vulnerability involved in sharing about death, it was important to me that there was time allocated for a proper debrief whereby resources could be where shared surrounding grief and bereavement. When hosting death cafés at the hospital where I worked, my partner, the spiritual care provider, and I always offered an intentional debrief. This allowed the people involved to share closing remarks and moments for reflection. In my debrief at the end of the research conversation, I initially planned on asking the group how they felt and how we could mindfully close the session. Some examples I had planned on using included a song or meditation exercise

to centre the participants and allow respite from a vulnerable topic (see Appendix H for the Closing Remarks process). The debriefs did not work out as intended. Instead, I took a moment after the conversation recording to ask summarizing questions about how the participants felt. I wanted to ensure that we were leaving the conversation on a positive note. I asked if they had more, they wanted to share and encouraged them to reach out to me if they needed to talk more about their emotions or obtain other resources from me. Part of the decision to reduce the debrief was to offer more space and time for the participants to share their experiences, and because of the amount of time we used to have our conversations, I wanted to be respectful of their leisure time.

I initially anticipated that each group research conversation would last approximately 90 to 100 minutes. However, participants were eager to share their experiences, and most conversations extended to around 105 to 120 minutes. The length of each conversation did not include the planned debrief, which added an additional 10-20 minutes to the research conversations. The length and depth of the conversations underscored the participants' deep need to connect with others who could truly understand their experiences with death. Many participants left the research conversation thanking me for the time to share their experiences. In future research, it is essential to note the time commitment ahead of time and potentially break the conversation into two separate hour-long conversations for the personifications and then the experiences.

I used reflective notes written during and after each session to note the body language, facial expressions, tone, and mood of the research conversation. Brief jotted notes were taken throughout the research conversation to avoid interrupting the flow of the research conversation. More detailed notes were written as soon as possible after each of the research conversations.

During the transcription phase, I revisited the recordings to take note of any nuance I may have missed during the research conversations and added these to my notes. After each research conversation, I manually wrote the transcriptions and returned to each recording to check for accuracy between the recording and the written transcript. I chose manual transcription instead of transcription software to familiarize myself with the data and ensure accuracy.

**Data Analysis**

There are many ways of completing interpretive phenomenological research analysis. One approach proposed by Smith et al. (1999) is an Idiographic Case-Study approach. This approach is most applicable to a small research sample which corresponds to my smaller sample of nine. The Idiographic Case-Study approach is a six-step approach, which includes: 1) looking for themes, 2) looking for connections, 3) creating a table of themes, 4) continuing analysis on other cases, 5) creating a master list of themes for the group, and 6) writing up. I drew on this approach, combined with analysis methods by van Manen (1997a) to analyze and interpret both the expanded personifications of death created by the participants and the transcripts of the research conversations.

***Looking for Themes: Identifying, Listing, and Naming Expressions of the Phenomenon as Presented by Each Participant***

The first step of this approach asks the researcher to read the transcripts a number of times by utilizing the margins to note interesting or significant phrases or nuances. This step requires the researcher to become as "intimate as possible" (Smith et al., 1999, p.220) with the data. To do this, I started by manually writing the transcripts of the first audio file to familiarize myself with the experiences of each participant involved in that research conversation. Since my study co-created meanings with participants in a group conversation, it wasn't easy to separate

the experiences of each participant. I went through each transcription at separate times to ensure that the themes emerging from the transcript were noted separately.

I used a physically printed version of the manual transcription to highlight and note insights that were emerging in the margins. Notes in the margins highlighted keywords that captured qualities in the text. For example, in Research Conversation One with Parker, Morgan, and Eleni, notes in the margins included words such as “conflicted”, “contrast”, “holistic views of death,” and “desiring acknowledgement for death”. At this analysis point, all data was treated as potential; nothing was omitted, and nothing was selected for special attention.

In this phase, I asked the following questions of the data: What is being described here? What does this statement tell me about the meanings and experiences of death for recreation therapists? What words or images are used to describe death? What does the experience of death feel like? It was essential in this stage to get as intimate with each transcript as possible.

### *Looking for Connections: Identifying and Naming Meaning Units that Reflect the Phenomenon for Each Person*

Still focusing on the first transcript, this step includes the creation of a separate document to list the emerging themes and search for potential connections between participants. To do this, I looked for connections between the passages of participants in the conversation. This step includes identifying and naming meaning units that reflect the phenomenon being explored. Typically, this is for each person being researched, but co-construction made it so that each transcript acted as a collection of meanings. In contrast, the personifications were used as individual reflections of meaning units.

During this step, the personifications and descriptions of their artwork from research conversations were used to identify meaning units and interpretations of death experienced by

each individual. Each personification was analyzed with their descriptions to highlight the critical elements that participants chose to focus on and how that reflected their individual meanings of and experiences with death.

To represent essences that were emerging from the data, I asked: a) does this statement or reflection contain a moment of the experience that may be important to describe the essence(s) of death? If so, is it possible to name the moment without tampering with the participants description? How am I understanding this component of experiences of death? I continued to add to this document with each subsequent transcript. This step represented van Manen's (1984) concept of existential investigation. van Manen (1984) suggested that the best way to investigate a phenomenon is to obtain descriptions of others' experiences; within this, it is an ongoing evaluation of how each example shapes and shifts our understanding. By identifying the meaning units for each person within their expanded personifications, I was also able to visually connect to the experiences of death of the participants and begin to see similarities and differences in their descriptions.

### *Creating A Table of Themes: Providing Examples that Reflect Essential Expressions of the Meaning Units*

This step includes the act of creating a master list of the emerging themes coming out of the first two steps focused on the first transcript. I created a table where the columns were used to identify the research conversation number and participants involved, and the rows represented the emerging themes from the conversations. Care was taken in this step to ensure that the themes were represented using verbatim quotations from the transcription. In this step, I highlighted the line numbers of the quotation, the participant speaking and the verbatim quotation. In this step, subthemes came to light, giving the opportunity to explore and remove

any redundancies in the meaning units and create examples that reflected the essential expressions of the meaning units for the transcript.

Reviewing and comparing each prior phase can also help in reflecting and creating a table of initial themes that can then be used to explore the essential themes further with other participants and research conversations. I did this by asking these questions of the table of themes: Are there similar expressions that seem to reflect the same thing? Of all the expressions I have used to reflect this similar aspect of the experience, which one best reflects this aspect of the experience? What expressions of the experience am I left with? As I continued my analysis in the next step, in order to visualize the connections among the different research conversation groups, I created a table with columns reflecting the research groups and rows containing verbatim quotations which addressed essential themes emerging from the data. I added information and quotes from one transcription at a time. The table allowed me to view similar or differing experiences among participants within and across the research groups.

### *Continuing the Analysis with Other Cases*

In this step, Smith and colleagues (1999) offer two ways to move forward. One way is using the initial master list from the first interview to guide the analysis of the next transcript. The second method is to begin the process from the top moving through: 1) looking for Themes, 2) looking for Connections, and 3) A Table of Themes for each. I used the second option to become equally familiar with each transcript. This step essentially repeats the first three steps for each of the remaining research conversation transcripts, whereby I added each consecutive research conversation into the table of themes to build a master list that could all be read together at the end of the data analysis.

### *Compiling A Master List of Themes for the Entire Group: Identifying Common and Different Meaning Units Across All Participants*

The previous step included the addition of each research conversation into separate columns on a table of themes to create a master list. In this step, the master list emerged. It was important to decide on the themes that would be focused on in the analysis based on importance, nuance, and reductions made in the earlier steps. Factors included in this step included indicating the richness of meaning of units of particular passages that illuminated aspects of the experience of death to the participants.

To identify expressions of experiences that were similar to each other, I asked the data: How are descriptive expressions of the experiences of death related to one another? Are there expressions that seem to fit together as a more significant expression of the experience of death? What seems to go together? How might meaning units/expressions of the experience be brought together into more prominent themes that reflect the essence(s) of the experience/phenomenon of death? What name best reflects the theme cluster or essence?

In this phase, I began to identify clusters, where several discrete meaning units or sub-themes came together into a larger cluster or theme. To do so, I created a new table which organized meaning units across all of the data into themes and subthemes selected from the primary list to reflect similar or varying experiences. In this new table, I used line numbers to correlate to the original table to ensure I was maintaining the accuracy of the verbatim quotations. This is where I looked to see if there were expressions of experiences of death that were similar in some way and might be linked together as examples or instances of a broader theme. At this point, it was also important to bring together the expressions of the personifications and the second half of the research conversations

### *Verifying Essential Essences in the Data*

To ensure that I had not missed anything and to verify my interpretations of all the data collected, I returned to my original data, exploring the expanded personifications again and re-reading all transcripts to ensure the theme clusters reflect the "whole" of the meanings and experiences of death shared by the recreation therapists, and to ensure that nothing potentially important had been overlooked. This was an important opportunity to ensure that I had documented exemplars for each of the meaning units and theme clusters reflecting the experiences of death. Important questions I explored at this phase of the analysis process were: Is this expression/meaning unit/theme/essence reflected in the descriptions? Which data sources contain this expression? Which ones do not? How is each expression/meaning unit/theme/essence reflected in the data? Do I have exemplar quotes from the data that reflect each expression/meaning unit/theme/essence? When are expressions/themes not reflected? Am I confident that the names I have chosen for the meaning units and theme clusters truly reflect the descriptions in the data and the overall essence of the experiences of death for recreation therapists?

At several stages in my analysis process, it was helpful for me to talk through my analysis and the emerging essence(s) with my advisor. This often involved sharing a table or master list created in one of these analysis phases with my advisor and then meeting to talk through what I had shared and how the essence(s) of death described by the recreation therapists were coming together. My advisor would ask important questions that helped me clarify similarities and differences I was seeing in the data and how I was referring to these meaning units and/or essences as they came together.

### *Writing Up the Essence of Experiences of Death for Recreation Therapists*

Within this step, the themes are translated into a "narrative account" (Smith, 1999, p.227), that provides a thick description (i.e., a composite summary) of the phenomenon or the nature of the experience using the theme clusters and quotes from the data to provide a detailed description of how the phenomenon is experienced. Within this phase of the analysis process, it was essential to differentiate between the ideas of the participants and my interpretations. In the writing-up stage, I asked: How can I use the meaning units/theme clusters/essences to describe the phenomenon/experience of death? What does the data say about how my participants describe the experience of death? What are the core components/essences of the experience of death for recreation therapists? What are the key differences in the experiences? How do the experiences of death shared by recreation therapists compare or differ from my experiences?

Writing relates to building the essences(s) of the phenomena. Within this step, van Manen (1984) offered a way to organize writing that highlights experience. My research aligned with the 'Existential' orientation which explores death through existing themes of temporality, spatiality, corporeality, and relationality, as described in detail in Chapter Two. To do this in my data collection, I divided the art guide questions to reflect the essence(s) of death, as it relates to lived time, space, body, and relations. In my writing and in my analysis phases, I needed to consider how these existentials of the lifeworld came together to illuminate experiences of death, and the best way to reflect this in my writing.

Writing up the essence of experiences of death also involves providing my interpretation of the data. At this point, it was vital for me to ask: What do the expressions/theme clusters/essences as described by the participants tell us about the experiences of death for recreation therapists? How are the expressions/theme clusters/essences similar to findings from

other studies? What new understanding(s) can be gleaned from the findings? How does this understanding contribute to existing literature on the phenomenon? At this phase, therefore, it was vital for me to return to the literature I had drawn on as I wrote the proposal for this research and bring in new literature that might help explain the phenomenon of death as described by recreation therapists.

**Ethical Conduct**

Qualitative research faces unique ethical issues throughout the process. Some issues are easy to identify at the start of the project while others surface within the research (TCPS, 2018). In this section, I will explore what it means to be a relational researcher, how I went beyond "do no harm" in my research, how I employed reflexivity throughout each stage of research, and how I ensured informed consent.

**A Relational Researcher**

I took a relational approach to this research. A relational researcher to me means working from a relational ontology. What it means to me to work from a relational ontology is the emphasis on a co-constructed research experience, whereby my experience and the participants' experiences are equally attended to and reflected in the research. It also commands an intentional attending to relational processes used in the research, such as how power might be functioning in interactions with participants. Working from a relational approach also reflected the responsibility to represent research findings in a way that is accessible to both scholars and the public (Clandinin & Murphy, 2009). To me this meant making my research available to practitioners who typically do not have the same access to literature as scholars. I plan to publish my work in an open access journal as well as displaying the personifications in a public space to represent the co-construction of our experiences of death as recreation therapists.

Finlay (2009) described the relational approach to phenomenology as involving four dimensions: open presence, embodied intersubjectivity, dialogic co-creating, and entangled selves. Finlay's relational approach involves "acknowledging the power of dialogue to bring life to new realities" (p.1). Below I outline how each element played out in my research.

a) Open Presence is represented by the researcher's capacity to be physically present in research and emotionally. To be relational, I needed to be connected to my emotions and thoughts while holding space for participants, their experiences, and their thoughts and emotions. Within open presence, the researcher must let go of control and be prepared to cope with the unknown or ambiguity. It also involved being open to vulnerability and supporting the vulnerability of the recreation therapists who agreed to support this research.

b) Embodied Intersubjectivity is deeply connected to displaying an 'open presence,' reflecting the shared feelings and experiences between two parties. Embodied intersubjectivity challenges the researcher to recognize their co-constructors as individuals while remaining in relation to them. It meant intentionally attending to the ways participants might share aspects of their experiences in an embodied way. Again, it also meant being open to vulnerability and supporting that vulnerability. It also meant ensuring I reflected participants' experiences as an element of truth, without capitalizing it as the capital 'T' truth.

c) Dialogic Co-creating is the ability to remain reflexive as the researcher. To do this I needed to be open to "strive to explore, reflexively and mutually, understanding[s] that emerge[d] through an evolving relationship" (p. 8). This recognized that each co-constructor has the autonomy to choose which elements of their experiences to

disclose and be respectful of that. Dialogical co-creation also recognizes that the researcher and participants equally impact one another on unconscious and conscious levels; it was important for me to reflect on this regularly and document the ways this was playing out in my research process in my reflexivity notes (Finlay, 2009).

d) Entangled Selves is the concept of a person's "multiple selves" (p.10), highlighting the inherent social nature of the self whereby people's identities merge the physical to the social/relational world. The way I understand this is that our 'self' is a chameleon to our environment; the self is contextual, and we are continuously formed by our interactions.

As a relational phenomenologist, it was also important to understand the space between myself and the participants by opening up to the possibilities of unpredictability. Within a relational approach, this meant centering reflexivity and relationality by keeping communication lines open. Like active interviewing, I needed to be aware of the unspoken by acknowledging dynamics and tensions that arose (Finlay, 2009).

Attending to rigour in phenomenological research is an important aspect of being a relational scholar (De Witt & Ploeg, 2006), I will speak more about this near the end of this chapter. Attending to rigour is also connected to considerations of ethics. In this research, it was important that I disclose the purposes of the research, the processes to be used, and provide enough time for participants to ask questions and discuss any concerns they might have (Berbary & Boles, 2014).

***Do No Harm***

Qualitative research aims to understand how people think, learn, interact, and act and ascribe meaning to those actions. This study explored a taboo topic in many cultures, which can

illicit complex emotions, including feelings of sadness, grief, and loss. It was important for me to make it clear what the focus of this research was and the potential risks in participating in the study upfront. This information was located in the risks and rewards section of the information letter. This document also highlighted my qualification as a death doula as one of the risk buffers. I provided each participant with phone numbers and resources to access in addition to my support during the research conversations should they be needed.

### *Reflexivity*

Creswell and Poth (2017) pose a series of questions that outline the importance of continuous revision as research progresses, such as: What is our role as insiders/outsiders to the participants? Where is the power? How do you recognize and address power? What issues may be fearful or triggering for participants to disclose? What do supportive and respectful relationships look like within the context of this research? Whose voices will be represented? Whose voices will not? Why? How will I write myself into the study? How will I reflect on my experience and interactions throughout the study? These questions helped me to recognize the power that we (the researchers) hold and the potential for harm if we enter research without reflexivity. I supported reflexivity of participants as well as for myself. Using arts-based methods provided a space for participants to individually reflect on their experiences of death and dying in the context of their work as recreation therapists. Bagnoli (2009) described how the use of visual methods provides opportunities to "gather a holistic picture of topics under investigation [which] take into account … [participants] different needs and expressive styles" (p. 549). By creating self-directed art pieces, participants were given the opportunity to explore and express their emotions and responses to the experience of death. Through the research conversations, participants were able to expand on how their personifications represented the ways they act and

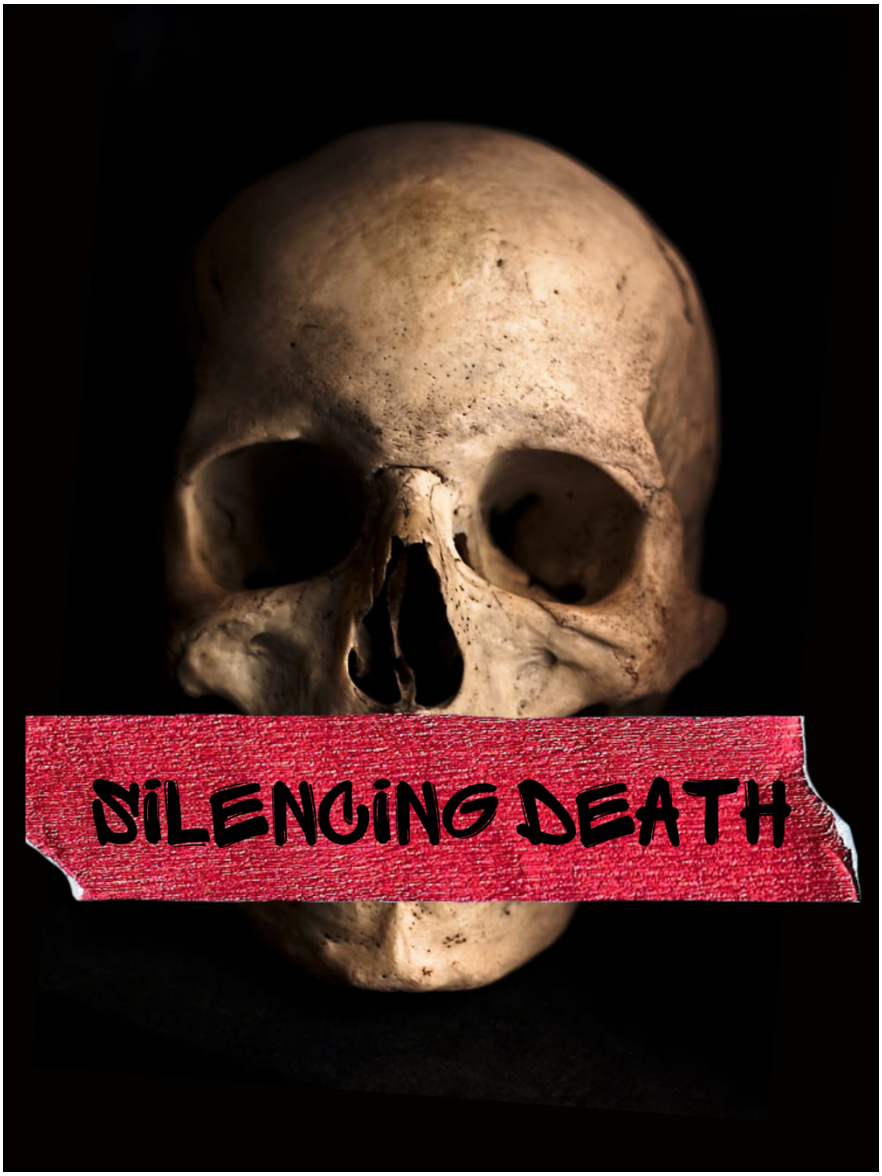
think in relation to the phenomenon. To address my reflexivity, I used reflexive art to express *my* emotions, learnings, and understandings surrounding the phenomenon, and to represent my thoughts. As I have worked through this process, I created four art pieces of how my ideas have shifted from the conceptualization of this project to this point in time. The first art piece reflected my initial ideas titled Blueprints (see Figure 6) reflecting how I would approach my thesis, and this contains theories, ideas, thinkers, books, experiences, and personifications that inspired me to get started.

**Figure 6: Blueprints – By Erin Delaney**



The second piece of art, Ripping the Tape (see Figure 7), reflected the silencing of death that I found to be so problematic. I wanted this piece to reflect the same shock I felt as I explored the literature and came upon a relatively barren landscape of work surrounding death education, especially addressing the needs of healthcare providers. This piece of art also reflected the shift in focus of my thesis to personification and how it could be used to express our experiences with death.

**Figure 7: Ripping the Tape - by Erin Delaney**



This is around the time I started to frame death as something I had a relationship with, making me think differently about the ways we could explore our experiences. Once I framed my study to center personification, I created a piece of art using paint to reflect my new 'image' of who death was to me. The key symbol is a skeleton, femininity and deep pockets stitched to death's coat, symbolized it as the keeper of my memories (Figure 8).

**Figure 8: A Pocket of Memories- By Erin Delaney**



My final artistic reflection, titled ‘Out of Reach’ (Figure 5, p. 62), related to my proximity to death. After all of the research going into this project, I still feel a sense of distance that cannot be reached, as I believe death is a peripheral experience. I used the creation of the art as a means to reflect on my understandings of death and how they were changing through my process and documented this in my reflexive journal, where I also regularly reflected on the questions in the first paragraph of this section on reflexivity and other questions that arose throughout the process.

Orienting to the emotional intensity of the topic, I needed also to attend to self-care practices. To ensure my safety and support, I planned regular meetings with my advisor to debrief and explore my own experiences, emotions and thoughts surrounding the topic. I also connect monthly with a therapist and continued to do this to take an active role in supporting myself throughout the process. It was vital to me to create a confidential space to explore my mental health while venturing into the ongoing study of death.

### *Informed Consent*

In researching a field in which I am employed, it was crucial for me to continuously reflect and negotiate how I am connected or build connections with individual participants to gain and maintain ongoing rapport (Berbary & Boles, 2014). Within this space of anonymity, there is some pushback for me in which identities, names, and contexts are important for understanding individual stories. I question if it is ethical to change aspects of someone's identity within research, as in changing their name or location, which could erase critical aspects of identity that are key to the informant’s story. To navigate this, I had individuals choose their pseudonyms and asked which aspects they would like to shield to maintain their anonymity.

It was also important that all participants be provided with enough detail about the project to make an informed decision about their participation. To obtain informed consent, participants were asked to read the letter of information (see Appendix D) and consent form (see Appendix E) containing the study's details. Participants were urged to contact me using my email if they had questions regarding the study details or consent form and were provided with the opportunity to ask any questions they had in our initial meeting. On the consent form, the participants were also asked to sign if they agreed that they have had the opportunity to ask questions related to the study, receive satisfactory answers, and obtain additional details if needed. They were reminded that the research conversations would be audio- and video-recorded for transcription, both in the Letter of Information and also at the beginning of the research conversations. They were made aware that anonymous quotations from the research conversations and their artistic expanded personifications may be included in the thesis, future publications, and presentations, understanding all identifying elements would be removed. The participants were also told that they could withdraw from the study at any time or request their data to be removed at any point prior to publication. Participants were asked to electronically sign or scan a physical copy to be returned to the researcher via email.

Before conducting research with the participants, this study was reviewed and received ethics clearance by the University of Waterloo Research Ethics Board.

**Summary of Methods**

To summarise, I used phenomenological methodology to guide my methods, including my approach to analysis. I also used personification theory to inform my use of arts-based methods. Relational and ethical principles guided all of my research and ensured I attended to relational and ethical processes throughout.

The following three chapters outline the findings from four group research conversations held with nine recreation therapists across Canada. As I wrote these chapters, I was intentional in ensuring that these chapters addressed all of the research questions guiding this study. Chapter Five walks through the recreation therapists' experiences and understandings of death, exploring the relational and emotional terrain professionals navigate in relation to death. Chapter Six explores the essence(s) of the expanded personifications of death created by the participants. Each art piece connects to the intimate experiences of professionals, sharing the duality of their perspectives between solace and finality. Chapter Seven explores how these experiences shared by recreation therapy professionals inform our understanding of the supports they need and how death education may benefit recreation therapists. This chapter highlights the hope and struggles for support in unsupportive environments. In each of the Chapters, I integrate the voices and experiences of the participants with the literature as a way to both interpret and contextualize the essences that emerged in this research.

## Chapter Five: Navigating the Emotional and Relational Terrain of Death in Healthcare

Being a recreation therapist involves navigating the emotional and relational terrain of death in the healthcare sector. This chapter explores how the recreation therapists described different experiences they have had with dying and death, including their high exposure to death and the challenges of navigating grief and role restrictions within different, often fragmented, healthcare settings. Despite these experiences, recreation therapists outlined the facilitation techniques and relational processes they utilized to ensure that beauty and life continued to be experienced by those who were dying and their family members.

### High Death Exposure Increases Risks to Burnout

High exposure to death within the role of the recreation therapist was highlighted repeatedly by the participants. The high exposure to death entangles the role of the recreation therapist with the experience of death. Eleni stated: *"I think a lot of my experience with death comes from work. I've had my own grief in personal life, but I definitely experienced a lot more death at work. So, I think that when I think about death it's very intertwined with what I do at work."* In fact, the high exposure to death was echoed by each participant, who shared that their work is where they interact and experience death the most. It is in this exposure and these experiences of death that their understandings start and grow from. Hernandez-Fernandez and Meneses-Falcon (2022) explored high exposure to death in their recent study, highlighting that overexposure does not lead to desensitization of death but creates a difficult scenario for coping with and grieving death when not addressed. Morgan reflected on this experience in their work at a children's hospice stating: *"... my exposure to death is with the kids that I work with that can be in a lot of different contexts. It can be kids that I've known for years, it can be someone that's just come in-house that day. It can range in different causes of death as well. That's been my*

*biggest exposure to death would be the work I do as a recreation therapist."* Participants working with older adult populations within long-term care and retirement care experience the same high death exposure. Felix described, "*I've worked for about two years, and it's just been with the older adult population so, … I, we've had a lot of death since I've started."* Eleni shared that a lot of her exposure to death has been negative working as a recreation therapist in hospital. Eleni stated "*I think because of the setting I work in, I often experience the more negative, I actually feel very comfortable speaking about death and … I find that the patients speak about how they feel content with their life and they're not seeking to die but they're just they are at that stage in their life, where they feel comfortable say "I'd be ok, if I passed away*"." Andy shared *"working with death and dying has made me feel a lot more comfortable and open about talking about dying and death. Whereas, growing up, if you would have asked me, where I would have ended up [working], this is the last place I would have gotten. Because as a society, we just don't talk about dying and death."*

It is essential to highlight the risks of high death exposure. For example, in Hoelter and Hoelter's (1981) study of 325 undergraduate students, there was a positive relationship between high death exposure and fear of the dying process and fear of premature death. High death exposure places healthcare workers at increased risk of burnout, especially during times of disaster, including the COVID-19 pandemic. This was true for the recreation therapists in this study. Burnout is experienced in a variety of settings, but R.G. described how grieving impacts the risks of burnout, particularly when grieving is not supported in the workplace. She stated, "*personal burnout, protecting yourself amongst the grief and still be expected to continue on with life, it's hard when you're 'a clinician' and, you have a close relationship and then the person's gone. It's hard that you can't grieve the same way the family can because that's not*

*appropriate*." As Wilson and Kirshbaum (2011) stated, high exposure to death has physical and emotional implications for healthcare providers which, make it hard to, as R.G stated, "*protect yourself amongst grief*." Blauner (1966) associated higher experiences of burnout with the medicalization of death that hides it from the general public to 'protect them' from exposure to a human corpse. This pushes the burden and responsibility of dealing with death solely onto health care professionals.

Gilewski's (2012) more recent study on *Encountering Grief in Patient Care* describes how high burnout levels were observed in 261 healthcare staff, including nurses, staff, and oncologists. One of the influential stressors of burnout was frequent exposure to death. The authors offered a strategy to discuss loss in a supportive environment by including interprofessional staff and medical staff in "death rounds" (p. e83), giving an option for ritual to counter the effects of high exposure to death at work (Gilewski, 2012). However, these opportunities are not always available to recreation therapists and depend on the settings in which recreation therapists work. For instance, in a hospice setting, facilities are created with opportunities for education and spaces for people to die comfortably. Death is not feared, and opportunities to talk about it are often provided. Andy shared details of the rooms provided in the 10-bed hospice where they work. Andy states "*we try to make it as homey as possible and as comfortable as possible. It's not like sterile at all. It's warm and inviting because we want to make this journey as comfortable as possible for the person who's dying, but also the family.*" In other spaces such as reactivation, rehabilitation, or long-term care, death is not often brought into the conversation and opportunities to talk about death with others in an intentional way are often not available, despite that fact that death is also present in these settings. Eleni shared her experience, stating, "*we are labeled as a reactivation care centre even though oftentimes people*

*actually aren't even coming to us to reactivate, it is really challenging to have those conversations with families, to ask them questions about death of their person*". If death is not discussed, it makes it challenging, if not impossible, to provide comfortable spaces to die.

Most of the recreation therapists in this study stated that working with the dying has helped them build comfort and confidence in speaking about death and dying. Andy, for example, reflected on their experience, "*working with dying and death, has made me feel a lot more comfortable."* This was not true for everyone, though. Without training on how to engage with death experiences, some participants did not know how to cope with the increased exposure. Jolene reflected on their experience: "*I was coping and surviving, disassociating rather than, connecting and being in the moment with the people. You just … providing [them] with the brochure as you sit with them. You try not to think about it when you leave work."* In my experience, I felt similarly to Jolene. It was challenging to stay in moments of death when supports were not offered to develop or recognize grief. My car became the space to grieve patients, a ritual I began earlier on without realizing it. My car offered me a space between work and home, which became the only seemingly appropriate place to be with work-specific death and grief.

Not acknowledging death and dying in healthcare settings not only impacts the staff working in those settings, but also affects the care provided. Eleni shared her experience working in Reactivation Care, where death and dying is not addressed: *"I work on the unit where death isn't like [at] the forefront of people's minds … We're not all well-trained within that setting. I think a lot of people are not getting the care they should be giving to somebody who's passing away or to those family members."* Within this statement, Eleni highlighted the issue of not addressing care decisions with the person being supported as well as the difficulty of death and

dying when the possibility has not been discussed with the person and their family. The presence of death in healthcare is inescapable; it is the reality of working with older, fragile, and physically vulnerable individuals. The manageable part lies with how we acknowledge, recognize, and appreciate the effects of death on staff, giving space and support for grieving individuals. This acknowledgement offers an opportunity to mitigate the risks of burnout in healthcare spaces.

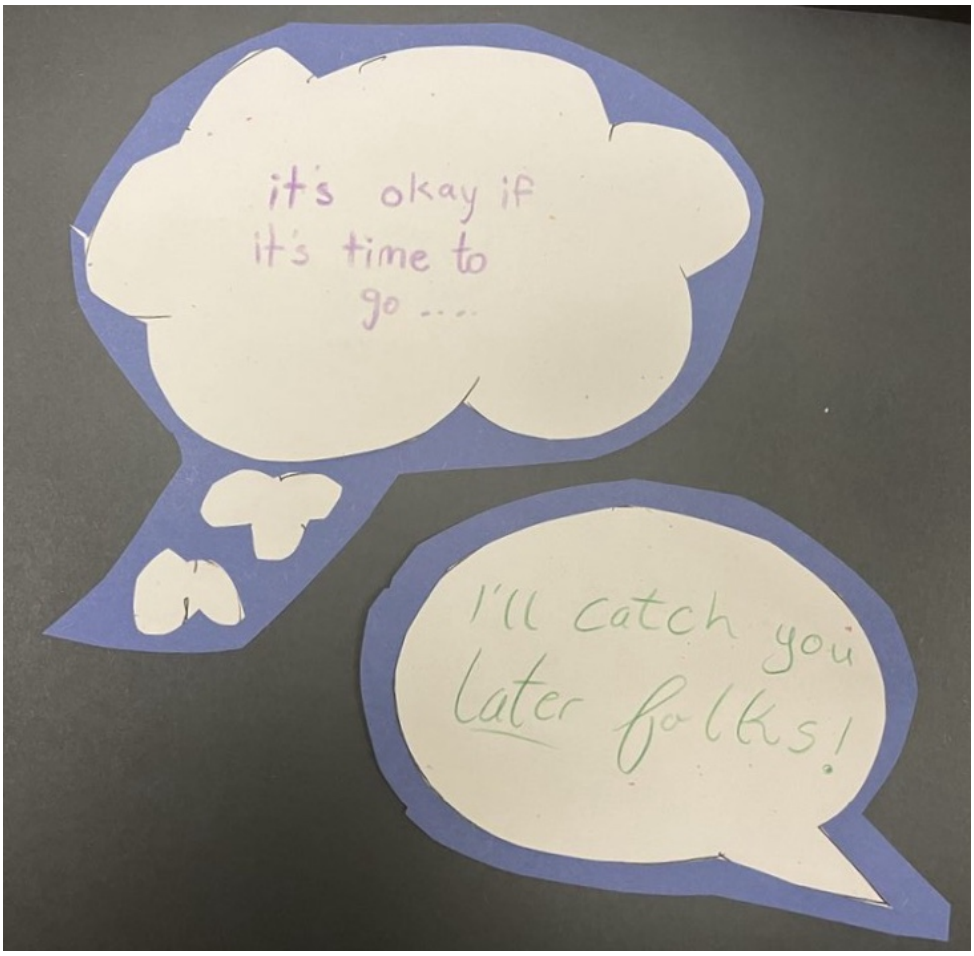
**Navigating Grief in Different Recreation Therapy Settings**

The conditions of the death created the experience of grief for the recreation therapists after the experience of death. These grief experiences can be different depending on where recreation therapists work. Two participants spoke about their experiences working in children's hospice and the impact of seeing young individuals die. They compared the experiences of watching a child die with watching an older adult die. Morgan, for example, stated: *"When it's a child, it never really feels ok. I think that's also a difference is the people I've lost in my life were older, and that doesn't make it any less sad or feel like any less of a loss, … whatsoever. But … it's been a difference I guess in my work and my personal [life]. I can definitely appreciate the difference in the loss of a child and a young person as opposed to someone that has lived a full life."*

The experiences of death and grief are not only impacted by the increased exposure and the age and condition of the person but the type of death (prolonged, sudden, traumatic). In describing experiences of death reflected in their expanded personification (see Figure 9), R.G. described two impactful memories of death and dying that have stayed with them. The first memory highlights the experience of being present with someone through prolonged death: *"I was sitting with a woman who was approaching her time of passing and just thinking, being like*

*it's OK, it's OK to go, she was in a lot of pain, she wasn't happy*." R.G. then shared a story of the shock experienced of watching a young person dying suddenly: *"This child that I had known for a while, he was doing a lot better, he was getting a lot more emotion, he was able to do a lot more by himself. And then I got a call a week later from the social worker saying that he had passed away."* The speech bubble in their personification, "*I'll catch you later, folks*," reflected the last words they spoke to the patient before their passing and the ways this recreation therapist was trying to make sense of this sudden, unexpected death.

**Figure 9: Situational**




No matter the circumstances of the deaths witnessed by recreation therapists, they all shared the grief they felt in these experiences. Their experiences are deeply rooted in their

relationships with the people they are supporting. Felix stated: *"It varies based on who passes away because even though you want to be a professional, make sure that you know all your patients equally well, [you] form stronger relationships with some just naturally."* These deep bonds with patients and the loss felt with death were represented multiple times in the data, from professionals reflecting on their first patient loss to the loss of a person they had worked with for a long time. Parker, who works in a long-term care setting, for example, shared: *"I had this one resident, he was our resident's council president. He really was … a big joy. We were a joy in each other's lives … and it was crazy because a week after I left, he passed away and we had both really created this strong bond. We had this quote in the home that was 'it's not what you say or do but how you made them feel' and [I] always remember how he made me feel."* The approach the recreation therapists take to their roles and care is vital to understanding their experiences of death. For this recreation therapist, who saw themselves as a relational carer, placing importance on creating and nurturing relationships with their patients/residents, the family, and staff was emphasized. I will describe this more later in this chapter. Developing relationships with all members of the care team meant creating strong bonds but also losing relationships frequently.

The experience of grief is not only impacted by the nature of the relationships and the human qualities of the dying, but the ways recreation therapists' work settings are set up to support them through their grief. Felix, for example, lamented the lack of time to truly be present with loss: *"I only ever look at the picture (of the deceased) … I don't even read it [the obituary] because it's such a busy job, [with] everything … you really don't have the time to sit with it and fully honour their memory like you could."* An organization's culture determines how much opportunity staff have to be present with death and grief. The culture also directly impacts how

staff grieve by either recognizing the impact and supporting that grief or turning a blind eye to their staff.

It surprised me in these research conversations that there was a lack of intense emotion surrounding the topic of support for the grieving process. Many had ideas on how they could be better supported but few showed anger, sadness, or frustration about their employer's lack of initiative and engagement with death and grief. It could be possible that the style of research conversation and the relationship to other participants prevented the recreation therapists from completely opening up. It could also be argued that many healthcare workers feel numb and silenced in their spaces to show or voice their emotions regarding the impact of loss. Staff members in a study conducted by Dupuis and colleagues (2024) spoke about the numbness that occurs in the healthcare sector when a job just becomes a job, and the focus is on completing tasks. Austen (2016) linked this numbness to the 100-year-old medical system created by Sir William Osler, who viewed detachment and neutralizing of emotion to the point of numbness as the appropriate approach to be taken by professional carers. In healthcare spaces driven by the medical model, there are many processes to follow, objectivity to maintain, and barriers set up to separate the patient from the person providing care (Austen, 2016). This is often explained as being important to protecting staff members and the people they support to buffer grief.

Recreation therapists within these cultures are often forced to fit into the medicalised culture. R.G. described this, stating: "*I find therapeutic recreation tries to fit into the biomedical model, which loses other aspects of well-being, because the biomedical model is so removed from spirituality it's hard to bring that [into practice] when it doesn't have value in the system that we're trying to fit.*" Jolene described the consequences of these sterilized spaces: "*[You] desensitize yourself to it, you get so used to it, it's just expected, disassociating rather than*

*connecting and being in the moment with the people."* However, culture change initiatives in healthcare have advocated for more relational approaches that emphasize the building of strong relationships between staff members and the people with whom they work (Dupuis et al., 2016). Culture change within institutions that supports intentionally and openly engaging with death and dying is essential to the physical and emotional health of professionals. For relational approaches to work well, staff need emotional supports to assist them with the grief experienced with loss.

**Navigating Perceived Role Restrictions within a Fragmented Healthcare System**

Recreation therapists providing end-of-life care may experience limitations in their roles. They work in settings where death is imminent but often lack the specialized training necessary to handle these delicate situations. This unpreparedness fosters hesitance, as they might not feel ready to tackle patients intricate emotional and spiritual requirements. Moreover, the fragmented structure of healthcare professions frequently results in a disconnect between recreation therapists and interdisciplinary teams, further hindering their ability to collaborate efficiently and contribute significantly to the comprehensive care of patients approaching the end-of-life. As an example, Eleni shared that she feels restricted in what she can offer in her role because the current environment of the hospital conflicts with how she sees her role. These conflicts are directly reflected in her expanded personification (see Figure 10). Eleni stated, "*The conflicted feelings and some of the images I chose are in direct contrast with each other like at the top corners there is music on one side (left) and noise and alarms on the other side (right) so, it's like um differences between how I feel things could be versus how they actually are."*

**Figure 10: Conflicted**



Eleni continued to share that these experiences and disconnection with patients were emphasized during the COVID-19 pandemic when Infection Prevention and Control (IPAC) restrictions were heightened to protect patients and their families. Some policies went as far as preventing visitation to limit risk, which directly impacted the dying experience for patients. Eleni emphasized, "*I see patients passing away and not being around their loved ones*." I shared this experience with many people throughout the pandemic, not being able to stand alongside my grandmother when she was dying from COVID during the pandemic. With strict restrictions protecting residents and family members from the virus, rituals, goodbyes and visitation came secondary to physical safety. These restrictions complicated the grieving process for my family.

Restriction is also experienced in the inclusion of recreation therapists on the larger interdisciplinary team. Parker explained her experience as a recreation therapist prior to

transitioning to a recreation managerial role, "*When I was Rec therapist, I didn't work alongside the interdisciplinary team*". Parker's experience was not isolated, as R.G. experienced and described similar moments of disconnection and isolation in different settings, especially those settings where siloing of professional roles and responsibilities was the dominant approach. R.G explained, "*I find pediatric memory making is a little different than other care environments; in the hospital, we are very siloed."* The siloing of professions is typically organization-specific; for example, the organization I work for in reactivation care does well to include recreation therapy in all interprofessional meetings and decisions. This, however, is not the typical experience for most practicing recreation therapists. Derrick (2018) highlighted the effects of healthcare workers working within silos, emphasizing that it is the patients' safety and efficiency of care that is ultimately affected. Teamwork and collaboration are vital aspects of interdisciplinary care to ensure safe, equitable, and timely patient care (Derrick, 2018). Interdisciplinary team members' communication is critical at end-of-life to ensure "good end-of-life care" (Curtis & Shannon, 2006, p. 2).

The feelings of isolation and restriction within roles are not limited to recreation therapists. Kalb and O'Connor-Von (2012) state, "One cannot heal in a silo; one cannot teach in a silo." (p. 44). Collaboration and the breakdown of siloed roles will only be possible when diverse healthcare professions are educated both about one another and alongside one another. (Kalb & O'Connor-Von, 2012). This effort goes hand-in-hand with offering a new model of care within our institutions, one which moves away from a bio-medical model of care to focusing on social models and including relational-centred care and relational caring lenses.

## Utilizing Relationality Capacities and Modalities to Ensure Beauty and Life are Present at the End-of-life

### *Building Relationships by Attending to Relational Processes*

Despite the overexposure to death and grief and the challenges recreation therapists experienced as part of their job, they continued to support the end-of-life process for patients and families in meaningful and relational ways. Though many participants did not define their approaches as relational, the modalities and facilitation skills highlighted in their descriptions suggest relational principles grounded their approaches. Some of the relational elements of their facilitation skills are exemplified through supporting moments of beauty and infusing life at end-of-life.

The recreation therapists in this study were striving and dedicated to living in relational ways. As Jonas-Simpson and colleagues (2021) stated, "relationships are not formed but lived" (p. 63). This quote emphasizes that relationships are not formed overnight; they are a process built on the shared commitment, time, vulnerability, and openness brought to the relationship by everyone involved. A relational lens extends past person-to-person connections; that is, we have relationships also with lived time, space, body, and other non-human relations (Jonas-Simpson et al.,2021). Additionally, we have relationships with our government, organizations, and their policies and practices. Each of these relationships are connected and often in flux.

Our experiences and understandings of death are shaped by the intersections of these relationships and deeply rooted in our peripheral experiences of death, including our personal and professional exposures. Each of these experiences are tied to the 'lifeworlds' of lived time, lived space, lived body, and lived relation to death, dead, or dying. Our recurring exposure to

death at a high rate without recognition and ritual is what is harmful to practicing recreation therapists more so than working with dying people and death.

The recreation therapists in this study described their roles at end-of-life as providing mentorship, building relationships, and providing a holistic approach to care. Recreation therapists support relational caring, especially in end-of-life situations, by fostering meaningful connections with patients and their families. By employing social models of care, they provide holistic support that emphasizes the relationships between individuals and their surroundings. This includes the person's interaction with time, space, body, lived experiences, and their connections to others, such as family, friends, pets, staff, and the environment. This approach goes beyond traditional person-centred care approaches, forming a supportive network that boosts well-being, particularly during end-of-life stages.

A common relational practice described by the recreation therapists was getting to know the patient and their family members. To provide relational care, recreation therapists used exchanges to get to know the person they are working with, including an understanding of what is important to them. Utilizing relational caring processes and modalities assisted them in countering the medical and clinical approaches that often dominate healthcare settings. Eleni described, in her role working in hospital settings, how she finds it vital to remember that patients are in an unfamiliar environment in the hospital, and how important it is to get to know the person in order to adequately support them in this new environment. Eleni shared, *"they [patients] kind of get thrusted into these places where they don't have their bed, they don't have the people around them, they don't have their creature comforts [e.g., material comforts that contribute to physical ease, such as foods they enjoy] and you know I think getting to know people more again in doing these assessments that we do is incredibly important, just advocate*

*to get to know the whole individual again."* Person-centered care can be limiting to fostering relational caring by "disregarding the interdependence of persons and their choices" and their connections and relationships with other things meaningful to them (Banerjee & Rewegan, 2016, pg. 401). This interconnectedness becomes especially important in end-of-life care when competing truths from varying perspectives (e.g., family, individual, and staff) complicate goals of care. We all have relationships with ourselves, the people we interact with daily (e.g., our family and friends), our things, our pets, our spaces—the list goes on. These relationships are important in shaping experiences and essential to consider as recreation therapists. The recreation therapists in this study emphasized getting to know the person, their family, their favourite activities, and what brings meaning to life. Layla described the importance of considering the whole person, stating, *"It's a good idea [to know the person] you think 'I'm a father, I have a daughter, I'm a farmer, loved my dog' whatever it may be, it requires a little bit extra care or thoughtfulness from you if their ringing their bell a lot, you remember 'this is who they were, this is what they were like' reflecting on that [personhood] you can add bits [to their care]."* The sentiment of knowing and accepting the person recreation therapists work with was emphasized through all research conversations.

Working from a relational caring approach also includes thinking about the individual as part of a family unit and supporting the individual's family. However, it can sometimes be challenging to balance differing values, perspectives, and ideas. Eleni described the difficulty for family members accepting an elderly family member's prognosis. Eleni shared, "*We've had a lot of families that they're like 98 years old, and they're still in like very, very deep denial of the inevitable of what is to come, and sometimes you think that this has occurred to somebody, but even when working with older adults a lot of people they haven't come to terms with it [death]*

*yet."* Marquis (2002) highlighted that relational care develops a safe(r) and trusting environment to develop social relationships with care workers. This environment is more conducive to open and meaningful conversation regarding goals of care. Family desires are intensified as the patient's condition changes. As an example, Felix reflected on the demands from family for their family member to continue participating when the patient no longer desired to engage. Felix stated, *"The biggest thing I hear from the children of older adults is that they lost all interest in doing anything, even when I try to involve them in meaningful activities that the children always say they wished mom, or dad would engage in more activities."* Open conversations with the family are important for ensuring the family understands what is going on and that the wishes of patients are respected. Goals of care conversations need to be communicated with all members of the care team to ensure continuity and holistic care that meets the needs of the individual receiving care. One way my organization provides this is through family meetings and interdisciplinary team rounds (discussions).

The relationships created by recreation therapists expand beyond the living; these relationships transcend the patient's death. Morgan shared her intimate experience of comforting a mother after the death of their child to cancer. Morgan stated, *"This little girl that I was very close with she died, and I wasn't around in the morning at that her time of death, but I came into work after, and I came into the room, and I saw her in the big king size bed … I just crawled into bed with her, and I was holding her hand, and her mom is standing beside the bed just talking to me. Her mom just needed to shoot the shit, like she needed to laugh; we were having conversations, and then she looked at me and said: 'Is it like weird if I get into bed with her?'"* Morgan demonstrated relationality in her experience through mentorship to the mother on approaching their dead loved one and through the continuation of relationships with her patient

after death. Relational caring supports open communication regarding death and dying, and the ways staff handle patient death can both shape the culture of dying within the setting and how families respond (Banerjee & Rewegan, 2016).

Creating space for authentic relationships only fosters trust and communication. However, many healthcare institutions still favour medical models of care which privilege the physical over patients' and the family's emotional and social needs. The key barrier to providing relational caring has been identified as a need for more time and resources. Healthcare workers face other barriers in providing relational caring at the end-of-life, "threatened by emotional exhaustion and burnout when they are needed most" (Banerjee & Rewegan, 2016, pg. 415). Andy shared her experience, *"You need to know your limits, right? Knowing when you can't emotionally or physically help or support anyone. That's important because, you know, I always find that before I enter a room, I need to ensure I'm a hundred percent okay. And that I'm going to be there and support them."* Banerjee and Rewegan (2016) argued that relational caring better supports staff, families and individuals by sharing awareness of the patient's condition, allowing more time for appropriate care for all parties. Recreation therapists play a unique and vital role in supporting individuals and their families through the end-of-life processes, offering both emotional and practical presence during this profoundly challenging time. By providing opportunities for patients to witness and reflect on the funerals of their peers, recreation therapists create space for meaningful rituals and connections. Additionally, they facilitate moments for family members to say goodbye, ensuring patients' end-of-life wishes are honoured and supported. In these critical moments, recreation therapists offer compassionate care, helping individuals navigate the emotional and spiritual complexities of dying with dignity, connection, and peace.

Being present with death is vital to the role that recreation therapists play when approaching the end-of-life with a patient. Presence may look different to everyone, depending on their relationship with the recreation therapist and their end-of-life preferences. Morgan described how being present removes the boxes we prescribe to/for ourselves on how we are "meant" to react during times of loss. These boxes are represented in her artwork (see Figure 11). Morgan shared, *"The most groundbreaking thing, while supporting someone or just being in the actual moments of death, is that those boxes go away, and you are just there. You have to be very present and remind yourself that you're in the circle of life."* Being present with death brought Morgan peace in her work. It helped her to make connections with family members, such as the example of her getting into bed with a patient who had already passed thus showing the family member how they might also connect with their loved one. Morgan described that presence in these moments was just as significant as love at the end-of-life, which she represented in her artwork as a heart (see Figure 11). Morgan shared, *"I have the little heart in the middle because love just tends to be the only thing that matters in those moments and honestly, whether it's like pure love whether, it's the sadness about the love you're gonna lose, or the lack of love you felt you gave."* In acknowledging love and connection as powerful at the end-of-life, Morgan emphasized that presence is the only way that we can foster rich moments at the end-of-life. As described earlier, these moments are only possible once we remove the boxes that limit our relational capacities at end-of-life. One reason for these boxes may be to disconnect emotionally from the death of an individual, something that is taught in the medical model as a means of creating distance to "protect" the carer from grief. Each participant's examples challenged the biomedical model and highlighted how recreation therapists are using their relational capacities in these institutionalized spaces without being formally educated to support individuals and their

families as they navigate death and dying. Love and presence at the end-of-life have been meaningful to practitioners, the patients, and the families in creating safe(r), more connected end-of-life experiences.

**Figure 11: The Only Guarantee**




***Supporting Beautiful Moments of Life***

Important roles and experiences described by the recreation therapists was providing moments of enrichment and enjoyment to create opportunities for community and belonging. These roles and experiences did not change at the end-of-life. The recreation therapists felt that supporting these experiences and moments of beauty were just as important for the people who were dying as they were for those experiencing loss. Without proper training or courses to

facilitate programming at the end-of-life, recreation therapists still worked hard to find ways to create moments of beauty, fun, silliness, and enrichment during critical times. The recreation therapists involved in this study discussed a range of modalities they use to bring beauty to life. Examples included adding to the standard recreation therapy offerings and tailoring moments to individual needs and wishes. Modalities highlighted by the recreation therapists included pet therapy, nail painting or hair dyeing, and exploring new initiatives, such as the Nordic wellness chair, to create a peaceful end-of-life experience. Whether it's a breath of fresh air, a game of Uno, or a cuddle with a dog, recreation therapists ensured that the end-of-life remained full of life.

Some went out of their way to provide opportunities for the individuals they supported to engage with their favourite things. Felix described one technique he finds meaningful for patients at the end-of-life: *"I bring my ShihttzuShih-Tzu to visit 1-to-1 with residents who are in their beds and who aren't mobile; they don't get a lot of recreation in groups, if any, so I bring my puppy to see them."* Felix shared the impact of bringing the dog into work and how it comforts his residents at the end of their lives. A family member saw the comfort that the dog brought to her mother and shared this with Felix: *"two [residents] have passed away, one was quite recent, the daughter, a week after the death came to me and said she was tearful, she said mother loved that dog."* Felix saw the importance of interactions with pets and, at a time when assistance of pet therapy volunteers was restricted or limited in facilities since COVID, he went out of his way to ensure his residents still had opportunities to engage with pets to bring comfort and joy.

Andy shared a similar experience of offering unexpected moments of life for patients living in hospice care. It was important to Andy that her patients continued to be involved in family life, like attendance at family weddings. Andy stated, *"We've also had some weddings*

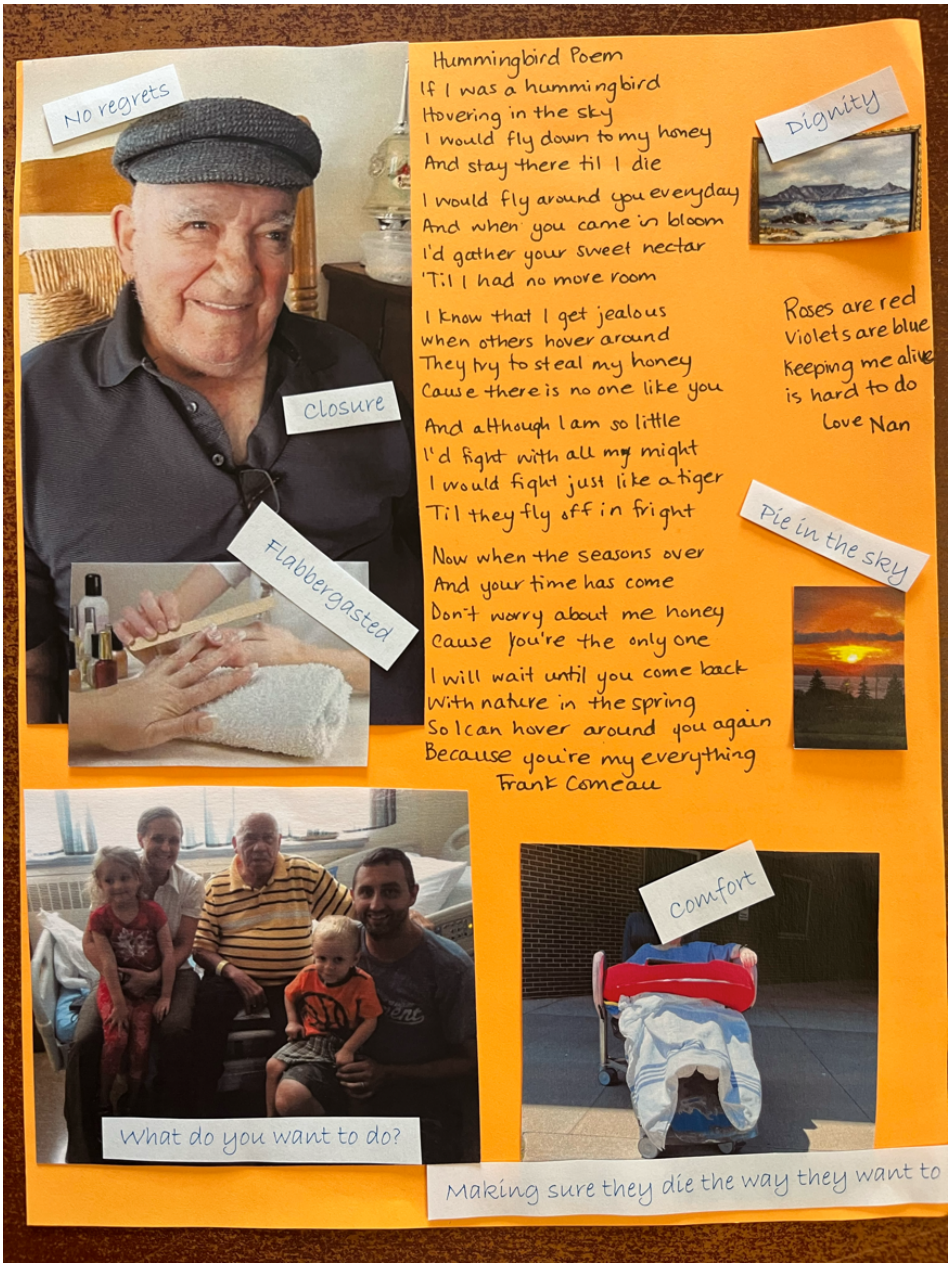
*happen in our courtyard here. Their dad was dying, and they wanted to get married, so they got married in our courtyard so their loved one could be present."* Andy also described how the hospice supported a patient in hearing her unborn grandchild's heartbeat: *"We had one of our doctors go outside, in the middle of COVID, on somebody's patio and use the sonogram, so the mom could hear her granddaughter's heartbeat before she died."* Within hospice settings, like the space where Andy worked, the staff worked hard to provide moments of beauty and engagement with life for individuals who were dying to, as Andy stated, *"to make people's last days as meaningful as possible."*

Morgan spoke similarly about her experiences working in a children's hospice and the vital role of interacting with patients even when they are *"no longer fully conscious."* Morgan explained what she can offer to the person dying, sharing, *"If the child is no longer fully conscious or their body is not moving, that doesn't stop my role, we'll do cuddles, we'll do nail painting, we'll do massage."* Her approach honours the importance of relationships by engaging with the living meaningfully, even if they may not be able to respond. It also involved ensuring family are cared for. Morgan explained *"[I] will spend time with the parent or whoever is there, and I think it's honestly the little moments like that that are like the most meaningful to the family after, I think the simplicity of things is like the most rewarding."*

Layla stated that the best way to describe what she can offer patients is *"pie in the sky."* She explained, *"Everything I do is whatever [they] want to do, I will try to make that happen."* For some patients, this means encouraging them to do things they haven't tried before, which might include using the Nordic Wellness Chair. Layla explained *"it's a very expensive piece of equipment and it doesn't do anything too exciting, but [it is] also magical at the same time. It sways just the right amount and plays nice music."* This equipment does not work for/is not

offered to every patient, but in particular cases, it can be comforting and an effective way to encourage dying patients to get out of bed and engage. Layla shared that *"this particular patient we tried it with was just amazing. It did what it was supposed to do, and she looked forward to it, and [it helped to] convince her to get outside and to take her around the building."* Layla represents her experiences in her expanded personification see (Figure 12).

**Figure 12: Pie in the Sky**



Providing moments of beauty and supporting living to the end-of-life is not limited to the dying but can involve the living and ones left behind as well. Morgan described how watching moments of play at the end-of-life provided good memories that remain with the family. She offered a story of a patient's doctor and herself playing a game of Uno with their patient: *"She beat us in two, me and the doctor, in two Uno games just by blinking. She died two days later; she barely had any [body] function, but she was still cognitive, and that is the memory that the parents are most proud of or love or continue to talk about."* Felix shared a similar sentiment in his experience creating art with patients, leaving important mementos for family members: *"resident artwork produces something tangible that they [families] have after the fact."* He went on to describe how the memories made in recreation therapy provide families with tangible moments to hold onto after their family member has died such as *"a plant or [watching a resident with] my dog, anything tangible that once the resident passes away that the family has*."

***Amplifying Comfort through Meaningful Connection***

The recreation therapists in this study also spoke about the importance of amplifying comfort through connection at the end-of-life. In my experience, this may look like holding someone's hand or providing music at the bedside. But I learned through experience that, in order to be comforting, it also has to be meaningful to the individual you are supporting. One experience I had was when I put on music for a patient so that they could hear music of their hometown. This particular patient was no longer speaking or moving much, and we did not have any information on their goals of care or their preferences. Their family was not involved in care decisions, and they had moved away from home decades before they came to hospital. The music player was brought to the bedside in hopes of providing comfort. The music played for a few hours before I returned to check on the patient and offer my hand; as soon as I touched her

hand, she croaked, "*Turn that off!*" At this moment, I realized the importance of goals of care conversations happening upon admission to help healthcare providers determine the appropriate comforts for individuals prior to starting the dying process as not everyone's comforts at the end-of-life are the same. This experience highlighted for me the importance of including goals of care questions upon admission and regularly reviewing these with patients and their families. In our organization, our personhood assessment—created and implemented by the recreation therapy team—has become a source for the team to use to ensure care is aligned to the individual's interests, needs, and desires. This assessment now includes music interests. More end-of-life questions/goals of care questions are needed in this assessment to give further insights into end-of-life comforts for each person.

The participants involved in this study shared many examples of their own experiences of providing comfort to the dying. For example, Jolene shared, "*It's different for everybody depending on their values. For some people, it's just being comfortable and not in pain because that can be really hard to end-of-life. [For other] people [they] might want to connect with their faith, some people want to have their family there, some people might want to be alone*." Jolene emphasized that everyone has different desires at the end-of-life and if we do not know these before the end-of-life, it can be difficult for the practitioner and family to make those comforting decisions. Jolene shared, "*There are people who don't have those wishes lined out for themselves; it's different for everybody. I have my perspectives of what I would like to have, and then I can imagine what other people would like to have, but at the end of the day, they may even have their wishes lined out, and that's not what they want at that moment*."

Providing these moments of comfort through meaningful connection and intimacy amplifies the importance of attending intentionally to relational caring processes. Part of the relational caring process is being open to vulnerability, a basic shared human condition experienced by all humans at some point in their life (Dodds, 2014; Mackenzie et al., 2014). The value of vulnerability within caring environments is building mutual bonds, maintaining interpersonal relations, and fostering ethical responsibility and responsiveness (Mirsha, 2019). Vulnerability is embedded in our lives and is a product of our interdependence with others, our mutual care, and connectedness. For professionals, being open to vulnerability is key to providing comfort in uncomfortable times. The moments of comfort recreation therapists provide do not remove the awkwardness or discomfort of death, but support dignity, autonomy, and compassion at the end-of-life. Eleni offered examples of providing dignity to patients at the end-of-life in ways that are not commonly offered in a hospital setting. Eleni explained, "Unfortunately, *people in the hospitals, often older adults, are not touched in positive ways, [only touched for] medications and personal care [reasons]*." This was represented in her artwork through the image of a gloved hand in comparison to an ungloved hand.



Many relational approaches support more positive relational caring processes through shared experiences, being open to vulnerability, and connecting. Eleni attended to relational processes was by thinking about the environment and how that might be changed to support a better end-of-life. She often used "*music [because] it is a big thing just to improve the*

*environment around them and maybe distract from some of the other things going on in the hospital*." In some of her experiences, people have died slowly or, as Eleni described, "*over months, [so I've] taken patients out for their last breath of fresh air, done somebody's nails or made them feel good by doing their makeup*." Eleni spoke about her work not being as she described *"formal legacy work,"* but she always considered the impact of small enhancements to life or, as Andy described them, *"moments of beauty."* Each enhancement reflected the compassionate, attentive, and relational approach each practitioner utilized to support comforting end-of-life experiences.

## Chapter Six: The Entanglement of Solace and Finality in Personifications of Death

The high exposure and different experiences that recreation therapists have had with death and dying helped shape their understandings of death and dying. In this research, practicing recreation therapists were able to explore the complexities of death through the creation of artistic expanded personifications of death. Interestingly, participants expanded personifications often reflected non-human qualities rather than human characteristics. Participants' expanded personifications emphasized the duality of solace and finality, capturing the multifaceted ways recreation therapists think about and experience death. Death is depicted in contrasting forms through each expanded personification. Solace was personified as and in nature, being at peace, or returning to somewhere. On the other hand, finality was portrayed as the interplay of darkness and light, emptiness, and the cold, clinical environment of a hospital. Death's finality symbolized the inevitable and inescapable nature of death. These dual representations reflect the complexity of human experiences and perceptions of death, revealing that death can be both beautiful and scary depending on the personal and ever-changing experiences of recreation therapists. Despite the complexities reflected in the expanded personifications, a shared personification of death as a "promise" emerged, offering a unifying essence of death. This concept of death as a certainty resonated with each participant, reminding us that while our individual experiences and perceptions of death may vary, the inescapable reality of our mortality remains the same for everyone. This promise of death, though often feared or misunderstood, serves as a common point of connection, bridging the light and dark interpretations and emphasizing the universal truth that death is both finality or an inevitable end and, for some, a form of peace or solace. The knowledge that death is a universal experience provides peace and comfort. I will describe these ideas next.

**Death as/in Nature**

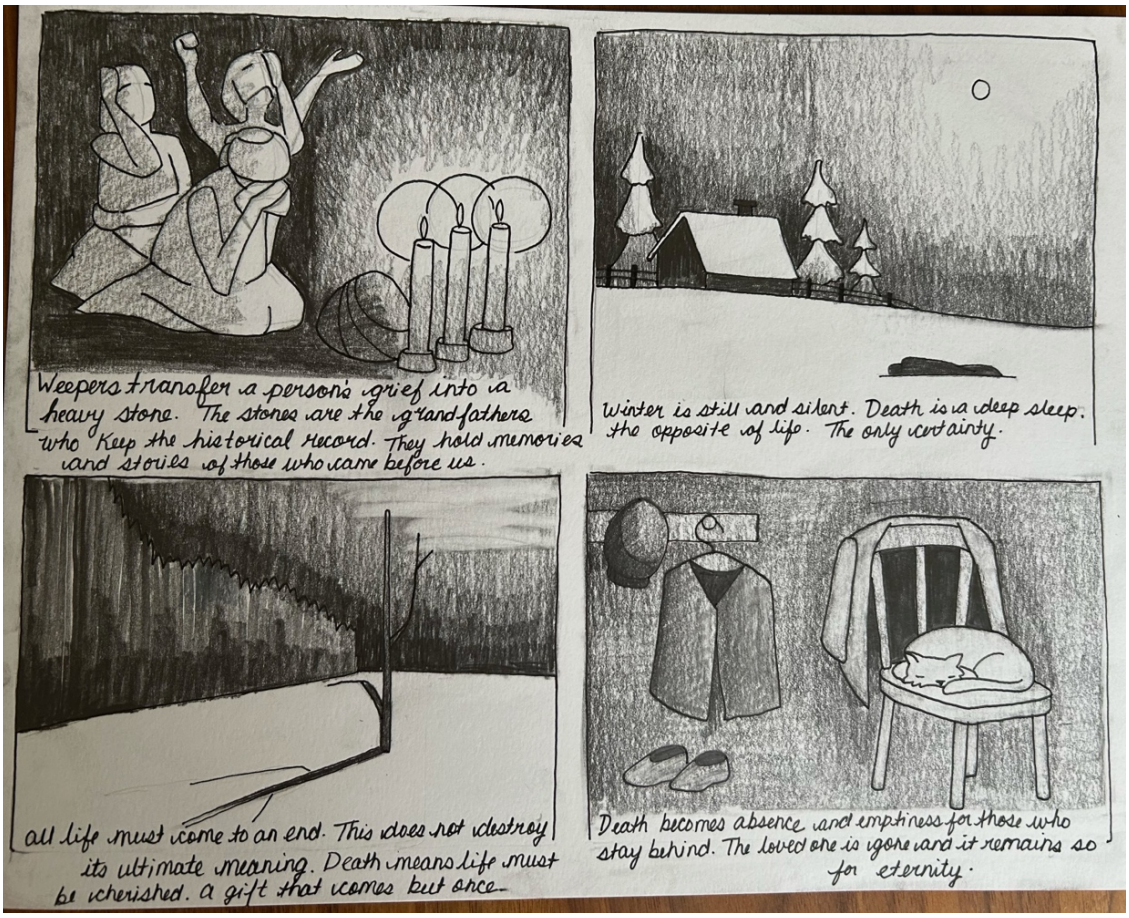
Looking deeper into how recreation therapists personify death, nature emerged as a powerful and grounding essence. For many participants, death shared a connection with the natural world, offering a tangible and cyclical example of life and death, like the changing seasons, waves, or even the life-death cycle of plants and animals. This connection between nature and death is not merely a metaphor but a lived experience highlighted by interactions between recreation therapists and their clients, especially when working with children or grieving individuals.

Morgan, who works with young children in hospice and their siblings, explained that she frequently uses the analogy of grief as a wave (see Figure 11) to help children understand the ebb and flow of their emotions: *"I use grief waves as an analogy, um, often"* Morgan shared. *"... they can be big, small, and come out of nowhere. They come and go, go but just kind of ... the grand explanation of what grief can be like to kids ... grief is like waves and that usually is like something that resonates with them."* This analogy, rooted in the nature of waves, reflects how death and grief are experienced, not as permanent states, but as forces that rise and fall in intensity. It's a clear example of how nature provides a safe framework for understanding complex and abstract emotions such as grief and loss.



The connection between nature and death is echoed by other participants, many of whom chose to personify death through the seasons. Felix spoke about the deep connection between death and winter. In his art, he created four distinct scenes (see Figure 13), two depicting winter landscapes, one barren and snow-covered, the other a single, leafless tree standing stark against the icy background. Felix stated, *"...winter is very still, and um it's cold so you know there is no life to it and it's dark so that to me was the opposite of life. And just as we know that winter comes you know, consistently each year ... it's as certain as death is."* For Felix, the stillness and isolation of winter made it an appropriate metaphor for the finality of death, a certainty that arrives with the changing of the seasons.

**Figure 13: The Weepers**



This connection between winter and death is not a new one. Historically, many cultures have linked the harshness of winter with the harshness of mortality. The Saxons, for example, personified death as *Father Winter* or *Old Man Winter,* a figure similar to *Father Time,* who was believed to bring winter's cold and darkness. The Saxons even believed that by treating Father Winter with kindness, they could soften the blow of the harsh season. As Kastenbaum (1992) noted, such figures are rooted in ancient traditions where death was often personified as a wise, old man, an association still found in death personifications today. Kastenbaum's work, which explored the personification of death in clinical settings, noted how death is often framed as a *Gentle Comforter,* which Kang's (2019) study highlighted is connected to deaths occurring at later stages of life, particularly at home. Felix's depiction of winter taps into this tradition, showing how death's cold, inevitable arrival can also be seen as a natural and unchangeable part of life. This is reflected in the research by Kang (2019), who found that in the final stages of life, the personification of death can take on a comforting role, just as winter offers a quiet, still environment for reflection and solitude.

The connection between death and winter is also found in literature. Robert Frost's famous poem *"Stopping by the Woods on a Snowy Evening"* (1923) describes winter as "lovely, dark, and deep," capturing the melancholy beauty and isolation of the season. The metaphor of winter as a beautiful and isolating experience parallels the complex emotions that come with grief, feelings of both sorrow and peace.

Nature also brings with it other symbols of death, like the raven. In Jolene's experience, growing up in Northern Alberta, the raven was often seen as a symbol of death, transformation, and the unknown. *"There's a story about the raven stealing light,"* Jolene shared, reflecting on an Indigenous legend from the Pacific Northwest. *"Many say that he transformed himself into a*

*baby to find out where the light was hidden and … then stole it from an old chief who kept them in his house locked away".* For Jolene (see Figure 14), the raven's role in these stories was not to symbolize death alone but to represent a "*part of the process."* Jolene shared that the raven is an *"interesting symbol, many people in many cultures symbolize death with crows and ravens."*

**Figure 14: The Raven**



The raven's connection to death is especially significant within Indigenous communities, where the bird is seen as both a creator and a trickster, someone who brings light but also takes it away. The raven's connection to the unknown, the mysteries of the world, and the inevitable cycle of life and death mirrors the complex ways death is understood in various cultures.

Expanded personifications represented elements and cycles of nature and reflected images of a 'return to nature.' Oliver spoke about his experience growing up Jehovah's Witness, which influenced his artwork 'Resurrection' (see Figure 15), especially the idea of "*Residents of*

*the Dust.*" He shared that the idea of returning to something was seen as comforting, and a belief held since childhood: *"a belief that I've grown up with is like in an earthly resurrection."* Oliver specifically resonated with the idea of returning to the earth, sharing that some *"scriptures talk about you returning to dust, you were made of dust, and into dust you will return."* Oliver further explained that though his relationship to religion has changed, resurrection remains a strong symbolism of death, he believes it might look like a return to dust, or earth, not in a human form but back to what 'we' are made from: *"you die you go into the soil basically gradually become part of it."* In many religious texts, dust is a symbol of life, love, and humility.

**Figure 15: Resurrection**



Nature's role in helping individuals understand death isn't just a metaphor for the therapists; it's also a tool they use in their work with children. In a study by Born and Schonfeld (2019), researchers found that death often enters the conversation when children are introduced to nature. The study involved bringing outdoor experiences into preschool classrooms, and the researchers found that children frequently asked questions about death when engaging with the outdoors, whether it was a tree that had fallen or a small animal that had died. Similarly, Morgan shared how children often find their way to the topic of death when learning about nature.

The ability to approach death through nature allows for a more accessible and less intimidating conversation. Nature doesn't carry the same emotional weight as direct discussions about death, making it a helpful tool for breaking down the fear and confusion surrounding the topic. As Jolene noted, *"It's only natural to have death, and I think that's seen in nature oftentimes; a lot of people make that association. It's easy to find symbolism in nature."*

The connection to death and nature is clear, but the expanded personifications of death by recreation therapists highlight the complexities in their experiences and understandings. The second essence echoed among participants in their personifications was death as darkness and emptiness.

**Death as Darkness and Emptiness**

Are you afraid of the dark? Could the deep-rooted connection between darkness and death stop us from walking into the dark? The personification of death as darkness, the colour black, and emptiness emerged strongly in the reflections of recreation therapists. Black was frequently mentioned as a symbol of death, evoking a sense of void and absence, a darkness that absorbs rather than reflects light. This portrayal of death captured its sense of finality and the

emotional weight it carries; an experience that many recreation therapists described as void-like, a place where light is snuffed out, leaving only emptiness behind.

For the recreation therapists in the study, black was often described as the absence of colour or a shade that absorbs light, which is linked to the sense of death's emptiness. Jolene highlighted how black is often associated with negative emotions and loss. She observed that *"... white is a positive colour. It's associated with purity and pureness, whereas black is a bad colour ... especially in media and marketing, black is bad. It's got negative connotations."* This perception of black as inherently negative ties into its historical and cultural significance, especially in mourning. According to Hutchings (2003), achromatic colours, black, white, and grey, are widely accepted across various cultures to signify mourning and death. However, the colour choice varies significantly depending on geographic and cultural traditions. For instance, while black is the accepted colour for mourning in much of Europe, white is more commonly associated with death in Chinese customs (Hutchings, 2003). This variation in the meaning of colour demonstrates that the symbolism of black as a symbol of death is not universal but is deeply influenced by cultural context. More culturally inclusive research is needed to uncover the presence of lightness and darkness and how it is culturally, religiously and contextually embedded in experiences of death.

In their expanded personifications, darkness was not used as a neutral background alone but a powerful force that could overtake light colours, symbolizing loss. This idea was reflected in the artwork and descriptions provided by the participants. Felix, for example, chose an achromatic colour scheme for his depiction of death (see Figure 13). In the zoomed-in image, the viewer is welcomed into a room with a woman, the multiple 'people' represent the motions or physical displays of grief. Felix described, *"Weeping into a heavy stone is based in [Eastern]*



*Finnish ancestry… it is a folklore tradition to try and transfer grief into a heavy stone ... maybe to represent how death is a heavy burden for people."* The darkness in each of the four images looks at the presence of death and the light reflects the continuation of life. He explained: *"I didn't think that death had any colour to it. That's why I wanted to use graphite. Just the black and white. So, the darkness probably represents the darkness that is coming."* Felix's use of black and white underscored the contrast between the finality of death (represented by darkness) and the vitality of life (symbolized by light). This choice reflected the deep cultural and philosophical connection between light and darkness as symbolic of life and death.

Parker (see Figure 16) explored her choice to use black as the backdrop for their piece, describing their vision of death, by stating, *"The background was going to be black, but down below was going to be a bit of light. He was going to be sitting on a red arm, which I thought would bring, like, again, kind of a pop of colour, um, a brightness to the darkness."* For Parker, the interplay of black and light represented a tension between the overwhelming presence of darkness (death) and the small but significant presence of light (life, hope) that can emerge even in the shadow of death. This vision is a powerful metaphor that, even in the darkest moments, there may still be traces of light—small, fleeting, and often hard to see.

The colour black, with its association with darkness and emptiness, also resonated with the emotional and psychological experiences that many people associate with death. When someone dies, there is often a palpable emptiness, a sense of something missing that can feel all-encompassing. This emptiness is echoed in the artwork and descriptions of death that the

recreation therapists created. For many, death felt like a void, something that existed outside the realm of life, a place where nothingness prevailed. This is consistent with how death is experienced as a peripheral phenomenon, as something that occupies our unconscious, often felt more intensely during moments of grief. As Felix noted, the darkness of death represents an impending loss, something that inevitably comes and erases the light of life. His use of black and white captures this feeling of emptiness and finality, providing a stark contrast that is both visually and emotionally striking. Morgan uses black boxes in her artwork (see Figure 11) to represent the boxes we put ourselves in in our expectations for grief and coping. She described, *"I had them open, not coloured in and I coloured them because [grief] is usually a dark place to be."*

**Figure 16: One Foot in, One Foot Out**



The association between darkness and death is a contemporary phenomenon and has deep roots in cultural, religious, and philosophical traditions. The juxtaposition of light and darkness has been a longstanding motif in the Global North, particularly within religious texts. In the Bible, Quran, and Torah, darkness is often linked to suffering, captivity, and death, while light symbolizes life, salvation, and the divine. As Lemmelijn (2013) note, darkness in religious and cultural texts is often portrayed as an enemy of life, which is overcome by the power of light. This religious duality of light versus darkness has had a lasting influence on how death is personified, especially in the Global North.

For example, the "Macabre" figure as discussed by Kastenbaum (1992) ties into this theme of death as darkness, with its associations to fear, the unknown, and the inevitable. The Macabre is often depicted as something foreboding, a force that emerges from the shadows to claim life. This personification resonates with the experiences shared by the recreation therapists, who described their feelings of darkness and emptiness when contemplating death. However, while many therapists linked death to darkness, they also expressed an underlying complexity in their views. As some noted, death does not always need to be portrayed as something dark and scary; it can also be seen as a peaceful, even beautiful, transition.

In conclusion, the personification of death as darkness, black, and emptiness reflects a complex and multifaceted understanding of mortality. It highlights the psychological and cultural dimensions of how we experience and represent death. The recreation therapists' reflections, particularly with the use of black and the interplay of light and darkness, capture the profound emotional impact of death, a force that, while inevitable, is not always without its moments of light, hope, and transformation. Whether in the form of a raven stealing light or the black-and-

white contrasts of an achromatic landscape, death's personification is a powerful tool for exploring the profound complexities of grief, loss, and the human condition.

**Death as a Peaceful Promise**

The third essence recurring throughout all research conversations was the idea that death was not always scary and dark but offered a calmness in its inevitability and universal nature. It offered a sense of community in that it was the one thing that we all had in common regardless of religion, race, culture, or location. When I took my death doula certification, the instructors offered a message that stuck with me: *"We only have two things in common as beings: we were all born, and we will all die."* This simple phrase has become integral to my relationship with death, offering a forbidden promise. In discussion with participants, some had differing versions of this statement, each offering the idea that the fact that we will all die gives a sense of peace.

Andy, for instance, spoke about their own expanded personification of death, trying to determine its age. She reflected, *"So what age is death? I think that death is all ages. And I see that within my work every day as well. So, I think, again, death is really universal, all ages, and can happen to anyone."* This view, shared by Andy, highlights death's universality and its inevitable nature. Andy demonstrated this in her expanded personification (see Figure 17), using scrapbooked images reflecting famous deaths in popular media at various stages of life. No one is exempt from it, and there is a quiet peace in this commonality. Death is not confined to a particular age or stage in life but is woven into all our experiences, regardless of when it arrives.

A similar sentiment surfaced in the familiar phrase, "*it's just the circle of life,"* often invoked during moments of grief or reflection on death. This phrase, which implies a continuous return, is deeply connected to the idea of *returning*, whether to the earth, to a spiritual afterlife, or to some other form of existence. Eleni reflected on the concept of the circle of life, and she

stated: *"Circle of life, I've also realized through just like work with death, that like the normalization and just the conversation around the circle of life kind of just generally is important and also a settling thing and that it's, it really is the circle of life. Like death is also something that you know we can't avoid."* For Eleni, the circle of life is both a reminder of the natural rhythms of existence and a grounding concept that brings comfort. Death, as part of this cycle, cannot be avoided; it is an integral, unchangeable part of life, and in accepting that, there is a certain peace.

**Figure 17: Lovingly Remembered**



In a world often filled with conflict, differing beliefs, and complex perspectives on death, it is not surprising that the unifying nature of death provided a sense of calm for many participants. Death is the one experience that connects all living things. Our reactions, our interpretations, and our understandings of it may vary widely, but the act of dying and the finality of death is universally true. I once had a co-worker with whom I worked closely in the context of death cafés ask me how I, as a non-religious person, could be comfortable speaking about death. The answer wasn't simple, and I still reflect on it today. But I eventually realized that the finality of death is what brings me peace; it reminds me that life is precious and that understanding death as a natural part of our existence helps me appreciate it more deeply. Death and life are intimately linked. Felix echoed this sentiment: *"All life must come to an end, and my personal belief is that it doesn't destroy its ultimate meaning and that we do, especially in therapeutic recreation practice, believe that life has meaning and it's a gift that should be cherished."* For Felix, understanding that life will end does not diminish its significance. Instead, it highlights the importance of living fully, of cherishing the time we have.

This peaceful perspective on death, rooted in its inevitability and universality, provided a sense of comfort and grounding for many of the participants. While death is often thought of as something to fear or avoid, the recreation therapists found that embracing death as a natural, peaceful part of life offered a different lens through which to view the end-of-life. Death is not a shadow or a monster, but a part of the same cycle that gives life its meaning.

The final essence that emerged from the expanded personifications, however, was distinct from these natural and universal connections. It reflects the specific environments in which recreation therapists often work, such as hospitals, long-term care facilities, and hospice care. Here, death is personified in the context of healthcare settings, where recreation therapists are

regularly confronted with end-of-life care. While many of the previous essences used to personify death reflected death as nature or as a universal experience, this last essence delved into the ways that death is experienced in (ill) spaces designed for dying.

**Death as the Undignified Hospital**

In many healthcare environments, death often takes on a more clinical and sometimes sterile quality, yet it remains an inescapable part of the work. Recreation therapists in these settings often walk alongside people at the end of their lives, offering support and comfort, and helping individuals and families process the emotional and physical aspects of death. The personification of death in these settings is unique in that it intersects with medical, emotional, and social aspects of the dying process. The themes of peace, inevitability, and universal connection are still present, but they are intertwined with the realities of living in the face of death, whether that's providing comfort, companionship, or helping individuals and families navigate the final stages of life in environments that support or limit compassionate dying processes.

As mentioned in the previous chapter, recreation therapists have an overexposure to death compared to the general population, a phenomenon that is faced by all healthcare professions who work in diverse healthcare settings. It is a part of the job that is never blatantly stated or addressed in our education. With this overexposure, it is not a shock to see the expanded personifications of death embodying qualities of the hospital. This overexposure shapes how death is perceived and personified. In many of the research conversations with participants, death took on the qualities of the hospital environment itself: sterile, noisy, uncomfortable, and impersonal. The hospital, as a place where the end-of-life often occurs, can feel unsettling, and, for many, it embodies a type of death that is distant from human warmth or comfort.

Eleni, a recreation therapist with significant experience working in hospital settings, shared her thoughts on the challenges of dying in a hospital environment. *"The hospital can be one of the worst places to pass away for so many reasons in terms of just being restricted by who can come to see you, not being in a comfortable setting, being in a noisy setting, all those things."* Eleni's perspective reflected the realities of death in the hospital, an environment that, while necessary for medical care, can feel alienating for those at the end-of-life. In this setting, death is often reduced to a series of clinical procedures and sterile surroundings that can strip away the dignity of the person dying.

In her artwork (see Figure 10), Eleni explored this duality, contrasting the cold, mechanical nature of death in the hospital with the warmth and dignity she provides as a recreation therapist. She depicted the medical environment on the right side of her piece with alarm bells, gloved hands, syringes, and a wilted flower, symbols of a death that feel detached from a warm human experience.





On the left, however, Eleni envisioned a more compassionate, holistic approach to dying, one that included therapeutic touch, hand massages, speaking to the person even if they haven't spoken in a while, and providing moments of light and peace. She explained, *"Yeah, so I feel like the opposite side of my artwork is really focused on kind of my role. I think a lot*

*of what I do around death is in like those covert interventions near the end, so things like therapeutic touch, hand massages, just holding a person's hand, speaking to them even if they haven't spoken in a while, or they don't present to become particularly present."* For Eleni, the contrast between the two sides of her artwork represented a core difference: how dignity is respected and reflected. In a hospital setting, death can feel cold and impersonal. Through the efforts of recreation therapists, there is potential for a more dignified death, one that honours the person's humanity, relationships, and their wishes in their final moments.



R.G. also connected death to the hospital, with absence of colour and a particular shade of blue. She stated: *"I associate the commonly used blue in the hospital sheets with death."* Commonly found in the hospital linens, gowns, and sheets in her artwork (see Figure 9.), R.G. uses blue as a background behind each speech bubble, illustrating how this colour has become embedded in her experience and understandings of death. This seemingly harmless detail, the blue of hospital linens, carries an emotional weight for those who work within these spaces and are forced to confront death regularly. In Walter's (1993) research, the medicalization of death was viewed as a social problem, which isolates the dying and views death as a failure. It is interesting to note that dying as a failure did not get portrayed in participants' expanded personifications. This may be because recreation therapists do not work from a biomedical model but see the human experience as holistic and encompassing death.

In contrast, the expanded personifications offered a hopeful outlook on the potential for beauty within undignified spaces. Their descriptions point to the environment and sterility of the

spaces which contribute to the failure in death care. Recreation therapy was portrayed as an important countering factor to the sterile environment, especially when relational caring processes were brought to practice. The medicalized experience of death in the hospital can be connected to the concept of the *Automaton*, a term used by Kastenbaum and Ainsberg (1997) to describe one of the four personifications of death. In their work, the Automaton is an unfeeling, robotic figure, one that is detached from human emotion and personal connection. Kang (2019) expanded on this, describing how the Automaton persona aligns with the nature of death in modern hospitals. Kastenbaum and Ainsberg (1972) stated that it is "objective, unfeeling, automatic, and soulless" (pp. 158-159), which represents the modernization of death focused on the termination of the human body. The automaton is the medicalization of death associated with the words *machine*, *facility*, *pain*, *suffering*, and *hospital bed* (Kang, 2019). With the hospital's sterile environment and emphasis on procedure over personal relational care, the hospital can often feel like the embodiment of this Automaton figure. In this place, death is reduced to a clinical process, devoid of the warmth and intimacy that many hope for in their final moments.

However, the work of recreation therapists contrasts the cold, impersonal environment by offering alternative ways to see death in these spaces, characterized by human connection, dignity, and compassion, as Elenis' artwork suggests. The role of the recreation therapist is to provide these moments of care in an environment that can often feel dehumanizing. Their facilitation techniques and relational capacities, such as therapeutic touch, communication, and the provision of comfort, directly oppose the sterile, mechanical qualities of the hospital setting. The tension between these two perspectives, death as something sterile, impersonal, and cold versus death as a profoundly human and relational experience, reveals the complexities of working in these environments.

In conclusion, the expanded personifications created by recreation therapists reflect the complex understandings and experiences of death and dying held by these professionals. The expanded personification of death as/in nature and as peaceful, inevitable, and universal provides a nuanced understanding of how death is experienced and understood in the context of recreation therapy/therapeutic recreation. While death is often framed in negative terms, something to fear, avoid, or mourn, the recreation therapists in this study highlighted the ways in which death's inevitability can offer a sense of peace and connection. The darkness of death was intertwined with light. Further, from Andy's reflections on death's universal nature to Eleni's comfort in the circle of life, the interviews and artwork revealed a profound understanding of death as a natural, unifying force. For some, like Felix and me, the awareness of death's finality makes life more precious. In embracing death, we are reminded to cherish the time we have. And in therapeutic environments, this understanding is not just academic or philosophical, it is woven into the very fabric of the work that recreation therapists do with those nearing the end-of-life. Recreation therapists, however, highlighted how the often cold, impersonal medical environments they work in often conflict with supporting the warm and dignified death which recreation therapists strive to offer. The hospital, where death often occurs, can be seen as a metaphor for the Automaton, a clinical, mechanical process that lacks connection to the individual's humanity. Yet, as the participants have shown, death does not have to be experienced in this way. Recreation therapists challenge the typical hospitalized death by providing moments of beauty, life, connection, comfort, and dignity.

## Chapter Seven: The Hope for and Cultivation of Support in Unsupportive Environments.

Recreation therapists providing end-of-life care are left to navigate emotional and professional terrain with minimal support. In our discussions, they described their hopes for and cultivation of environments that would better support them with their experiences of death and dying. They need rituals and ceremonies to honour death, moments that allow them to process grief and find validation for the discomfort and vulnerability they experience in confronting the realities of death. They need training on death and dying embedded in educational programs, so they feel better prepared to support end-of-life processes. Yet, currently, the lack of structured education on death and dying forces recreation therapists to fend for themselves, relying on informal avenues to gain the skills and knowledge necessary for such complex work. This often involves self-educating, often at their own expense, by joining committees, paying for courses, or advocating for their role in palliative care. Jolene reflected: *"it is frustrating because you seek out your own education your own comforts, your own needs, [but] there is never support, in my experience. Personally, I think it's a really valuable thing to put your time and energy into doing [death education], it's a very important part of your life. Like I said it brings up a lot of emotion, frustration because I just wish people had the support."*

Before staring work in hospice, Andy took a variety of courses, some as requirements for the job and others for additional support. She shared, *"I did my death, dying and bereaving certificate at Laurier University,"* and *"HPCO, Hospice Palliative Care Ontario, we have a variety of education sessions that we do pretty frequently."* When prompted, she shared that the course was expensive, *"it was three, four hundred bucks a class."* Looking into the HPCO programming, they offer a variety of courses, including 'In-Home Hospice', 'Hospice Residence', 'Both In-Home and Residence' and 'Additional Services.' To take and maintain the

accreditation for three years, the cost is $9760 CAD (HCPO, 2024). The cost of programs varies across different organizations, but the burden of being required to use personal time and money to complete supportive education may leave practitioners feeling a significant emotional and financial toll, and isolated in their efforts to provide ethical, compassionate care. The need for systemic recognition, validation of grief, and formal support is undeniable. Without it, these professionals are left to carry a heavy weight alone. This chapter describes the supports that recreation therapists emphasised were needed to better prepared and supported in their roles.

**Being Supported in Grief through Ritual and Ceremony**

As described in Chapter Five, recreation therapists experience grief as a regular part of their jobs, yet these grief experiences are rarely recognised. There are often few opportunities for recreation therapists to talk openly about death, dying, and the grief they might be experiencing. The participants in this study emphasized how grief experiences can be supported through ritual and communal opportunities to grieve and reflect with others. They provided a number of examples of rituals used in their own settings, or that they were aware of, in our discussions. Even though these rituals are called something different (e.g., Code Angel, Recognition of Passing, Honouring Ceremony, Flag Raising Ceremony) and may be approached in different ways (e.g., including a song or poem picked out by the family, providing a meaningful covering for the body as it leaves the setting, displaying a candle, sharing an email sent by the concierge, sharing an image of the deceased), each play an important role in helping recreation therapists, family members, and other members of the healthcare team grieve, accept, and acknowledge the death of individuals receiving care.

Various rituals currently provided within the healthcare spaces of the participants were highlighted within the data. Parker, for example, described “Code Angel,” a type of ritual which

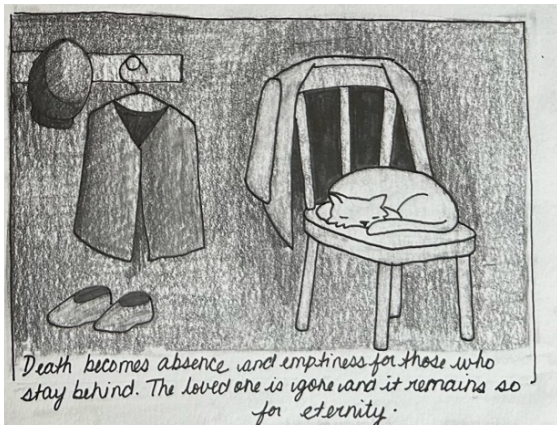
is utilized after a resident has died: "*Code Angel, at least for us, is when in long-term care if someone passes away, they'll make an announcement over the PA that someone is passed, and then all the managers, staff, and residents if they want to come out, if they can. You stand in the hallway as the body leaves the residence."* While I was working at Sunnybrook Veterans Center, a similar process was practiced, called the 'Flag Raising Ceremony.' Other rituals described by the participants were simple but meaningful, such as recognizing a person's death and displaying an announcement on a wall or mantle. Felix shared, "…*when someone passes away at our facility, at the concierge desk, they always put their obituary in the picture frame for everyone to read, and then there's a flower bouquet behind it."* Layla described their experience of finding out about a patient's death through the patient list, stating, *"We print off our list, every morning, he was at the top of the list, and I'm like, well, he's not there today."* No opportunity was provided for Layla to reflect on their grief and celebrate the person with others. Andy described a contrasting experience they had in palliative and hospice care. Andy shared, *"After we've said goodbye to the person, the care team, and whoever would go into the nurse's station. We usually have a tea ceremony just with the staff, and we also do frequent debriefs. We've been admitting young patients, which is difficult. We'll also have debriefed together as a team to ensure that we're checking in with each other and doing okay."*

In some cases, it is the recreation therapist's role to create these rituals for themselves, other staff, other residents/patients, and/or family by creating displays, creating cards for the family, running grief groups, or providing online opportunities for others to attend their community members' funerals. Oliver shared that the responsibility to create a legacy and acknowledge death has fallen into their role. This included using money donated by families to purchase legacy items to display onsite. Oliver described an example: *"The family of a resident*

*who passed had inquired of the recreation department to purchase [something] in memory of their dad."* The responsibility to facilitate ritual and recognition was highlighted by other participants, such as Felix who shared, *"We have a theatre/Chapel that we put on a big screen, the virtual streaming of the funeral."*

The workplace is not the only place recreation therapists draw upon for rituals in navigating loss. Some participants also describe personal rituals they had created outside their workplaces. R.G., for example, described a ritual that they find comforting: "*I find candles are fantastic when I have somebody that I'm thinking of; I find lighting a candle for them [to be] nice."*

In reflecting on the importance of ritual to these recreation therapists, I was reminded of Walter's (1991) work on connections between death, taboo, and ritual. Within his work, Walter described our lack of engagement with death, which enforces the taboo. Walter suggested that we must reexamine several areas influencing the taboo, the first being the distrust of rituals. Rituals related to death heavily relied on religious institutions and cultural norms relating to the treatment, sanitization, and funeral ceremonies throughout history. As North America continues to gravitate towards a secular society, becoming "ritually impoverished" (p. 1), our distrust in these institutions has affected our death rituals (Kayr et al., 2024). Roberson and colleagues (2018) highlighted that the purpose of a ritual is to support the ones left behind after a death. This sentiment was echoed in Felix's expanded personification whereby the impact of death extends to our pets who are *"waiting for us to return"* even after we have died.



The presence of rituals within healthcare settings has been highlighted by practicing recreation therapists in this study as an essential way to recognize the passing of a patient/resident and give space for them to grieve at work in the presence of and supported by others impacted by the death. Settings that do not offer opportunities for ritual and communal gathering don't adequately acknowledge death and the impact it has on people working within these spaces. By not acknowledging death, there are few, if any, opportunities provided to learn about what support staff working closely with the dying may need. This can lead to distrust in the workplace, burn out, and frustration. Jolene stated: *"... administration and other staff should be there to support you ... there's such a systematic disconnect in the process of death and dying that is frustrating."* Jolene went on to describe an experience working in a religious organization where she had a very different experience than working in a public healthcare setting: "*[The religious organization] had a nun who lived there and worked there every single day, and so this, the journey, it was acknowledged. It was smooth, it involved staff, had processes that were clear and guided by each person's individual spirituality*."

The findings in a qualitative study by Benbenishty et al. (2020) on ICU nursing death rituals aligned with the sentiments of the recreation therapists in this study regarding the importance of ritual. In their sample of 23 nursing staff, over half of their participants described performing individual rituals while their patient was dying and after they had passed. Some of the nursing rituals were there to provide structure, some provided local guidelines for handling the body, and others were used as expressions of mourning. Rituals benefitted nursing staff by helping them find meaning in death and sacredness in their care for the dying and dead.

Cultural consideration is essential when addressing ritual. Death rituals are honoured and performed worldwide but vary based on cultural and ethnic backgrounds. Oliver emphasised that

cultural perspectives would be an important element to learn about in education surrounding death and dying. He stated: *"I think there should be some degree of course content about death and dying, not like specific to one culture, but talked with in different worldviews, [from] an intercultural viewpoint."* Participants also discussed the importance of educating family and patients on their condition, finding out their wishes for end-of-life, and ensuring they were noted before death. This was a critical process described by Parker, noting that within her organization, wishes are noted upon admission and taken by the recreation therapy staff. Staff and families must know that these practices may only be well-received in some cultures.

For example, in Her-Xiong and Schrepfers' (2018) article on Hmong end-of-life beliefs and rituals, speaking about death with a terminally ill person was perceived as taboo; to speak about the dying person's death is believed to bring about a premature death. Conversations regarding wishes and preferences that value and respect the cultural experiences and preferences of patients and their families are crucial to ensure culturally relevant end-of-life processes. In the case of Hmong persons, their preference for how and when death and dying are talked about would be essential to support dignified care for the dying in that culture (He-Xiong & Schrepfer, 2018). Cultural humility is essential in healthcare spaces for acknowledging the diverse realities of end-of-life wishes and recognizing that practitioners, patients, and families may all come from differing positions and perspectives in end-of-life care.

The importance of language has been emphasized not only in the literature but through the participants' voices. Andy shared that the words *death*, *dying*, and *dead* need to be used in our language to provide clear insights to the healthcare team and patients' families. In her work in palliative care, Andy stated, *"We refer to somebody who is dying as 'dying' and not 'passing.' In hospice, especially the language around death is important. We try to use dying, died, dead,*

*death because we want to normalize it. Especially when I work with children one-to-one who have had a parent who died, I find it's important."* Andy went on to share that using the words death, dying, and dead are helpful to ensure that your message is *"direct and straightforward."* She went on to explain that using this language is essential, especially when working with children, to ensure they understand what has happened to their family members. Andy shared, *"Children take things so literally that if you use the word 'past' or 'loss,' there'd be like, 'Oh, but they're just lost, they're going to come back' [then you have to clarify] no, they're dead, they're not coming back."* Andy also stated that this is important in her work in hospice care and addressed in a course she took at Seneca College, highlighting the need to use direct language over passive language such as 'lost,' 'passed,' 'in-transition,' and so forth. Tercier's (2013) research emphasizes this point, believing that the use of these passive words reinforces societies discomfort surrounding death.

Within healthcare spaces, there should be space for organized rituals for staff, individual rituals, and culturally appropriate rituals for all involved, including the individual recreation therapists support, their families, and staff at end-of-life. Cultural humility is essential in healthcare spaces for acknowledging the diverse realities of end-of-life wishes. It is also important to recognize that practitioners, patients, and families may all come from differing positions and perspectives in end-of-life care. Ways to acknowledge and recognize these differences include educating practitioners to have conversations surrounding the end-of-life; creating systems that ensure a compassionate dying process that is meaningful to patients, families, and healthcare providers; and having opportunities to be present with their grief and be able to talk openly about death and dying.

**Building Nurturing Support Networks and Attending to Self-Care**

In addition to accessing rituals and ceremonies, recreation therapists also identified a number of additional important supports. Access to strong support networks is vital for ensuring recreation therapists have the resources they need to navigate their grief. The participants in this study highlighted the importance of these support systems, including connecting with experienced recreation therapists. Morgan described that most of the workplace processes in her setting were set by previous recreation team members. Morgan stated, *"It was a couple of rec therapists before me that developed [grief groups]."* A strong support system, including other recreation therapists, allows for the exchange of ideas and strategies to better meet clients' needs and improve therapeutic outcomes. Collaborating with peers also provides emotional support, reducing burnout and enhancing professional growth.

Participants talked about having other recreation therapists and/or other healthcare professionals to draw on, learn with and from, and the importance of supporting each other. Jolene, for example, described it like this: "*Connecting to other recreation professionals, to see how they're navigating it within their world, it's a little bit different for everybody, but nice to not be alone in the process*." Creating relationships with those you work with was seen as vital to preventing burnout and providing continuous support through grief. The research conversations themselves offered opportunities for participants to share experiences with others working in the field. Throughout conversations participants thanked me for creating spaces for these expressions. Parker expressed, *"I think what you're doing Erin is really special and important because it's really valuable to talk about these things …, because people don't usually do it [talk about death], even people in our settings we work around death all the time, or we've had death in our own lives and we keep quiet and carry on, but you got to talk about it."*

Gabriel and Herman's (2022) research focused on the prevention of combatting employee burnout by creating healthier workspaces. Their findings supported the positive impact of close relationships especially in times of crisis. Their research highlighted the importance of encouraging social support by management and organizations by 1) fostering high-quality relationships between management and employees, 2) providing opportunities for employees to converse and debrief their work, 3) reducing stressful and unnecessary interactions such as meetings, and 4) encouraging employees to use support networks outside of the workspace to reduce burnout.

Relational caring recognizes reciprocity in knowing that the relationship is a two-way, mutual engagement where individuals receiving care can also provide something to the relationship (Jonas-Simpson et al., 2021). In the experience of the recreation therapists, this looked like support from the clients themselves. Jolene shared that she finds *"connecting with the clients is meaningful to me, they're going through this or that, and your feelings are external from their journey, it's interesting to have their support."*

The recreation therapists in the study also talked about how they served as important members of the support systems for patients and their families. Morgan emphasized that building relationships with the patient's family is essential to providing support. Most of her job involved playing with the child who is dying and their siblings to create positive connection and memories. Within that, they are also support the parents of the child, Morgan shared that they have adopted the language of *"supporters"* in her setting so as not to be confused with the work that counsellors do in the setting: *"*[we are] *not counsellors, because I did not go to school for any of this, and it is just something I learned as the time goes on."*

Participants also discussed the importance of self-care, supporting the self. This looked different for different participants. Oliver, for instance, shared that he does not have expectations of his employer because grief is his own personal experience: *"It is a very personal thing to cope with your existential responsibility to find a way to cope; that's your learning path."* Despite not having expectations on his workplace, Oliver believed that he is better able to cope because of the rituals, acceptance, and recognition of death, and involvement of family members within his workplace. All of these provided space for Oliver to explore and develop coping strategies that were meaningful to him. As mentioned earlier, the use of personal rituals such as lighting candles in memory of a client who has died, or other means of reflecting on the life and death of a patient away from the workplace, helped coping with personal grief and loss.

**Recognizing and Valuing Recreation Therapy's Role in Influencing Caring Landscapes**

The culture that the workplace creates with the staff, the family members, and the patients impacts the ways that death is acknowledged, accepted, and processed. Oliver reflected that this connection extends to the family members and their role in shaping the workplace culture, for example, in the ways that they "*bring in the reverence and elegance and honour for someone passing away*." Jolene believed this may be a different experience if she worked in a less close-knit environment where "*everybody is like replaceable and dispensable, and you feel like that nihilistic worldview*." Some spaces where Jolene and Oliver have worked had a nun onsite to facilitate reflection and ceremony during death, which was highly supported in the culture. Jolene shared that the nun's support extended to the staff, stating, "*The nun who was great and she was an excellent guide for people and gave emotional support*."

The work environment policies, practices, and engagement were brought up by participants as being important to supporting the death and dying processes for all**.** In some

healthcare spaces, recreation therapists have been isolated from interdisciplinary teams and committees that make decisions about policies and practices surrounding end-of-life. The participants believed that the exclusion of recreation from these committees and meetings is due to a lack of education on the recreation therapist's role on the interdisciplinary team and in end-of-life processes. Eleni, for example, described the lack of education for interdisciplinary team members on the role of the recreation therapist, stating: *"Not only within end-of-life care, I think all care, I've had people ask me like, oh could you do this for this person? and I'm like yeah it's already being done, like already doing it."* Clark (2018) explored the importance of interprofessional education (IPE), explaining that it is not enough to teach about collaboration but also to have experiential learning opportunities that utilize realistic clinical situations to appreciate the contributions of each health profession in that context. Dupuis et al. (2019) also found that when diverse professionals have opportunities to learn and dialogue together, they are better able to gain a better understanding of the roles of other disciplines, gain empathy, and even find ways they can support each other in the workplace. Parker explained that now that she works in a managerial position, she has been enforcing recreation therapy participation on these committees so they can be more involved in decision-making on end-of-life processes. Parker stated, *"They have like palliative committees [and I have been] ensuring that everyone is a part of these committees, not just one discipline but everyone. I notice that Rec isn't always involved in decision-making."* Parker has also been empowering her recreation therapists to see the importance of their role in end-of-life processes; sentiments she offered her staff were: *"You guys are just as valid and essential."*

One critical role that recreation therapists provide in end-of-life processes is gaining, understanding, and sharing a comprehensive understanding of the patient's and family's end-of-

life wishes and goals of care. Parker described the implementation of end-of-life questioning for residents living in long-term care upon admission at their facility. Parker stated, *"we implement[ed] that [End-Of-Life (EOL) Questions Program] working alongside interdisciplinary team members to ensure that therapeutic rec is a part of their end-of-life care because it's extremely important, it's their values, their needs, their leisure, and their life."* By offering questions upon admission, the recreation therapist and interdisciplinary staff learn what is essential to the residents as they live within the long-term care setting. This is necessary for supporting the residents' end-of-life journey in long-term care in ways that are meaningful to them. This process also helps staff identify different ways they can be involved in the individual's care and involve the interdisciplinary team into goals of care conversations.

Parker expressed since implementing the EOL Questions Program, some recreation therapists have described some discomfort with this process. The questions within the EOL Questions Program ask the residents if they would like to be "free of pain" and if they want to "be in hospital or home." Parker stated that this process is *"intense, but I think it's important, and a lot of the residents appreciate it because their needs and their wishes are being met [at] end-of-life."* Most of the recreation therapists working there are in *"their first ever real job,*" and they are coming in without training on death and dying. Parker shared that these new young professionals are often surprised about this part of their job, with young recreation therapists stating, *"Woah, I have to ask this person how they want to die."* This particular setting was in the process of moving the facilitation of the EOL Questions Program to a social work role. The assignment of end-of-life care responsibilities primarily to Social Work can create tensions around the scope of practice for recreation therapists. Participants in the study expressed a desire for greater involvement in end-of-life care. However, rigid role divisions risk distancing

recreation therapy from death and dying, rather than allowing the profession to expand and meaningfully engage with this important area of practice. Rather than role division and further siloing professions this may present an opportunity for interprofessional collaboration and service education for new staff. However, recreation therapists play a key but different role in supporting the end-of-life wishes of the people in their care, and they need to be involved in these discussions. This highlights the urgent need for additional education on death and dying for recreation therapists, so they are better prepared and feel more confident being involved in and even facilitating these discussions.

A space where the policies and practices have better-supported end-of-life processes is within palliative and hospice care settings. Even within the small sample of nine, two participants working in palliative care discussed a level of comfort with death shared by their interdisciplinary team. This may be that those already comfortable with death may be more drawn to work within these settings. Or it could be a testament to the organization's effort to build supportive environments where death and dying are seen as a normal part of the lifecycle and rituals, ceremonies, and support are provided within these spaces for staff, families, and clients. Andy shared that in her experience, the *"two main things we do when somebody dies are a tea honouring ceremony and a debrief."* This experience directly contrasted with Layla's experience in the hospital, where the fast-paced environment did not provide time for rituals or debriefs. Layla emphasized that before you know it, "*they're [the patient who has died] gone, you take them down to the morgue, and you're already potentially looking at who's gonna come up and clean the bed*." She reflected on Andy's experience and stated: *"We don't debrief or anything that is beautiful. We do weekly rounds; we'll talk about whether someone has just passed, or I might ask the nursing staff how it went. Was the family able to make it? But there's*

*nothing set in place for us to debrief."* Layla's experience echoes my current experience working in a hospital. I often find out someone has passed by reviewing the patient list and seeing their name missing. Layla said it may be beneficial to have time to debrief, stating, *"It probably wouldn't be a bad thing to process."* Offering debriefing and acknowledgement within the workspace supports staff and moments of reflection. These moments provide space for vulnerability which enforces a relational caring lens and builds connections between staff (Dupuis et al., 2024, 2019; Jonas-Simpson et al., 2021).

## Preparing and Supporting Recreation Therapists for Death and Dying Processes through On-going Education

### *Embedding Death Education into the Recreation Therapy Curriculum*

In our discussions, recreation therapists talked about the lack of preparation in their education programs for working with people who are dying. Jolene contemplated why this is: *"there's a natural avoidance, whether people know that when creating the education, it's not an easy thing to navigate, it's the challenging thing to talk about or to teach, do we just not learn it because it's complicated [to teach]?"* Participants emphasized the need for death and dying to be an important part of recreation therapy education. Eleni reflected on her education experience, *"I feel like I took so many electives, because there weren't enough therapeutic recreation (TR) specific courses. There was a psychology of death and dying course which I didn't take, which I should have taken, but I feel like that course should have been required."* Parker agreed with Eleni in her emphasis on the need for TR-specific education, she stated, *"I think speaking about death in school, though it's a tough topic, I think it's good to prepare people and give TR a framework to talk about death and to have strategies and coping mechanism."* As reviewed in Chapter Three, death education is sparse across all interprofessional partitioners. Hernandez-

Fernandez and Meneses-Falcon (2022) noted that though healthcare workers interact with death at increased frequency compared to the general public, they are educated by the same processes. Jolene shared an emotional experience in learning that her educators could not offer support or advice surrounding experiencing death. She stated, "*When I was in college for my recreation therapy diploma, I remember going up to my teacher and asking her what if I have a hard time with death and her not having an answer.*" When the question was approached around the participant's experience in death education, Andy shared that "*there isn't, unfortunately*" a course on death and dying in their education. Layla described a similar experience: "*I don't think they talked about death at all, to be honest. I just knew that I was going to walk in at some point and find somebody dead somewhere. I was just thrown in.*" Many experienced similar experiences to me, being thrown into internships without ever being taught about approaching or engaging with death. The lack of education on death and dying described by the recreation therapists did not surprise me. As I pointed out in Chapter Three, I was able to find very few programs in Canada that offer death education, with no Canadian schools offering death education specific to recreation therapists. The lack of death education is not caused by a lack of learners desiring this education. In fact, Prentice and Narushima's (2022), study of 487 recreation professionals highlighted their need for specialized courses surrounding death and dying to assist in coping with loss.

Recreation therapists in this study identified the need for interdisciplinary education that not only highlights the importance of recreation therapy in these settings but also educates staff about the specific populations they serve, the deaths they may encounter, and the expectations of their different roles. The fear and taboo surrounding death may contribute to a lack of clarity among staff about how to support patients, leaving both staff and patients underserved.

Ultimately, our patients deserve better-educated staff and uncertainty should not compromise their care. Eleni emphasized that *"people who are passing away deserve better than everybody around them just doing what they think they're supposed to be doing."*

So, what should this education look like? There were differing views among participants on whether courses involving death should be offered as elective or compulsory. Reflecting the taboos and fears surrounding death and dying, R.G. worried about the consequences of making death education mandatory: "*I think making it a requirement would steer a lot of people potentially away from this field, where they might have a lot to add, but they're very uncomfortable with death and dying*." Felix reinforced this sentiment by thinking that death education could be "*an elective for students who intend on working with older adults or individuals who would, you know, populations where death is an experience that you're going to come across*." In another research conversation, Parker argued that death education should be offered earlier on in the degree program, stating: "*it would be good to start younger, speaking about death in school, and I know it's like a tough topic, but I think it's good to kind of prepare people for [it]*." Additionally, Morgan argued that death education needs to begin far before university, stating it needs to start "*right away and like education system with young kids. I've met with siblings, and their classmates don't believe them that their sibling has died*." Though participants debated whether death education should be mandatory, death remains a reality for any recreation therapy practitioner, including those working in the community. Regardless of how it is offered, the participants all agreed that there needs to be some offering of death education to enable the profession to be better prepared and grow.

How could death education be offered to future recreation therapists? Participants spoke about being educated by experienced individuals. They wanted to hear from those living in

caring environments, those who have had people pass away, and from those from various spiritual and cultural backgrounds. Morgan described how she envisioned death education could look: "*I think in terms of a course it should be hearing people speak, like Indigenous persons, [anyone who] is in the world of like grief, death, and dying, any people outside of the western world, mindfulness practices but not like individual mindfulness practices, like communal mindfulness practices. Learning from families, speaking about what helps them in their journeys, learning outside of textbook learning, having tangible goals, that's where you're gonna learn the most*."

In fact, many of the participants shared their desire to learn relationally through learning from those experiencing death and dying from different perspectives. Eleni shared that she wanted to learn from "*people who have had the experience. It's hard maybe to have people that are palliative themselves speaking but maybe people that have gone through it, maybe a family member or supporter of somebody who's passing away and hearing those perspectives*." Learning from those experiencing death from varying vantage points and from people of different cultural and spiritual spaces was critical for expanding recreation therapists' knowledge and preparing them to work with diverse clients. R.G described their vision: "*I think it would be cool if you could bring death perspectives [from] other communities, but also [having] religious leaders talk about kind of [those] perspectives [and] traditions*." Oliver emphasized that there should be "*course content about death and dying not like specific to one culture, incorporating different worldviews to understand from like an intercultural viewpoint*."

This education should also make it clear what different roles recreation therapists might take in dying processes. Recreation therapists also described their desire to have tangible skills related to death and dying addressed in their education, such as building toolboxes of programs

and facilitation techniques, developing strategies to cope with death, and how they might be more present. Parker shared that we need "*to have strategies and coping mechanisms because it happens in the field, no matter what population we work with, so I think it's important to advocate and give people the tools and resources to work with it*." Participants such as Jolene desired "*digestible information*" surrounding their role at the end-of-life, and the expectations organizations may have for them in the workplace.

Participants felt that education on death and dying needed to provide them with a toolbox of programs and approaches they could have at their fingertips when they start working with people who are dying. R.G. stated, "*I'd like to know interventions, programs, activities, and 1:1 sessions for people becoming palliative*." The only article that I could find on recreation therapy program-specific recommendations for death awareness was by Stensrud (1993) who attempted to fill this gap with the 'timeline' program. The research, however, is now 30 years old with no further research on the implications or evaluation of death education being embedded into leisure education through this or any other program. Recreation therapists like Morgan emphasized how a lot of their work is in the moment, *"they only have a few seconds to react."* Having strategies, they can remember and easily draw on from the toolbox was seen as essential to better supporting the death and dying process. Morgan described the education most helpful for her in building a toolbox, "*the main tools that I have taken to build my toolbox are foundational things like before you walk into a room like 'please remember to take a deep breath' when someone says something that overwhelms you; you do not have to respond right away, you just have to stay calm*."

Learning relational principles and strategies for translating relational principles in practice was also an important component of the toolbox. For example, recreation therapists

desired to be truly present with the people they care for and needed to learn on their own how to best do that. Morgan, for example, described that presence is the most powerful tool in her work in children's hospice. Her reminder is that "*you have three seconds to take a breath before you respond, understand your body language, and remember to think about the depths of your role."*

Most importantly, they desired transparency from educators on the real-life interaction between recreation therapists and the dying. They saw this education coming from real-life experiences, as described above, focusing on an arts and humanities lens which moves away from the biomedical model. Felix described: *"we really need to have more of a solid foundation in the arts and humanities, at least some, and philosophy because too much of the focus [is] on the positivist scientific view."* Durlak and Reisenberg's (1991) study explored in Chapter Three concluded that many death education teaching methods lack connection to theory and evaluation of the students' experiences. Durlak's subsequent (1994) review reflected the descriptions of experiential learning that the participants in this study desired. Durlak (1994) also emphasized the importance of experiential opportunities for students to engage with death and dying, through workshops, role-playing, death awareness education, and grief activities to confront discomfort.

***Having Access to On-Going Education in the Workplace***

Participants also discussed the importance of having workplace-specific education provided to all staff. They outlined the importance of incorporating interdisciplinary education within the workplace to outline the potential of the recreation therapist's role at the end-of-life. Participants also discussed how being oriented to the different types of deaths they might encounter in their jobs would be helpful. Oliver stated, *"I think that the agency you work for should ensure you are trained properly."* In my experience, I have never been trained in my workplace on procedures surrounding death and dying. The only element of death that is

addressed is the 'Code Blue' button in patient rooms. This unit covers when to push the button and the series of operations that follow but no elaboration about the processes or avenues to follow in the case of death is provided. Jolene reflected a similar experience: *"[there is] such a disconnect, not a lot of education provided, and by that, I mean none, there was no education provided."* She spoke more about the lack of education not being because of lack of interest, with people *"inquiring about people wanting more education."* There is belief that the employers may be holding back because of the *"question of the quality of education"* or the avoidance to teach because it is a *"touchy subject to teach but is inevitable [that the] people [being supported] are going to die."* Employers not offering education puts the pressure on the individual to be educated and seek external learning opportunities. Andy had educational opportunities through her position in hospice. The company provides education for staff and the community. Andy stated: *"we do a lot of death education for the community. We have our education coordinator, who works at [two local] hospices. We have a core one, core concepts, education, palliative education. And we offer that to the whole community of [the] Region. A lot of our volunteers who come in to volunteer will have to take that course before they become a volunteer. It's [an] introduction to palliative care, what is hospice, appropriate language to use, how to work with people who are dying."* This course was important for ensuring all in the setting were prepared to navigate their different roles at end-of-life. Training at work also needs to consider the population you are working with. For example, Oliver shared his experience working in mental health support and the education needed varied from what he needed to work effectively in long-term care: *"when working with young people who are potentially suicidal, we had to do ASIST training for suicides."* Within mental health support, these trainings are essential for the protection of the individual being supported and the staff responding.

**Valuing Death and Dying in Recreation Therapy Regulations**

A lot of skills recreation therapists need to provide care to the dying are not coming from their education or a regulated body; recreation therapists are gaining this knowledge and many of these skills outside of school. Eleni stated, *"A lot of us just figure it out and just do it. But it's not because somebody told me, I taught me how to work with somebody who's palliative, and I feel like those people deserve better."* Eleni believed this is caused by the profession's lack of regulation, especially around death and dying, which causes disadvantages to the patients we care for. She emphasized the need for *"a framework of the end-of-life best practices specific to TR."* This could include care models and codes of ethics specific to death and dying processes. However, Eleni critiqued the frameworks currently in palliative care, stating they're *"very medical-focused frameworks*." What is needed are frameworks that focus on relational-centred care, programming, and skills specific to recreation therapists at end-of-life. Eleni believed, *"One struggle within TR is we're not regulated, so there is no one way of practicing."* Being regulated and having protocol can be beneficial in varying care environments, it could give recreation therapists a foundation for conversational and relational skills with programming grounded in a relational caring model. Regulation could allow ethical frameworks to be in place specifically related to death and dying to reduce healthcare providers' risk of burnout and provide resources to guide decision-making when supporting end-of-life processes. Recreation therapy is not considered a regulated health profession with a licence to practice like the other therapies present in hospitals. In part because of the infancy of the field of work and the argument that recreation is not therapy but is relational. Arai, Berbary and Dupuis (2015) called for conversation to re-imagine therapeutic recreation by emphasizing recreation (leisure) relationships. Recreation (leisure) relationships focus on the "non-instrumental interactions" such

as intrinsic motivation, enjoyment and subjective outcomes rather than "repairing the person" (Mobily & Dieser, 2018, p. 2). I argue that the problem is not in the accreditation of therapeutic recreation but in the education within the field itself. Accreditation and regulation historically have steered the field closer to the biomedical model with little focus on the changes needed within the environments where recreation therapists work and where individuals are cared for. This study highlights that, in fact, the "regulation" that is needed is within the education system where recreation therapists receive their training. Professionals want to learn about relational caring, they want to have toolboxes to approach difficult and vulnerable conversations, they want to learn about death and how to open up conversations about it, and they want to learn strategies for coping with grief. Grounding codes of ethics and core competencies communicated and advocated for and by recreation therapy/therapeutic recreation professional organizations in relational caring philosophy and principles are also important for supporting recreation therapists in navigating death and dying after they finish their formal education.

Recreation therapists in this study identified the gaps in the environment and supports they need to work effectively and relationally in their roles. Dying does not only need to be scary; it can also be beautiful. As recreation therapy/therapeutic recreation continues to grow. I believe recreation professionals have the opportunity to create space for recreation therapy's involvement in creating a dying experience that is beautiful, full of life, and centered around meaningful relationships.

## Chapter Eight: The Hopeful Promise

This study has illuminated the complex relationship that recreation therapists have with death, dying, and grief. While their exposure to death is high, their understanding of it is far from simple. Their perspectives on death are shaped by dualities, entanglements, and tensions between the personal and the professional, and the challenge of working in medicalized settings where the physical body is often prioritized. In these settings, death is often approached as a medical event requiring detachment and technical care. Yet, recreation therapists work hard to counter this approach, instead embracing relational caring processes that centre connection, compassion, and creativity. Even without formal death education, recreation therapists are able to leverage their unique position within healthcare settings to engage with death, dying, and grief in meaningful and humanizing ways.

The participants in this study spoke candidly about the types of support they feel would prepare them to face death in their roles and the ways they envision death education being integrated into their training. They expressed a desire for more robust death education that could have supported them before they first encountered death in their professional lives. Though exposure to death can increase the risk of burnout, they also highlighted that there are numerous ways to engage with death meaningfully, in ways that buffer the negative narratives that often surround dying. Their reflections demonstrated the intricate balance between the sorrow of death and the comfort of knowing that it is an inevitable and unifying experience for all living beings. The sentiment from Olga, my instructor in becoming a certified death doula, comes full circle, *"We only have two things in common in this life: we are all born, and we all die"*; what a powerful and unifying truth.

This study's guiding question "What is it like to experience death?" has yielded an answer that, though not definitive, offers hope: the experience of death has the potential to be deeply human, even beautiful. It can be full of ritual, presence, and connection, especially within the context of medical institutions. While we can never fully know what it is like to experience death ourselves, as recreation therapists, we have the ability to change the way death is experienced within hospitals and other healthcare settings in the future.

**Significance of the Study**

This research is significant for its pioneering exploration of the experiences of recreation therapists in relation to death and dying, filling an important gap in the literature on leisure, death, and dying. This research has important conceptual/theoretical, methodological, and practical implications. By integrating two conceptual perspectives, phenomenology and personification theories, and employing art-based methods, the study sought to explore how professionals can better understand difficult, often ineffable experiences. This is one of the first studies that I know of that has integrated phenomenology with expanded understandings of personification to explore death and dying experiences. Building on the research of Kastenbaum and Ainsberg (1972), this research contributes to much-needed theorizing around experiences of death for recreation therapists that could be built upon in future research with other healthcare practitioners. The findings from this study demonstrate the complexities embedded in understandings and experiences of death and dying for therapeutic recreation professionals. It begins to articulate a framework necessary for supporting relational end-of-life processes for individuals receiving care, families, and the staff who work with them, including recreation therapists. Most importantly, it highlights the relational nature of end-of-life processes in the

context of recreation therapy and the relational capacities needed to support compassionate end-of-life processes that continue to bring beauty and life to the last days of one's life.

Methodologically, using art-based methodologies to reflect the expanded personifications of death and death experiences created a safe(r) and accessible methodology and methodological process that other researchers might utilize in future explorations of challenging, emotionally charged, and/or taboo topics. Having the opportunity to reflect individually as they worked on their expanded personifications was an important first step in the process and prepared the participants for the discussions that came in the research conversations. The research conversations provided an open space where recreation therapists could discuss a topic, they rarely have the opportunity to talk about, providing them with the space to hear and learn from others in similar situations. This research provides a methodological approach, grounded in phenomenology and expanded notions of personification, that could be used to investigate the varying experiences of death for other various healthcare workers, and may also be useful when working with people experiencing death and dying. Outside of healthcare, this methodological approach could be used to explore experiences of death, which explore in a variety of geographical, cultural, and religious contexts to gain a more robust understanding of the experience of death.

The art guide could also be used in future research connecting to the lifeworld existentials in the experience of death and dying. The art guide gives flexibility to the research and to the participants to explore the aspects of death that are most important to their experience. My recommendation to any future researchers using the guide is to allow participants time to explore their artwork. Having the opportunity to create art prior to the research conversations was brought up by participants as offering ample time to explore the guide at a time and headspace

that worked for them. Some participants even created their artwork alongside their children like Layla and Morgan (who created hers alongside one of the children she works with), while others chose to explore the project independently. If researchers use the art guide as an in-person workshop or information gathering session, it may be helpful to provide collage materials for participants to reference and utilize.

Finally, my research will help create a platform for death education advocacy within recreation therapy/therapeutic recreation by highlighting the experiences of recreation therapists. It also has important practical implications by identifying specific ways to better support recreation therapists with their experiences of death and grief. The recreation therapists' candid sharing of personal experiences and insights revealed not only what could have better prepared them for their roles but also what can be done to better support future practitioners in their roles. Ultimately, we need to eliminate the fear and stigma surrounding death and dying. If death was seen as a natural part of life, the experiences of recreation therapists and those they serve might be very different. Eliminating entrenched stigma of death that also serves the death industry will take much time and hard work. In the meantime, the insights shared by the recreation therapists in this study provide important recommendations for better supporting experiences of death and dying in practice. Below are key individual, organizational, and educational recommendations based on these findings:

**Individual Recommendations**

- *Commit to Self-care**:*** Develop consistent self-care routines that support mental, emotional, and physical health in the face of high exposure to death.
- *Develop Personal Rituals*: Encourage the creation of personal rituals that can help process and cope with grief.
- *Build Caring Support Networks*: Build a network of colleagues, friends, and mentors who can offer emotional support.
- *Create and contribute to a Community of Practice*: Create spaces where professionals can share experiences, challenges, and coping strategies related to death and dying, and contribute to these forums.

- *Don't be afraid of death and dying*: Death and dying are natural parts of life. Lived experiences of death and dying can be important opportunities for learning about death and how best to support all during the dying process and after death.

### Organizational Recommendations

- *Create Rituals and Acknowledgment of Death and Dying*: Implement organizational rituals and ceremonies to acknowledge the deaths of patients and others in the workplace and the emotional toll it takes on everyone within the setting. Provide opportunities to talk openly about death and dying (e.g., death cafes).
- *Provide Opportunities for Population-Specific Death Education***:** Offer targeted death education that is relevant to specific populations (e.g., children, elderly, patients with terminal conditions) within the workplace and ensure this education is regularly updated.
- *Orient New Staff through Onboarding and Training*: Integrate death education into the onboarding and orientation processes for new recreation therapists and other healthcare professionals.
- *Provide Opportunities for Interprofessional Education*: Provide education on interprofessional roles in death care, emphasizing collaboration across disciplines, and provide opportunities for different disciplines to learn and share together.
- *Embed Accessible Grief Support for All***:** Ensure that grief support, including counselling and peer support options (e.g., debriefing with others), is easily accessible to staff, patients/clients, and family members.
- *Include Recreation Professionals in Interdisciplinary Decision-Making/Committees*: Recreation staff play a critical role in supporting patients/clients and their families throughout the dying process and after death and must be included as valued members on interdisciplinary committees and planning.
- *Ensure Access to Management and Organizational Encouraging Social Support:* Employees need opportunities to foster high-quality relationships between co-workers and management, and employees need opportunities to converse, debrief, and have access to encouraging social support networks outside of work.

### Educational Recommendations

Education will ensure that recreation therapists are better prepared to cope with death and dying in their practices and could serve as a means to expand the scope of practice to include end-of-life.

- *Embed Death Education in the Curriculum***:** Provide informed and comprehensive death education with recreation therapy/therapeutic recreation curricula that addresses both theoretical knowledge and practical skills.
- *Ground Education in Relational Theories and Processes*: Educate future professionals on the importance of relational processes in their practice, especially when dealing with patients and their families at the end-of-life.
- *Support the Development of Tangible, Practical Skills*: Teach tangible skills that professionals can immediately apply in their work, especially when engaging with patients and families during end-of-life care.

- *Educate About Death and Dying Modalities and Programs*: Create and educate about programming designed specifically for people and families experiencing dying relevant to diverse settings.
- *Prioritize Experience-Based Education*: Include experiential learning that draws from the lived experiences of the dying, their families, and healthcare professionals.
- *Create Learning Opportunities that Inspire Culture Change Agents***:** Design death education specifically for recreation therapists, considering their unique role and skills in end-of-life care, including their roles in supporting others in the death and dying process and in being change agents to better support compassionate, relational end-of-life experiences in their workplaces.
- *Grounded in Cultural Humility:* Provide education that recognizes the cultural variety in engaging, experiencing, embracing and honouring death and dying. Cultural humility embedded in education challenges colonial thinking to address institutional inequities within death care.

**Limitations and Future Research**

While this research contributes valuable insights into the experiences and role of recreation therapists in the context of death and dying, several limitations exist. The sample primarily consisted of participants between the ages of 26 and 40 and did not include those who have been in the field for 20+ years. Future research should explore the experiences of more seasoned practitioners to gain a deeper understanding of how perspectives on death and experiences of death and dying evolve over time. The absence of practitioners with 20+ years of experience may be limited as professionals transition to managerial positions within organizations or transition careers. Future studies may need to change the inclusion criteria to include those who have transitioned to higher-level roles.

Additionally, the study did not include participants from all sectors of recreation therapy, with the community sector being notably absent. Further research is needed to understand how recreation therapists working outside of long-term care, hospital, and hospice settings experience death and dying. The sample was also not culturally diverse, and future studies should focus on the experiences of Black, Indigenous, and People of Colour (BIPOC) professionals in death-related work. Given that immigrant and BIPOC populations represent a significant portion of the

healthcare workforce, including nurse aides, orderlies, and patient service associates (78.7% as of 2016, Government of Canada, 2020), research is needed on how the immigrant experience shapes death work.

Future research is needed that explores the impacts of different types of current and new supports and education opportunities targeted at recreation therapists in preparing them for and supporting them in their jobs. There is an opportunity for evaluation research using art-based expanded personifications. For example, this could look at participants' personifications of death prior to receiving death education and personifications of death following a semester of death education. This research could also investigate the impact of death education on fears, understandings, and experiences of death, and confidence in working with people dying. Finally, this study focused on the experiences of recreation therapists, but as the participants highlighted so strongly in this study, death and dying are relational processes. Future research should examine the experiences of death and dying for patients/clients, family members, recreation therapists, and potentially other interdisciplinary team members within the same study.

## Death and I: A Personal Reflection

My relationship to death has changed throughout this process. Unfortunately, death and I met several times during the writing of my thesis. I met the premature death of a beloved childhood friend who took their own life. I lost a writing buddy who slept long hours in the basket beside my desk. I shook hands with death as I held the hands of patients as they "went home." Each experience brought a different perspective of who death is for me. The participants paint the picture of death well, showing that each person has a relationship to death that is unique to them. The most important essence of death that came out of this research is that death is not to be feared but needs to be supported. Death is not the terrifying part; it is the absence of relationships at the end-of-life and the feeling that there could have been more done but not having the foundation to do it. In meeting death over the two and a half years of this thesis, I approached it differently than my experiences before. I opened up about my grief, I brought people in who opened their arms and hearts to hearing my stories. I asked for time when I needed it, stepping away from writing when I needed to process my own experiences. Becoming more familiar with death did not change the impact of grief in my life but gave me tools to speak about the ways I felt without the fear of not knowing what to say.

As I finish up this project, I continue to reflect on the findings and on the discussions, we had at the oral defence of this thesis, I have perhaps more questions than answers. I continue to think about how my understandings of phenomenology and the phenomenology of death continue to evolve, partly shaped by my own experiences with death and dying. I see opportunities to bring in existential theory to further inform my understandings of the phenomenology of death. As Arai et al. (2015) stated: "…existential exploration … enables us to place language around the mystery in life [and death] and to explore what it means to be living as

we sit with existential anxiety, sadness, and guilt that arise as we negotiate life's experiences", challenges, and life transitions (p. 306). I look forward to exploring this more as I continue to advocate for more discussions and work on death and dying.

Further, the art-based methods gave me a "voice" without words. Art has always given my grief the space it needed to express the deep-seated feelings of loss. The poems I've written for the ones I lost are a capsule to return to, a reminder of the impact they left on my life and a legacy to share with others. I wanted to highlight in this final piece all of the images that death takes on, all the shapes and impacts it makes in our lives. I wanted to bring in clear reverence from the expanded personifications of the participants while expressing who death has become to me. Death to me, now more than ever, is the experience of the lifeworlds, the relation to lived time, space, body, and relations. Especially lived relation, as it is in our relationships that death is given beauty, life, and impact. It is relational in the ways we experience death, the gatherings after death, the stories we tell others who never met people we have lost, it is the legacies we carry with us into future experiences. Death for me is shaped by all the people I have lost in my life, who have taught me to grieve, to live, to listen, to be kind, to be present. Each relationship and experience offering a new lesson. To me, death is an entanglement of our collective experience, the intertwined web of the self, our relations, and the unknown. The final page of this thesis honours poetry as an outlet for my grief; I wrote a poem to highlight my images of death now that this project is completed.

# DEATH IS...

DEATH IS THE TEAR THAT FALLS
BECAUSE THE BOND EXISTED,
THE WAVE THAT CRASHES,
BEAUTIFUL, FIERCE,INTENSE.

DEATH IS THE GROUND BENEATH,
CRUNCHING UNDERFOOT,
LEAVING ROOM FOR WHAT COMES NEXT.
IT IS A FEELING WITHOUT WORDS,
SHARED BETWEEN THE LIVING,
THE MOURNERS AT THE GRAVE,
THE CAT ON THE CHAIR,UNSEEN BUT KNOWN.

DEATH IS THE RAVEN
STEALING LIGHT FROM THE SKY,
THE MIRROR REFLECTING BACK
OUR FRAGILE SELVES.
IT IS THE PAIN THAT DOESN'T NEED
TO BE EXPLAINED,
THE VULNERABILITY WE CANNOT ESCAPE.

DEATH IS THE UNKNOWN,
THE PERIPHERY,
A RETURN TO DUST.
IT IS THE HOSPITAL WALLS PAINTED WHITE,
THE FEAR OF BEING FORGOTTEN.

DEATH IS THE RED CHAIR,
STANDING STARKLY
AGAINST THE BLACK AND WHITE.
IT IS THE LACK OF COLOR,
WHETHER BLACK OR WHITE,
AND THE FEAR OF LOSING
THE LOVES WE HAVE.

DEATH IS THE RISK OF LIFE—
FULL OF LIFE,
NOT OLD OR YOUNG,
BUT A UNIVERSAL AGE,
SHARED BY EVEN THOSE
IT SHOULDN'T TOUCH.

DEATH KNOWS NO BOUNDS.
IT IS THE HEART FULL OF LOVE
FOR WHAT WE HAVE,
WHAT WE'VE LOST,
THE LIFE WE CHOOSE
AND THE LIFE WE LEAVE BEHIND.

DEATH IS THE BUTTERFLY,
THE BIRD,
THE SYMBOL THAT REMINDS YOU
OF WHAT COULD BE.
IT IS THE PERIPHERY,
EXPERIENCED THROUGH OTHERS,
UNTIL IT IS OUR TIME.

DEATH IS THE MUSHROOM,
STRIVING ON WHAT IS LEFT BEHIND,
REACHING FROM THE DECAY,
LIFE BORN FROM DEATH.
DEATH BEGS THE QUESTIONS:
WHAT AM I DOING HERE?
WHAT AM I MEANT TO DO?
WHAT DO I WANT TO LEAVE BEHIND?

DEATH IS THE HAND
REACHING OUT TO YOU,
A FRIEND,
PART OF YOU
FROM THE BEGINNING.
IT IS INFINITY,
THE CIRCLE OF LIFE,
NEVER STOPPING,
RELENTLESS AND CONSTANT.

DEATH IS SCARY
WHEN NOT FILLED WITH RELATION,
DIGNITY, AND LOVE.
IT IS A CALL TO HOME.

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## Appendix A

## Participant Descriptions

| Pseudonym | Personhood |
|---|---|
| Morgan | Morgan is a 27-year-old professional with over seven years of experience in Therapeutic Recreation. Morgan started working at a Children's hospital on their CTRS placement while completing her TR degree. After their placement, they volunteered for a year before moving into casual and full-time positions. They have been familiar with the medical field since their diagnosis of Type 1 Diabetes when they were nine years old. Morgan has been an athlete their entire life, competing in soccer, rugby, gymnastics, and skiing. Their leisure consists of 'flow-based' outdoor activities, hiking and skiing. Their leisure directly implicated their work in children's hospice, where most activities center on flow and legacy work. Being a recreation therapist means being a friend, an escape from medicalization, providing comfort in the most uncomfortable times, time and capacity to connect with family, clients and professionals. Though it was not their original plan to work in pediatrics, Morgan has only ever worked in children's health and doesn't plan on leaving anytime soon. |
| Eleni | Participant is a 30-year-old Greek woman living in the Greater Toronto Area. She graduated from the University of Waterloo's Therapeutic Recreation program; she has been working in the field for over seven years. Participant has worked primarily with older adults, currently working in a reactivation care center for the past 6 years. Participant loves where they work as they feel they are providing care to patients the system has "given up on". Participant is non-religious and instead identifies as spiritual. They love being in nature and participating in activities centered around cooking and baking. Participant highlighted that TR is about providing dignity, response and treating people as people, by looking at all of domains of well-being. They believe that TR provides an opportunity for personal connections, building personal relationships and bringing light to people in need. |
| Parker | Parker is a 28-year-old eastern European, white woman and self-identified country girl. Parker enjoys playing sports, including biking, skiing and creative activities such as music and art. Parker graduated from the University of Waterloo's Therapeutic Recreation program. Parker identifies as spiritual, does not practice a specific religion, believes energy cannot be created or destroyed and is curious about the unknown. Parker has worked in various settings including mental health, geriatrics and youth programming, now in a long-term care setting. What TR means to Parker is to meet people where they are at, creating bonds and relationships and creating experiences. |

| | |
|---|---|
| R.G. | R.G. identifies as a white-Mennonite woman in their early twenties. They recently graduated from the University of Waterloo's Therapeutic Recreation program. R.G. highlighted that their learning disability has profoundly affected their experiences in the world, especially in early life. R.G. has struggled to find their leisure identity outside of work, currently participating in sports and independent activities to gather as much experience as possible. They have experience working with various demographics, including older adults, children with autism and adults with intellectual disabilities. They believe these experiences help them to understand the world around them and make them well-rounded. R.G. has been working in TR for 1 year and currently works with children's oncology. R.G. is still figuring out what TR means to them, highlighting their current definition that it is the practice of providing activities to achieve something... and that something can just be fun. |
| Felix | Felix is a 26-year-old Finnish Canadian homosexual man, born in Ontario and currently living in the Maritimes. Felix grew up Jehovah's Witness; however, is no longer practicing. Felix is heavily involved in the arts, participating in dance and playing accordion and piano. Felix has worked in TR for 2 years, working with older adults living with dementia in a long-term care home. Recreation Therapy to them means taking a holistic approach to well-being by considering all domains of well-being, focusing on recreation and leisure solely without expectation for therapeutic goals, developing healthy leisure, giving life meaning and providing a high quality of life. Felix follows a social model in their practice, believing that recreation and leisure are worth it on their own. |
| Oliver | Oliver is a 27-year-old Finnish Canadian gay- man, currently residing in St. Johns, Newfoundland, after growing up in the large Finnish community in Sudbury. Oliver is introverted and enjoys hobbies focused on culture and arts, identifying himself as an artist. Oliver is spiritual and religious, though they do not follow a specific religious group. Oliver has been working as a recreation therapist for two years following a master's thesis focused on using logotherapy in therapeutic recreation. Recreation Therapy to Oliver means providing activities that are meaningful to everyone. Focusing on meaning as providing creative value, experiential value or attitudinal value to participants. Oliver values developing good relationships with residents and providing opportunities for autonomy in long-term care settings. |
| Jolene | Jolene is a 30-year-old, seniors support business owner in rural Alberta. Jolene identifies as a white woman, with no cultural connections, she is non-religious but connects spiritually with the process of death and dying. She is married with no human children, only dogs. She is close to her family and spends most of her leisure time trying new things, kayaking, socializing, camping and pottery. She has been working in recreation therapy for 10 years working mainly with older adults. She has a master's degree in health sciences. Jolene believes recreation therapy means to provide connection through leisure and play, it means giving beyond activities of daily living and not just filling the time but making time fulfilling. |

| | |
|---|---|
| Layla | Layla is a 40-year-old, mom of 3 human children, and four fur babies, and lives in her hometown in Nova Scotia. Her leisure consists of community involvement such as volunteering to coach, referee and volunteer for the local soccer league. Layla works on a rehabilitation unit which includes stroke, mobility, amputees, palliative at home, it is a medical floor for people to wait for their next placement, such as long-term care. Layla graduate from Dalhousie's recreation therapy program in 2006 and started working the following year in 2007. For Layla recreation therapy means quality of life, providing chances to make memories and build relationships, most importantly she believes that recreation therapy is the missing piece in the healthcare system to providing authentic connection. |
| Andy | Andy is a kind, compassion and hardworking person, who was adopted from China was she was a baby and resides in Newmarket, Ontario. She is non-religious and does not identify with a specific culture. Andy participants in many active leisure such as basketball and hockey and loves listening to music in her leisure time. Andy has 4 years' experience working in recreation therapy specifically in hospice care after graduating from Dalhousie's recreation therapy program. To Andy, recreation therapy means helping people because we love to do it, trying to make peoples last days as meaningful as possible, and full of love. Andy believes everyone has the right to die with dignity. |

## Appendix B

## Email Script

Subject Line: Personifications and Experiences of Death Among Recreation Therapists
Subhead: Participants Needed
Body: My name is Erin Delaney, and I am a master's student working under the supervisions of Dr. Sherry Dupuis in the in the Recreation and Leisure Studies Department at the University of Waterloo. I am contacting you because you recently provided your name and contact details through the ***[insert text explaining where contact details were received]*** and indicated you would be interested in being contacted about my study 'Personifications and Experiences of Death Among Recreation Therapists' needing participants. The reason that I am contacting you is that I am conducting research for my thesis aiming to understand the experiences of death from a recreation therapist's perspective. I noticed a need for more information on this topic and for death education after working in recreation therapy for three years during the pandemic. I hope to use this research to identify how to better support recreation therapists and the topics essential to explore in death education in recreation therapy/therapeutic recreation program.
I am looking for recreation therapists to participant in my study. To be eligible to participate, you must:

- Be over the age of 18
- Currently work in Canada in recreation therapy/therapeutic recreation as a recreation therapist, recreationist, activity aide or other recreation role in a healthcare or community care setting (e.g., long-term care home, hospital, rehabilitation facility, hospice, retirement home, community home support program, etc.).
- Have obtained a degree or diploma in recreation therapy/ therapeutic recreation.
- Be open speaking about death and dying.

Participation in this research is completely voluntary. If you agree to participate in this project, you will be asked to participate in two phases of the project. In Phase 1, you will be invited to independently create an arts-based representation of death from your perspective. I will provide you with detailed instructions and guided questions to support you with this task. In Phase 2, you will participate in a 90–100-minute small group research conversation with three to four other participants conducted on-line using TEAMS or Zoom. In this session we will share our representations of death and use those as a starting point to explore your experiences of death.

This study has received ethics clearance from a University of Waterloo Research Ethics Board (ORE#46064).If you fit the study criteria, are interested in participating, and/or have questions about the study, please contact me by emailing this address: epdelane@uwaterloo.ca. Thank you for helping to improve the experience of death and dying for recreation therapists.

Best,
Erin Delaney
University of Waterloo, Recreation and Leisure Studies

**Appendix C**

**Recruitment Flyer**

XIII

ARE YOU A RECREATION THERAPIST?

I am looking for people to participate in a research study to understand Recreation Therapist's experiences of Death.



Participation includes:

1. Independently create an artistic representation/ personification of death using a question guide.
2. Discuss in a research conversation group of 3-4 practitioners how death is experienced by recreation therapists and what death education could look like.

For questions about the study, CONTACT:

Erin Delaney, epdelane@uwaterloo.ca

DEATH

## Appendix D

## Letter of Information

**Project Title:** "Personifications and Experiences of Death Among Recreation Therapists"

**Principal Investigator:** Erin Delaney, Department of Recreation and Leisure Studies, University of Waterloo, epdelane@uwaterloo.ca

**Supervisor:** Dr. Sherry L. Dupuis, Department of Recreation and Leisure Studies, University of Waterloo, sldupuis@uwaterloo.ca

### Introduction

You are being asked to participate in a two-part research study exploring how recreation therapists experience death. This letter explains the study, participation, possible risks and benefits, and your rights as a research participant. Please read the details of your involvement in the study before engaging. You should print/save a copy for your records. If you need help understanding something in the letter, please reach out to me, the primary investigator, Erin Delaney, before consenting to participate.

### What is the purpose of this project?

Over the years, recreation therapists have played a key role on allied healthcare teams in diverse settings including long-term care, hospital, rehabilitation, home care, and other community care settings. Within many of these settings, death is present, and yet few studies have explored the experiences of death and dying for recreation therapists. The limited research that does exist strongly suggests the need for death education for recreation therapists, including a call for support in complex grieving and with end-of-life care. This project aims to create a foundation to understand the death experiences from the recreation therapist's perspective. More specifically, my research aims to address the following research objectives:

- To create a safe space for recreation therapists to talk openly about their understandings and experiences of death.
- To create and explore personifications of death held by recreation therapists and what they might illuminate about experiences of death; and
- To use this information to make recommendations to inform death education in therapeutic recreation programs.

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### Who can participate?

I am looking to recruit up to eight recreation therapists to participate in this study. To participate, you must be 18 years or older, currently work in Canada as a recreation therapist/therapeutic recreationist in a healthcare or community care setting (e.g., long-term care home, hospital,

rehabilitation facility, hospice care, retirement home, community home support program, etc.). You must have obtained a degree or diploma in recreation therapy or therapeutic recreation and be open to speaking about death and dying.

**What will your participation involve?**

If you agree to participate in the project, you will be asked to participate in two phases of the project. Only those participants who consent to participating in both phases will be included. Phase 1 of the project involves participants independently (on their own) creating an arts-based representation (i.e., a personification) of what death looks like and means to them. Participants can use any medium they feel comfortable with, such as collage, painting or using on-line platforms such as Canvas. I will provide detailed instructions and prompts to assist participants with this phase of the project. Participants will have three-weeks to create their representation of death.

In Phase 2 of the project, you will be asked to participate in a small group research conversation facilitated by me with three to four other participants. Recognizing the busy schedules of recreation therapists/therapeutic recreationists, the research conversations will be conducted online using TEAMS or the Zoom, whichever is most comfortable and accessible for the participants.

Research conversations will last no more than 90-100 minutes and will be audio- and video-recorded onto my computer using TEAMS or Zooms technology. Questions explored in the research conversations include: A) What does your personification of death tell us about your meanings and/or experiences of death? B) Tell me about the elements of your personifications, if any, that represent your experiences of death in recreation therapy. C) Tell me about the experience of making your personification. D) Tell me about your experience with patients at the end-of-life. E) Tell me how your role impacts your relationship with death.

Before conducting research conversations, participants will also be asked to provide some information about themselves, which will be collected over a short (15-minute) telephone conversation with me. You will be asked to describe yourself, aspects of your identity you feel are essential to your experience in the world (e.g., age, gender, culture/ethnicity, etc.) and your experiences as a recreation therapist, specifically how long have you been a recreation therapist, where you have worked as a recreation therapist, and where you currently work, and what it means to you to be a recreation therapist.

This initial conversation will also be used to provide instructions on Phase 1 of the project and answer any of your questions about the study.

**What are the risks associated with participation?**

In this study, it is essential to note that participating in research conversations about death and dying may make you feel discomfort or elicit an emotional response. The topic of death is difficult, especially for those who have been diagnosed with depression. You should consider not participating in the study if you feel the topic may be too upsetting and emotional for you. If you

do choose to participate, you may decline to answer any questions that you prefer not to answer. You can leave the research conversation at any time by hitting the "End Meeting" or "Leave Meeting" button on Zoom or TEAMS, or letting the researcher know that you would prefer to leave the session. I will reach out to you after the research conversation and will provide you with a list of resources should you require additional support.

This study will be using either TEAMS or Zoom to facilitate the research conversations. When you start the session, you will be asked to enter a name. Please use what you are most comfortable with sharing/using online. Both TEAMS and Zoom have implemented technical, administrative, and physical safeguards to protect the information shared during research conversations from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. However, no Internet transmission is ever fully secure or error free. Further, I will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device.

**What are the benefits associated with participation?**

It is important to note that participants may not receive any direct benefit from participating in the study. Some participants may find it helpful to have a space to share their experiences with death openly and without judgment. Others may find it helpful to know that the information from the research project may act as a catalyst for change in death education specific to recreation therapy, ensuring that recreation therapists are better prepared for and supported when they do experience death.

**How will your confidentiality be protected?**

If you agree to participate in this study, you should know that information will only be collected from you directly.

All audio/video recordings of the research conversations will be saved in a password-protected file to my local computer (i.e., in the computer hard drive) and not on the Zoom cloud (i.e., an external internet server/location). These recordings will then be transferred to a password-protected secure server (MS TEAMS) at the University of Waterloo and deleted once transcribed and verified for accuracy.

The information transcribed from the video/audio recordings collected for the study as well as copies of the artistic representations of death created by participants will have all names and identifying information removed. Documents with identifying information (i.e., information and consent forms, recordings of research conversations) will be stored separately from the rest of the data. Only I will have access to the study materials that contain identifying information. Electronic documents (i.e., transcripts of research conversations, signed consent forms, copies of the representations of death) will be stored on the University of Waterloo server for a minimum of 2 years following the completion of the study.

All research conversation group participants will be instructed to respect the confidentiality of all comments shared during the sessions, although the primary researcher cannot assure that every

participant will honour this request. You can share what you contributed to the conversation with others should you choose to do so.

Your name will not appear in any paper or presentation resulting from this study. However, with your permission, quotations may be used with a pseudonym instead of your real name. In our initial telephone conversation, you will be asked to provide your own pseudonym.

**What is the nature of participation?**

Your participation in this study is voluntary. You may decide not to be in this study or to be in the study now and then change your mind later.

You may leave the study at any time by notifying me, the primary investigator Erin Delaney, at epdelane@uwaterloo.ca. The data collected from you will be removed from the research unless you permit me to use what you have already contributed. You may withdraw your consent and request that your data be deleted by contacting me until the study findings are submitted for publication. It is not possible to remove data once the findings have been published.

**Who should you contact if you have questions about the study?**

This study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB ***[#46064]***). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca.

For all other questions or if you would like additional information to assist you in deciding on participation, please get in touch with me by email at epdelane@uwaterloo.ca. You can also contact my supervisor, Professor Sherry Dupuis at 519-888-4567, ext. 41688 or by email at sldupuis@uwaterloo.ca

If you are willing to participate in this study, please go to the next page and complete the consent form and email it to me at epdelane@uwaterloo.ca once completed. If you would prefer to go over this information letter with me and provide verbal consent, please contact me and I will arrange a time to meet with you on Zoom or over the telephone. Should you choose to participate, you will be given a copy of the signed consent form (see next page).

I look forward to speaking with you and thank you in advance for your considering participating in this project.

Yours Sincerely, Erin Delaney

## Appendix E

## Informed Consent Form

## WRITTEN CONSENT FORM

Study Title: "Personifications and Experiences of Death Among Recreation Therapists"
Principle Investigator: Erin Delaney
University of Waterloo
epdelane@uwaterloo.ca
By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

---

I have read the information presented in the attached information letter about the study conducted by ***Erin Delaney*** from the **Department of *Recreation and Leisure Studies*** at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers, and obtain any additional details I wanted.

I understand that I am consenting to participate in two phases of this project: an independent phase involving the creation of an artistic representation of death, and a small group research conversation with three to four other participants.

I understand that research conversations will be audio- and video-recorded and consent to this recording.

I am also aware that anonymous quotations from their research conversations and the artistic personifications may be included in the researcher's thesis, publications, and/or presentations of this research with the understanding that the quotations and the presentations of the artistic personifications of death will be anonymous. A pseudonym of my choosing will be used in place of my real name. I agree to the use of my information as described in this form.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher. I understand that data cannot be withdrawn after results have been published.

I understand that this study has been reviewed and received ethics clearance through the University of Waterloo Research Ethics Board (REB #46064). If I have questions for the Board, I can contact the Office of Research Ethics toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or reb@uwaterloo.ca. I understand that for all other questions, I can contact ***Erin Delaney at epdelane@uwaterloo.ca.***

With all this information in mind, I agree to participate in this study of my own free will.
Participant Name: _____ (Please print)

Participant Signature: _____

Date: _____

## Appendix F

## Assent Script and Research Conversation Guide

Preamble: Hello, my name is Erin Delaney. I am a graduate student at the University of Waterloo in the Department of Recreation and Leisure Studies. Thank you for agreeing to participate in my study. I want to ask you some questions about your experience with death as a recreation therapist. I am interested in learning about your experiences with death and exploring the meaning and understanding of those experiences. Lastly, the interview will explore your recommendations for death education and any support you feel may be missing for recreation therapists to navigate death.

Today, we will participate in a 90–100-minute research conversation, where we will be exploring your experiences collectively with the help of guiding questions and prompts. The first half of the interview will center around the personifications you have created and how they represent your understanding and experiences of death. The second half of the interview will center around your experiences as a recreation therapist navigating client loss, experiences of death at work, death education and potential supports.

You are being video- and audio-recorded so that I can have an accurate account of our conversation today. I will be transcribing the recording so that I can use it in my analysis process. The recordings will be deleted after they are transcribed. All names and identifying data will be removed and replaced with the pseudonym you provided during my individual telephone conversations with you.

Here are a few reminders before we begin:

- Your participation in this project and this conversation is completely voluntary.
- The topic of death may make you feel uncomfortable or emotional. You may decline to answer any questions that you prefer not to answer. If anyone feels like they need to pause our discussion, please feel free to leave the conversation and come back when you are ready.
- You can leave the conversation any time by letting me know you want to leave. Should you leave the research conversation, I will reach out to you after the research conversation and provide you with a list of resources should you require additional supports.
- Your name will not appear in any publication or presentation resulting from this research; however, with your permission, quotations and copies of your artistic personifications may be used with a pseudonym in place of your real name.
- You may leave the study anytime by notifying me. The data we collected from you will be removed from my research unless you permit me to use what you have already contributed. Removing your data will not be possible once I have submitted the research for publication.
- Reminder: this study has been approved by the University of Waterloo Research Ethics Board. Should you have any questions resulting from your involvement in this study, you are encouraged to contact this office using the contact information in the Information Letter and Consent Form.

Do you have any questions before starting the conversation? (Yes or no).

Please indicate (Yes or No) if you agree to share your death experiences from a recreation therapist's perspective in this recorded conversation (yes or no).

**Interview Guide**

Before we begin, I want to remind everyone that because you are participating with others in this research conversation, it is important that you respect confidentiality during this session. Any information shared by others in this session must remain in the session and not be shared with others outside. However, I cannot guarantee that everyone will honour this request.

Let's get started.

**Part One: Personification of Death**

This interview is conversational. During the session, I have several questions that I would like to ask, but we can explore new ideas as they arise. With this first set of questions, I want to explore your personifications of death, what you included in your artistic representations of death, and what that might tell us about your experiences of death.

I have a copy of each of the personifications and am going to share my screen so that we can share and explore each of these representations. Each person will have five minutes to describe their personifications with the group. I you have a title for your personification, please share that along with what that title represents for you. I would like you to then describe how death is represented in your personification, the elements you included in your personification, and what those elements mean to you. Who would like to begin?

**Research Question #1: Understand how death is personified by practicing recreation therapists…**

*1A) What does your personification of death tell us about your meanings and/or experiences of death? …*

Follow-Up Questions:

A) How is time reflected in your personifications of death? How is space/place reflected in your personifications of death? How is the body and/or are experiences of the body reflected in your personifications of death? How are relationships reflected in your personifications?
B) What are the similarities you are noticing in the personifications of death (e.g., colours, images, etc.)?

C) What differences are your noticing?

D) What do you think has shaped or influenced your understanding or experiences of death as reflected in your personifications?

*Lead Question 1B) Tell me about the elements of your personifications, if any, that represent your experiences of death in recreation therapy.*

Follow-Up Question

E) Tell me about the images that represent your experiences of death in recreation therapy…
F) Tell me about how your role in end-of-life is represented…
G) What elements related to your experiences of death in recreation therapy did you want to include, if any, but did not? Can you explain why this was…

*1C) Tell me about the experience of making your personification…*

Follow-Up Question:

H) Tell me about your experience creating the personification …
I) What challenges did you face while creating it?
J) Tell me about the process of creating it …
K) Tell me about the prompts you were drawn to in the art guide…
L) Tell me about prompts you found difficult in the art guide....

**Part Two: Focusing on Experiences and Support for Recreation Therapists**

**Preamble:** *Okay, we have covered all the questions in the first part of the interview. Before we continue, is there anything else you would like to add? This next set of questions focuses on your experiences of death as a recreation therapist and what education could be put in place to support you in your death and dying experiences better.*

**Research Question #3: Explore how death is understood by recreation therapists…**

*3A) Tell me about your experience with patients at the end-of-life…*

Follow-Up Questions:

M) Tell me about the role you play at a patient's end-of-life ….
N) Tell me how your relationship with death has changed since working in health care….
O) Tell me what you think is most valuable at patients' end-of-life ….

*3B) Tell me how your role impacts your relationship with death…*

P) Can you describe to me a time you experienced death in your roles as recreation therapists? What was that like?
Q) How has your understanding of death changed, if at all, since working as a recreation therapist?

R) Tell me about what your role looks like at a patient/client's end-of-life? What does your role look like following a patient/client's death?
S) How do you navigate the loss of a patient/client?
T) In your jobs as recreation therapists/therapeutic recreationists, when have you felt supported in your experiences of death? How were you supported? In what ways did this change your experience of death?
U) How could you be better supported in your work?
V) How might death education have supported you when experiencing death? If death education were offered, what topics would be important to explore?

‘

## Appendix G

## Art Guide

Personification is a communication device that gives a concept human qualities and identity. This practice is meant to demonstrate the invisible phenomenon of death. By highlighting the sensory experiences, facts, and opinions we apply to the experience. Personification allows us to articulate our fears, emotions, and experiences without the restraints of spoken language, within this experience. In this exercise you are being asked to create a personification, or artistic representation of death – what it looks like and means to you. I am not asking for you to draw a human figure, instead I am asking you to explore qualities such as emotion, colour, seasons, and images you associate with death and experiences of it.

I appreciate your interest in this project. This instruction sheet provides guidelines for the creation of your personification. Keep in mind everyone has a different comfort and skill level when it comes to creating art, and this process is open to your interpretation. The hope is that you will create some type of visual representation of death. You can use whatever techniques and materials you are most comfortable using to create your personification of death. For example, you might use paper cut-outs and glue, or free images found online to create a collage; paint, markers, pencil crayons, or other art materials/textures to create an artistic representation; online software packages such as Canva or Adobe to create your personification; or word art to create a mind map. Your personifications can include images, symbols, words, or a mixture of these.

If you need access to materials, please indicate this to Erin Delaney at epdelane@uwaterloo.ca, and I will organize to have materials mailed to you.

You have three weeks to complete your personification. Please submit your personification to me by email two days before your scheduled research conversation.

Keep in mind there are no right or wrong answers. Each personification reflects your individual and personal understandings and experiences with death. Think about the following prompts as you create your personification of death:

***Temporality***

- What does death/the experience of death look like? What images come to mind? What does death look like?
- What is the proximity of death?
- What is the connection between death and time?
- What time do you associate with death?
- What season is associated with death?
- What age is death?

***Spatiality***

- What is the location of death?

- Where does death take place?
- What spaces/places do you associate with death?
- What surrounds death? What setting, background or scenery is associated with death?

***Corporeality***

- How do you feel death in the body?
- How is death experienced in the body?
- What parts of the body do you associate with death?
- What actions or behaviours are associated with death?
- What emotions are associated with death?
- How does death feel?
- What is the reaction to death?

***Relationality***

- What relationships are associated with death?
- Who is present at death?

***Other***

- What colours are associated with death/what are the colours of death?
- What textures represent death?
- What (if any) leisure does death participate in, or do you associate with death?

Once you finish your personification, please scan it, take a photo of it, or download it and send a copy of it electronically to Erin Delaney at epdelane@uwaterloo.ca.
If you need support with this, please let me know.

## Appendix H

## Closing Remarks for Debrief

Debriefing: Thank you all for your thoughtful reflection and presence. I appreciate the time and space that we have created together. In recognition of our topic, I would like to take the last 10 minutes to debrief our experience in the group. In this debrief, I challenge you to focus on the emotions, feelings, and challenges you have experienced through our research conversation today.

If you feel comfortable, I would like to go around the room and ask how your energy looks. Using your hands, I want you to demonstrate to the group how you are feeling. If you are uncomfortable demonstrating your feelings through movement, I welcome you to use one word to describe how you feel in the moment.

*[One by one, we will go around demonstrating with slight hand gestures what our energy looks like or how we are holding our energy; this is to get an idea of how everyone is feeling before beginning the debrief. If participants are holding their energy in a way that is seemingly cumbersome or using words such as heavy, this will allow me to prompt where unrest is coming from and give an opportunity for me to recognize who I may need to speak with following the conversation]*

Since we have created a confidential and intimate space through our discussion, I would like to share a collective moment through a song, meditation, or silence to exit the conversation.

- As a group, what do you think would honour your experience here today?

*[From this discussion, we will share in a final closing moment together that is separate from speaking about death. In most of my experiences, this has been done through song, having the group select a song that is meaningful, hopeful, joyful or a song of oneness]*

Thank you all for taking time out of your busy lives to be here as a group and speak openly about your experiences. I appreciate your time spent in the group and your commitment to completing your personifications to tell the story of your experiences.

- Are there any last words or thoughts anyone would like to share before ending our meeting for today?

## Appendix I

## Creating Rapport

Preamble: Hello, my name is Erin Delaney. I am a graduate student at the University of Waterloo in the Department of Recreation and Leisure Studies. Thank you for agreeing to participate in my study. I am conducting this conversation to get an understanding about yourself and give you an opportunity to ask me any questions regarding the study. This conversation is expected to be at most 15-minutes.

I am using this call to collect demographic information that is important to you. I want to get a better understanding of the identities that shape your experiences in the world. This method of collecting demographic information, compared to an online survey, is aligned with my study's phenomenological structure, which centers on experiences and relationality.

In this conversation, you will be asked to describe yourself, including aspects of your identity you feel are essential to your experience in the world (e.g., age, gender, culture/ethnicity, etc.) and your experiences as a recreation therapist.

To understand these aspects, I would like you to…

- Tell me about yourself…How would you describe yourself to someone else?
- What are important aspects of your identity important to you (i.e., culture, race, ethnicity, leisure interests, geographical location, birthplace, religion, etc.)?
- Can you describe your experiences as a recreation therapist?
    - How long have you been a recreation therapist?
    - Where have you worked as a recreation therapist, and where do you currently work?
    - What does it mean to you to be a recreation therapist?

Thank you for sharing the aspects of your identity that are important to you. Before ending the call, I want to remind you that within this study, defining factors of your identity (i.e., your name and place of work) will not be disclosed. To honour the uniqueness of your identity and perspective, I want to ask you at this time how you would like to be identified in the written work of this research.

- Is there a name you would like me to use as a pseudonym instead of your name?

Thank you for your time, energy, and willingness to participate in this research. I look forward to viewing your personification in 3-week's and speaking with you again in the virtual research conversation on _____ 2024.