Shaping Experiences: Exploring the Impact of Legislation, Policy, and Programs on Family Members of MAID Recipients

by

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Abstract

Published literature on family members’ experiences with assisted dying is minimal, with only a limited number of studies exploring the perspectives of bereaved family members. Studies have shown family members can play a significant role in assisted dying. My study aimed to understand the experiences of bereaved family members who have had a loved one receive medical assistance in dying (MAID) and describe how MAID implementation, policy, and processes in two different settings in Canada influenced these experiences. The study used interpretive description, a qualitative research methodology framed by the theoretical lens of relational ethics. A total of 31 family members and 15 key informant participants took part in the study. The analysis of the data identified three descriptive themes: (a) they want MAID, now what, (b) prepared but maybe not ready, and (c) evolving understanding of this type of death, with associated subthemes that revealed the complex and layered experience of family members whose loved one received MAID. Study findings also revealed the experience of family members was influenced not only by individual-level factors but also by meso-level factors, including programs, processes, policy, and macro-level elements, including MAID legislation. These elements did not operate in isolation; instead, they interconnected to influence family members. Based on study findings, recommendations focus on policy, practice, and education, as well as future research and propose options to address the elements that affect the experiences of bereaved family members of MAID recipients.

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AHS	Alberta Health Services
BC	British Columbia
CASN	Canadian Association of Schools of Nursing
CCS	Care Coordination Service
CIHI	Canadian Institute for Health Information
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COVID-19	Coronavirus disease 2019
HA	Health authority
HREBA-CHC	Health Research Ethics Board of Alberta - Community Health Committee
MAID	Medical assistance in dying
NP	Nurse practitioner
REB	Research Ethics Board
SCC	Supreme Court of Canada
VIHA	Vancouver Island Health Authority

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Chapter 1: Introduction

History shows that in much of the developed world the trajectory toward death and the process of dying has dramatically changed, moving from an intimate social experience to a solitary one influenced by the health care system's focus on curing illnesses (Stajduhar, 2011; Thorne, 2008a). This shift has led to death being something to be feared and controlled rather than a natural and inevitable part of life (Ariès, 1974; Arnup, 2018; Storch et al., 2013). Changes in public attitudes related to peoples' choice and desire for control at the end of life are now part of the complexity of death and dying in jurisdictions across the world. This results in pressure for significant legislative and policy changes to enable access to euthanasia and assisted suicide (Emanuel et al., 2016; Raisio et al., 2015; Salem, 1999). As a result, not only are individuals who want assisted death impacted but so are their family members and friends.

This chapter provides context for my dissertation by outlining the historical background and significance of my study. This chapter also includes a description of my study's purpose, research questions, aims, and underlying assumptions. Additionally, I briefly explain the methodological approach used and provide definitions for key terminology. Finally, I conclude by reviewing the organization of my dissertation. Throughout this dissertation, I have used identifiers (e.g., KI-01 through to KI-16, excluding KI-08 as they withdrew, for key informant participants) to ensure participants remained anonymous and to protect their confidentiality.

Situating the Study in a Historical Context

On June 17, 2016, Canada entered the complex end-of-life landscape of assisted dying when medical assistance in dying (MAID) became legalized. MAID legislation (Bill C-14, 2016) resulted from decades of advocacy, activism and reflection by individuals, organizations, groups, and the government. In the years that preceded the legislation (Bill C-14, 2016), critical elements came into focus, including justice, reasonable limits on the right to refuse treatment, as well as the discrimination believed to exist as a result of the decriminalization of suicide (Arnup, 2018; Emanuel, 1994). After prior legal attempts were unsuccessful,[1] in February 2015, the Supreme Court of Canada (SCC) issued a unanimous decision in *Carter v. Canada* (2015), supporting that provisions against assisted suicide as outlined in the Criminal Code were invalid because they infringed on the right to life, liberty, and security as defined in the *Canadian Charter of Rights and Freedoms* (1982). Through Bill C-14 (2016), MAID legislation became the product with established requirements and safeguards for assisted dying in Canada.

According to the federal government's most recent annual report on MAID, more than 44,000 Canadians have received MAID since 2016, with many more having connected with it because of being a family member, caregiver, or friend of a recipient (Health Canada, 2023). The total number of MAID deaths accounted for approximately 4.1% of estimated deaths in Canada in 2022 (Health Canada, 2023). Cancer-related diagnoses were the most common underlying health condition; this reflects international data. Private residences were the primary location reported nationally for MAID provisions (39.5%), with Ontario (48.1%) and British Columbia (43.8%) reporting a more significant percentage of MAID provisions in this setting (Health Canada, 2023). Before 2019, reported rates between the facilitation of MAID at home and hospital settings were relatively comparable, with British Columbia consistently demonstrating higher provision in home-like settings compared to the rest of Canada (Health Canada, 2018, 2019, 2022b).

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[1] Most significant of note, Rodriguez versus the Province of British Columbia; the Supreme Court of Canada decided 5-4 against amending the Criminal Code to allow assisted death (1993).

Since the implementation, MAID has been taken up differently across the country, with the highest MAID deaths reported in Québec, Ontario, British Columbia (BC), and Alberta, and fewer MAID deaths recently reported in Yukon and Manitoba (Health Canada, 2022b, 2023). There has also been considerable variability in provincial and territorial policy, processes, and implementation of MAID legislation (Alberta Health Services, 2016; Beuthin et al., 2018; Downie & Chandler, 2018; Government of BC, n.d.-a; Health Canada, 2017a, 2017b; Robertson & Beuthin, 2018). Various factors, such as geographical location, regulations, and cultural norms, contribute to the differences in the implementation of MAID.

The impact of including MAID in clinical practice has been significant, affecting both individuals and the broader health care system. Canadian research on MAID primarily focuses on the attitudes and perspectives of health care team members (Antifaeff, 2019; Beuthin et al., 2018; Brown et al., 2021; Gallagher et al., 2019; Rousseau et al., 2017; Shaw et al., 2018) or the health care system in the context of this option (Ball et al., 2018; Beuthin, 2018; Downar & Francescutti, 2017; Fujioka et al., 2018; Heggerud & Faulder, 2018; M. Li et al., 2017; Oczkowski et al., 2017). While this research is important, the implications of MAID are much broader than what these studies address. Specifically, how variations and the accompanying policies and procedures in different jurisdictions affect family members still needs to be studied (Health Canada, 2017a, 2018, 2023). The conceptualization of death and dying is a process that affects the family in its entirety (Stajduhar et al., 2013; Steinhauser et al., 2000; Storch et al., 2013) as the diagnosis of a life-limiting illness affects not only the individual but their loved ones as well. The relationship dynamics may shift, and family members must navigate the inevitable transitions as their loved one nears the end of their life (Davies et al., 1995). While there has been research on how family members experience palliative care, little knowledge is available on their experiences when their loved one chooses assisted death as their end-of-life option. Although there is existing international research on assisted dying practices, including studies by Hurst and Mauron (2003), Kouwenhoven et al. (2018), Rurup et al. (2012), and Snijdewind et al. (2015), and research on those who choose this type of death by Buchbinder (2018), Dees et al. (2011), Maessen et al. (2014) and Van Den Noortgate and Van Humbeeck (2020), there is still limited knowledge about the experiences of family members who have lost a loved one through assisted dying even though there are known challenges associated with this type of death (Buchbinder et al., 2018; Gamondi et al., 2018; Ganzini et al., 2009; Swarte et al., 2003). It is clear within MAID's layered complexity that there is a need to expand our comprehension of the experiences of bereaved family members who have had a loved one receive MAID. This is the focus of my dissertation research.

Background to the Problem

The deleterious effects of caring for a dying loved one are well documented, in part because of the responsibilities that family members have to fulfill their caregiving duties (Anderson & White, 2018; Aoun et al., 2005; Arnup, 2018; Brémault-Phillips et al., 2016; Hudson, 2004; Schulman-Green & Feder, 2018; Stajduhar et al., 2010). Taking care of an ill person involves many responsibilities, including providing transportation, attending medical appointments, offering emotional and psychological support, managing symptoms, and aiding in decision-making and financial management (Kristjanson & White, 2002; Statistics Canada, 2018; Wilson et al., 2018). This can place a heavy burden on family members, leading to overwhelming demands and unmet needs for information, communication, and support from health care professionals and the health care system (Anderson & White, 2018; Aoun et al., 2005; Arnup, 2018; Brémault-Phillips et al., 2016; Genworth Financial, 2018; Hudson, 2004;

Starks et al., 2007; Stenberg et al., 2012). After a loved one dies, family members may face ongoing challenges throughout the grieving process (Starks et al., 2007). Studies conducted in countries with assisted dying laws indicate that the experience of family members may become more intense in this context (Buchbinder et al., 2018; Gamondi et al., 2015; Gamondi et al., 2018; Holmes et al., 2018; Snijdewind et al., 2014). However, there are still gaps in our understanding of this phenomenon.

The research on assisted dying mainly occurs in the jurisdictions of Switzerland, Belgium, the Netherlands, and Oregon, where laws, society, and cultural perspectives may differ from Canada (Dees et al., 2013; Ganzini et al., 2008; Kouwenhoven et al., 2018; Lemiengre et al., 2014). Published literature on family members' experiences with assisted dying is minimal, and only a limited number of studies have explored the perspectives of bereaved family members (Buchbinder et al., 2018; Gamondi et al., 2019; Gamondi et al., 2015; Gamondi et al., 2018; Ganzini et al., 2009; Holmes et al., 2018; Lowers et al., 2020; Swarte et al., 2003; Wagner, Keller, et al., 2012; Wagner, Müller, et al., 2012). Studies have shown that family members can play a significant role in the assisted dying process (Buchbinder et al., 2018; Gamondi et al., 2019; Gamondi et al., 2015; Ganzini et al., 2009). Regardless of their level of involvement, they may face moral dilemmas (Buchbinder, 2018; Gamondi et al., 2015; Gamondi et al., 2018; Ganzini et al., 2009), feel isolated and compelled to keep the process a secret (Gamondi et al., 2015; Hales et al., 2019), with a range of grief and bereavement experiences reported (Beuthin et al., 2021; Gamondi et al., 2019; Ganzini et al., 2009; Swarte et al., 2003; Wagner, Müller, et al., 2012).

Over the past 7 years since Canada legalized MAID, the number of published studies on the experiences of family members whose loved ones have chosen MAID has gradually increased. In the first 3 years following implementation, only two published studies focused on the experience of family members of MAID recipients (Holmes et al., 2018; Shaw et al., 2018). The first study, by Holmes et al. (2018), comprised a convenience sample of 18 individuals whose significant others requested MAID through a clinic in Vancouver, BC. The findings revealed that participants eventually supported their significant other's decision and that their roles and responsibilities during the MAID process involved emotional and practical assistance. In reflecting on death, participants perceived their significant other's death as "peaceful" (Holmes et al., 2018, p. e392).

In the study by Hales et al. (2019), a sample of 11 family members and friends of individuals who received MAID at an academic hospital setting in Toronto, Ontario, identified the complexities of the MAID process that influenced their experience. Family members felt judged by some health care professionals, had privacy concerns, and thought that grief and bereavement support might be beneficial. The findings also highlighted that some aspects of the legislation, specifically the requirement for a waiting period, influenced their overall experience (Hales et al., 2019).

Since these two studies were published, the research has expanded and focused in the provinces of Nova Scotia (Crumley et al., 2023), Ontario (Frolic et al., 2020; Hashemi et al., 2021; Thangarasa et al., 2021), Québec (Laperle et al., 2022; Roest et al., 2019), Saskatchewan (Brown et al., 2020b), and BC (Beuthin et al., 2021). Publications have also demonstrated that research teams are designing studies within multiple study settings, which allows for a broader perspective on the experiences of bereaved family members (Oczkowski et al., 2021; Smolej et al., 2022). The literature provides a minimal description of the sampling strategies used in the studies (Goldberg et al., 2021). Limitations of these studies included small sample sizes (Beuthin et al., 2021; Hales et al., 2019; Hashemi et al., 2021; Laperle et al., 2022; Smolej et al., 2022). The knowledge from these Canadian studies is valuable and provides a beginning understanding of family members' perspectives in the MAID context; however, gaps remain. The literature did not contain any studies that examined the impact of policy, system, and implementation strategy differences on the experiences of bereaved family members. As such, when my dissertation study commenced, there was a pressing need for knowledge generation regarding MAID, given its relatively recent legalization, diversity in implementation strategies across the country, the vital role of family members during end-of-life care, and the scant publication of research on the experiences of bereaved family members and MAID.

Purpose of the Study

My study aimed to understand the experiences of bereaved family members who have had a loved one receive MAID and describe how MAID implementation, policy and processes in different provinces influenced these experiences. The knowledge produced from this study will be used to inform MAID practitioners, health care providers, health care leaders, health and social care educators, and advocacy groups about the perspective of family members; and has the potential to inform supportive interventions, policies, and programs for family members who have had a loved one receive MAID. As such, this study provides important information on the experiences of family members whose loved one acquired an assisted death, contributing to the global understanding of this topic and beginning to fill a significant gap in knowledge within the Canadian context.

Research Question and Aims

For this dissertation, I explored the following overall research question: What are the experiences and perspectives of bereaved family members who have had a loved one end their life through MAID? The specific aims of my study were as follows:

1. Describe bereaved family members' experiences of having a loved one participate in MAID, including moral and ethical dilemmas associated with this choice.
2. Gain an understanding of the ways in which the implementation of MAID legislation has influenced family members' experiences.
3. Provide direction for interventions designed to support family members.
4. Provide health care professionals, MAID practitioners, health care administrators, and advocacy groups who influence decision making, with knowledge to inform policy directions related to bereaved family members and MAID.

Assumptions Underpinning the Dissertation Research

There are several assumptions underlying the study purpose and research question. These include that MAID is ethically layered and morally complex, the health care system is innately complex, which can be challenging for family members to navigate, and the expected family members will take on responsibilities for their loved ones during the end-of-life process. Additionally, supportive interventions can help bereaved family members and health care professionals who lack confidence discussing death and dying.

It is essential to acknowledge that access to MAID may differ based on the region or jurisdiction, and this can affect both individuals seeking MAID and their families. Additionally, some of the eligibility criteria and safeguards outlined in the MAID legislation (Bill C-14, 2016) may pose challenges for those seeking MAID, such as the requirement for late-stage consent. Furthermore, there are disparities in the availability and quality of palliative care across Canada.

Methodological Approach

I used the qualitative research methodology of interpretive description, framed by the theoretical lens of relational ethics (Bergum & Dossetor, 2005), to address my dissertation study's research question and aims. Interpretive description is situated in a paradigm underpinned with naturalistic assumptions, thus ensuring that the knowledge identified is socially constructed through the person experiencing it (Thorne, 2008b). In health care ethics, the relational ethics approach acknowledges that actions, decisions, and experiences are all interconnected. It also recognizes individuals' complex understandings in this context (Bergum & Dossetor, 2005). Within this orientation and using an interpretive description approach, I undertook critical analysis, conceptualization, and reconceptualization of study data to distinguish possible micro-, meso-, and macro-level understandings. My goal was to create knowledge that would benefit bereaved family members both individually and within the broader system. Additionally, I expect to share this new knowledge with nurses, health care practitioners, and leaders who work with family members and make policy decisions related to MAID, palliative care, and care following a life-limiting diagnosis.

Terminology

For the purposes of my dissertation research the following terms are defined.

Assisted dying and assisted death: Death that takes either of two forms: euthanasia or assisted suicide (Sumner, 2017).

Assisted suicide/physician-assisted suicide: When a physician provides an individual, at their explicit request, with a lethal prescription or medication with the intent that the individual can then end their own life at a time of their choosing (Emanuel, 1994; Sumner, 2017).

Bereavement: The state of losing someone through death and covers the time period of grief (C. Hall, 2014; Machlin, 2009).

Bill C-7: Reflects the evolution of federal MAID legislation. It is also referred in the literature as *An Act to Amend the Criminal Code* (*medical assistance in dying)* and received Royal Assent on March 17, 2021.[2]

Bill C-14: This was the initial MAID legislation, also referred in the literature as *An Act to amend the Criminal Code*, that articulated assisted dying provision in Canada. This legislation received Royal Assent in June 2016.

Clinician-Assisted Medical Assistance in Dying: The MAID practitioner performs the act of aiding in the death of an eligible person, through intravenous injection of lethal medications (Bill C-14, 2016; Government of Canada, 2023b).

Euthanasia: The intentional ending of an individual’s life through the administration of lethal medication, generally by a physician, and at the explicit request of the individual receiving it (Emanuel, 1994; Sumner, 2017).

Family Member: Any individual who had significant ties regardless of kinship ties, common household, biological relationships, or marital status (Vanier Institute of the Family, n.d.).

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[2] Recruitment of study participants for this dissertation occurred prior to *Bill C-7* legislation being enacted.

Grief: A complex reaction to the loss of someone or something that affects people emotionally, physically, cognitively, socially, and spiritually (C. Hall, 2014).

Guidelines: An evidence-based course of action (Villeneuve, 2017).

Implementation: A process of initiating or completing planned actions (“Implementation,” n.d.).

Intervention: Actions or treatments performed while interacting with the individual, patient, and family (e.g., administration of medication, counselling during grief; Engel, 2024).

Legislation: An exercise of the power and function of making rules through individual laws or sets of laws; the government has the authority to make the rules or laws and provides directives to enact them (Villeneuve, 2017).

MAID practitioner: A unifying term to encompass both physicians and nurse practitioners (NP) who engage in MAID assessment, MAID provision, and MAID assessment and provision.

Medical assistance in dying (*MAID):* Describes assisted dying that is available in Canada. Two types of assisted dying practices comprise this term: voluntary active euthanasia, referred to as clinician-assisted medical assistance in dying in the legislation; and assisted suicide, identified as self-administered medical assistance in dying in the legislation (Bill C-14, 2016; Government of Canada, 2023b). If there is a need to differentiate between the two practices of MAID in my dissertation, the specific term will be used.

Policy: A set of decisions relating to a specific issue that an organization or government needs to address, including to support new or revised legislation and regulations (Villeneuve, 2017); a policy describes a plan of action or direction resulting from a decision-making process that applies evidence, values, and reasoning (Villeneuve et al., 2019). Policies exist in both public and private sectors and reflect the context in which they are developed (Villeneuve, 2017).

Procedures: Established or official ways of performing a task or activity (Villeneuve, 2017). In the health care context, a procedure is often evidence based.

Process: A term that refers to the "elements of the care or services actually provided" (Clarke, 2015, p. 440) to an individual, patient, or population.

Program: Comprises an initiative or project with a specific focus, need, goal or objective (e.g., palliative care program, MAID program). A governmental, non-governmental, or non-profit organization can create a program. Developing a program involves multiple stakeholders and requires funding, human resources, and infrastructure. Programs can be evaluated, and, based on feedback and evidence, they can be modified or adapted (Villeneuve et al., 2019).

Self-administered medical assistance in dying: The MAID practitioner prescribes or provides lethal medications to an eligible person, who then self-administers it to cause their own death (Bill C-14, 2016; Government of Canada, 2023b).

Standards: Established expectations and legal guidelines for the provision of safe and competent care. May be outlined in written policies and procedures in the health care context (Shapiro & Dunsford, 2024).

Structure: Comprises components such as human and physical resources, care provision contexts, organizational elements, and decision-making mechanisms (Clarke, 2015).

Organization of the Dissertation

This chapter offered a brief overview of my dissertation research. Specifically, I discussed the problem, study purpose, research question, study aims, and underlying assumptions. Additionally, I briefly explained the methodological approach used and defined key terminology. Chapter 2 reviews relevant literature, MAID legislation, and policy to give context to the study’s focus on family members and MAID. Chapter 3 outlines the study’s methodology through a review of the interpretive description methodological approach, the study design, and ethical considerations. Chapter 4 presents the research findings, while Chapter 5 offers an interpretation of the descriptive findings and outlines the implications for nursing, MAID and palliative care practitioners, MAID teams and services, palliative care programs and services, advocacy groups, and senior health care leaders. I also present limitations of my study. Finally, in Chapter 6 I put forward recommendations for policy, practice, education and training, and future research. I conclude my dissertation by proposing knowledge translation activities.

Chapter 2: Review of the Literature, Legislation, and Policy

This chapter delves into the literature on the experience of family members who have lost a loved one through MAID. Firstly, I explore the relevant literature on the experiences of family members dealing with end-of-life situations. Following this, I examine assisted dying in international and Canadian contexts and review research on family members' experiences with assisted dying. Next, I provide a summary of MAID legislation (Bill C-14, 2016), followed by an overview of the organization of MAID at the federal, provincial, and territorial levels. Finally, the literature concerning this topic area, including the gaps in knowledge that my study attempts to address, is summarized.

When someone is diagnosed with a life-limiting illness, their family members are also affected by the changes in their relationship and the inevitable transitions as their loved one approaches death (Davies et al., 1995). While there is research on family members' experiences with palliative care, there is not as much information on their experiences when a loved one chooses an assisted death as their end-of-life option. Additionally, there is a lack of understanding about how the organization and implementation of assisted dying legislation, practices and policies might impact the perceptions and experiences of family members.

Family Members' Experiences at End-of-Life

In Western society before the 20th century, death was a constant presence due to epidemics, accidents, wars, and risks related to maternal-infant health (Arnup, 2018). Most people died at home, with their families caring for them and receiving support from their local community (Ariès, 1974). As a result, individuals became familiar with death and its processes through personal experience (Ariès, 1974; Arnup, 2018).

In the latter half of the 20th century, scientific and technological progress shifted toward a “cure-focused ideology” (Stajduhar, 2011, p. 9). This changed expectations around health and life expectancy, resulting in more people living with chronic life-limiting conditions (Aoun et al., 2005; Ariès, 1974; Arnup, 2018; Battams, 2018; Doane & Varcoe, 2015; Kortes-Miller, 2018; Storch et al., 2013). Research has shown that these conditions affect the individual and impact their family members (Dees et al., 2013; Stajduhar et al., 2013; Stajduhar & Davies, 2005; Starks et al., 2005; Statistics Canada, 2018).

In the following section, I review the research on family members’ experiences when their loved one has a terminal illness to establish a foundation for the current knowledge in this area. The literature focuses on the involvement and experiences of family members in providing care to their loved ones at end of life, as well as the challenges they encounter.

When Loved Ones have a Terminal Illness

Research on caring for individuals with terminal illnesses has primarily focused on seniors (Battams, 2018; Brémault-Phillips et al., 2016; Durepos et al., 2018), those with chronic conditions (including children; Ferrell et al., 2013; Silva et al., 2015; Spillers et al., 2008; Stenberg et al., 2012), and end-of-life and palliative care (Funk et al., 2015; Giesbrecht et al., 2013; Holm et al., 2013; Rainsford et al., 2017). Many of these studies center around cancer as the primary medical condition (Canadian Hospice Palliative Care Association, 2013).

Within this body of literature, a particular set of studies conducted by Davis et al. (1995) provides a detailed analysis of the challenges faced by family members of individuals with life-limiting illnesses. The research identifies seven dimensions encompassing the experience, including redefining roles, feeling burdened, struggling with paradox, adapting to changes, seeking meaning, living in the moment, and preparing for death. Family members experience these dimensions when they realize their loved one’s illness is advancing and there is no hope for recovery. These dimensions are closely intertwined and cannot be separated (Stajduhar & Dionne-Odom, 2019), and are experienced differently based on a member’s position in their family (e.g., spouse, adult child, adolescent, a young child; Davis et al., 1995). During this time, family members also tend to adapt their perspectives on their loved one, themselves, other family members, and the family as a unit. This period can also affect their lives, such as socializing, employment, relationships, and roles (Stajduhar & Dionne-Odom, 2019).

When a terminal diagnosis happens, Davis et al. (1995) identified that it was essential for individuals to work on creating, enhancing, and adjusting relationships within the family (Q. Li & Loke, 2014). This aspect appeared crucial for each family member’s connection with their loved one and embodied what Davies et al. called redefining. For spouses, this dimension begins as they attempt to continue on their usual path with their loved ones. However, as they acknowledge the disease progression and altered functioning while coping with new responsibilities, spouses feel sorrow and experience ‘reciprocal suffering’ in their redefined relationship (Davies et al., 1995). Adult children also face the challenge of redefining their relationship with their parent(s) as their loved one’s illness progresses, and they approach the end of their life. This dimension tends to be even more challenging for younger children and adolescents as they navigate their emotions and attempt to adjust to the situation (Davies et al., 1995; Huizinga et al., 2011).

The level of ‘burdening’ experienced by family members appears influenced by how much the terminally ill family member has redefined their identity and relationship with others (Davies et al., 1995). When couples have adequately redefined roles and expectations, they are more likely satisfied with the support and care they provide to their loved ones, even if they may feel overwhelmed. However, individuals in relationships where ‘redefining’ has yet to occur, express exhaustion and underappreciation (Davies et al., 1995).

Adult children caring for a dying parent experience a mixture of satisfaction and fatigue as they navigate role changes and additional responsibilities. This combination of feelings and changes is commonly called the “burdening” dimension for adult children (Steele & Davies, 2015). If these adult children have both parents living, the health of the well parent partly influences this dimension for them. For example, when the well parent offers the care and assistance, it may help reduce the stress and responsibility for their adult child (Davies et al., 1995). Similarly, when an ill parent redefines their relationship with their adult children, it can have a positive impact. This can also lead to increased pride and support from the adult children toward their sick parent. Adult children who can manage their time and prioritize their responsibilities overall seem to have a more positive experience, resulting in feelings of being less burdened (Steele & Davies, 2015).

Davies et al. (1995) conceptualized that the spouse of a terminally ill individual experiences a paradoxical struggle. This arises from the tension between their desire to spend time with their loved ones and their interest in returning to their previous way of being while also adapting to their redefined self. In order to address this issue, spouses try to prioritize self-care and attend to their needs. Neglecting to do so appears to lead to exhaustion and potential health problems (Steele & Davies, 2015).

For adult children, there are several dominant paradoxes identified in this dimension. The primary struggle is one between (a) wanting their parent to live and realizing the potential suffering or continued suffering that may result and (b) yielding to the trajectory that includes the death of their ill parent (Davies et al., 1995). As the child grapples with this dilemma, they may become exhausted and experience “decreased ability[y] to concentrate or focus on other aspects of their lives” (Davies et al., 1995, p. 30). The second paradox involves a tension between wanting to engage in their everyday world and the desire to spend as much time as possible with their ill parent. Sometimes, children decide to “put certain aspects of their lives on hold” to begin to confront death (Davies et al., 1995, p. 31). The third central paradox for adult children is the strain experienced between their multiple roles and the associated responsibilities. The struggle between the need to spend time with their terminally ill parent and their own family often comprises this dilemma. Adult children invest much energy in addressing this tension.

Adolescent children may experience a sense of confusion known as ‘struggling with paradox’ when their parents do not communicate openly and honestly about their illness and prognosis (Davies et al., 1995). This can create a dilemma where they want to know about their parent’s situation and what to expect but do not want to engage in a discussion that could cause emotional pain for themselves or their parents.

The dimension ‘contending with change’ characterizes one of the core features of families that experience terminal illness in one of their members. Changes in this context seems to happen in every aspect of an individual’s life, but each family member may experience and undergo these alterations uniquely (Davies et al., 1995). According to Davies et al. (1995), the most meaningful change a spouse experiences is in their relationship with their partner who is terminally ill.

For children, however, a more extensive change is noted throughout their life. They start to feel responsible for caring for their sick parent as they become more vulnerable, while the well parent becomes more stressed, tired, and requires assistance themselves. This role shift is noticeable in their behaviour towards their parents (Davies et al., 1995). Assuming more significant responsibilities within their family of origin can bring a sense of fulfillment to children but can also lead to exhaustion (Davies et al., 1995).

When faced with the impending death of a loved one, family members often engage in the process of “searching for meaning” (Davies et al., 1995). This involves reflecting on past experiences and trying to gain perspective on the present to reevaluate and develop coping strategies for their current situation. They also confront their mortality during this period. According to Davies et al. (1995), when family members find significance in their situation, they can engage in daily living instead of just enduring it (Stajduhar & Dionne-Odom, 2019). Adult children, however, tend to be impacted by their competing roles and responsibilities as they search for meaning. According to the researchers, children seem to understand that their parents do not want them to sacrifice important aspects or events in their life, and through this, they try to prioritize. However, they may still face difficulties and obstacles in this dimension (Davies et al., 1995).

In the dimension ‘preparing for death,’ practical aspects are addressed by family members (Stajduhar & Dionne-Odom, 2019). When a person is diagnosed with a terminal illness, family members tend to become “decision partners” to help their loved one make important choices regarding end-of-life care. By working together, these family members can assist in fulfilling their loved ones’ wishes (Stajduhar & Dionne-Odom, 2019). To fully address this dimension, family members appear to also consider spiritual and emotional components. This includes a dedication to the family unit and preparing oneself mentally for the expected loss (Davies et al., 1995).

Caring and Supporting Loved Ones

Research indicates that family members are typically the primary source of assistance for individuals with terminal illnesses approaching the end of their lives (Hudson & Payne, 2011; Ullrich et al., 2020). In Canada, an estimated 46% of the population (equivalent to 13 million people) have provided unpaid care to a loved one in this circumstance (Battams, 2018). It may be necessary to care for a loved one if they have a disability, chronic illness, are frail, or have a life-limiting medical condition. Many family members take on this role, but it can be challenging and only sometimes straightforward, even though it is essential (Anderson & White, 2018; Brémault-Phillips et al., 2016; Dees et al., 2013; Giesbrecht et al., 2015; Hudson & Payne, 2011; Linderholm & Friedrichsen, 2010; Rainsford et al., 2018; Stajduhar et al., 2013; Stajduhar et al., 2008; Ullrich et al., 2020).

Family members' roles and responsibilities vary in end-of-life and palliative care, depending on a significant other's condition and change in health (Canadian Virtual Hospice, n.d.). Deterioration in mental status, for example, is particularly challenging for family members as they adjust to the resultant demands (Hull, 1990).

The environment where a significant other resides also influences family members' roles and responsibilities (Canadian Hospice Palliative Care Association, 2013; Wong & Ussher, 2009). According to Funk et al. (2022), many people prefer to receive care and die in their own homes. In many cases, managing this process requires unpaid care and support from family members (Canadian Hospice Palliative Care Association, 2013). Consequently, family members are typically the only ones with ongoing awareness of their loved one's health status, level of comfort, and overall condition (Milberg & Strang, 2003; Rabow et al., 2004).

Despite the challenges, many family members feel it is essential that they support their loved one with a terminal illness to be cared for in the home. Studies indicate that supporting a loved one at home can improve family connectedness, reduce obstacles to maintaining other relationships, and provide easier access to support systems (Davis et al., 1995; Milberg & Strang, 2003; Proot et al., 2003). Family members also perceive that maintaining the home environment as the location of death makes the end-of-life experience more peaceful and dignified for their loved one (Sinead Donnelly & Battley, 2010; Wong & Ussher, 2009). Overall, this can have a positive impact on family members. However, when family members provide support and care to a loved one with a terminal illness in the home environment, emotional stressors like worry, anxiety, and depression can also intensify (Burton et al., 2012).

In the home environment, family members' activities range from providing routine tasks[3] to specialized care[4] through direct[5] and indirect[6] measures (National Alliance for Caregiving, 2009). Balancing new roles and responsibilities alongside existing commitments while caring for a loved one can be stressful for family members. It often requires effective time management, support from other systems, or hiring a caregiver to assist with these demands (Stajduhar & Dionne-Odom, 2019).

Having a loved one with a terminal illness in a hospital or hospice setting is characterized by roles and responsibilities for family members that are no less crucial (Sarah Donnelly et al., 2018; Sinead Donnelly & Battley, 2010; Evans et al., 2006). Assuming roles as advocate,

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[3] May include the preparation of meals, housework, outside home maintenance, and transportation (Genworth Financial, 2018; National Alliance for Caregiving, 2009).

[4] May include medication management, symptom monitoring, emotional support, spiritual care, and assistance with activities of daily living.

[5] E.g., medication and wound management, activities of daily living.

[6] E.g., health care decision-making, emotional support, and appointment coordination.

information agent,[7] emotional and spiritual companion, and physical care provider can be essential to the dying individual and meaningful to family members (Funk et al., 2022; Stajduhar & Dionne-Odom, 2019). Depending on their loved one's condition and perspective, their physical location and the overall setting may provide additional stress and challenges for family members as they support their loved one (Dionne-Odom et al., 2014; Sarah Donnelly et al., 2018; Ullrich et al., 2020). In some cases, the hospital or hospice may be the location of death; however, discharge from these environments to the home setting may occur, adding to family members' responsibilities as they coordinate the process and initiate care.

Challenges and Needs of Family Members

Research has shown that family members tend to become caregivers for their loved ones when they are nearing the end of their life. However, these family members need proper preparation and support to fulfill their caregiving duties effectively (Etkind et al., 2018). With adequate support, they may avoid additional challenges and unmet needs (Appelin et al., 2005; Given & Reinhard, 2017). In particular, family members require better support when communicating and exchanging information (Bee et al., 2009). They typically need more information about plans, the palliative care process, and potential complications. Various obstacles, such as practical, process and relational barriers, may impede communication for family caregivers, which can be problematic in their roles (Kristjanson & White, 2002). As a result of an unclear exchange of information, family members may seek answers from other sources like the internet, friends, or other family members instead of asking for guidance directly

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[7] May include providing historical background about medications and conditions and conveying and reinforcing information between their significant other and health care professionals, and vice versa, gathering and holding information.

(Kristjanson & White, 2002), which can lead to a trial and error approach to caring for their loved one (Bee et al., 2009).

Studies indicate that caring for a loved one can be burdensome for family members, regardless of age. Providing physical and emotional support can be challenging (McNamara & Rosenwax, 2010; Proot et al., 2003). Physical care tends to be demanding for family members and may trigger emotions such as anxiety, fatigue, and being overwhelmed (DePasquale et al., 2015; Reid et al., 2010; Roth et al., 2015). As a result, family members may feel encumbered and struggle to keep up with the responsibilities of caregiving (Funk & Obedzinski, 2019; Roth et al., 2015; Stajduhar et al., 2010).

Feeling a sense of burden and being overwhelmed is linked to the emotional health of those who care for loved ones (Holland & Neimeyer, 2005; Ullrich et al., 2020). According to the research by Choi and Seo (2019), spirituality as a means of support and coping for family members can be beneficial. Their study revealed that having solid spiritual well-being seems to be associated with lower levels of burden. According to Yoon et al. (2018), complex and stressful situations may end up harming the spirituality of family members.

The literature highlights that in addition to feeling a degree of burden, family members can associate supporting and caring for a loved one with isolation (Koenig Kellas et al., 2021). Their roles and responsibilities tend to affect their time, regular activities and socialization (Given & Reinhard, 2017), creating additional tension and psychological distress (Koenig Kellas et al., 2021; Q. Li & Loke, 2014; Milberg & Strang, 2007; Torke et al., 2014). Feelings of isolation may become even more intense if their roles and involvement in care go unnoticed or unacknowledged by others, including health care professionals (Etkind et al., 2018; Hunstad & Svindseth, 2014; Lundberg et al., 2013).

For family members who support their significant other in the home environment, financial stressors can occur and are seen to be related to the loss of income[8] or general costs[9] for which they become personally responsible (Genworth Financial, 2018; National Alliance for Caregiving, 2009). Family members may experience a significant burden related to the financial aspect of care, which is tends to be disregarded by health care professionals (Gardiner et al., 2016).

Summary of Family Members' Experiences around End-of-Life

When an individual is diagnosed with a terminal illness, their family members experience dynamic changes as they prepare for the impending death of their loved one. According to Davies et al. (1995), this transition occurs within seven dimensions as they adjust their perspective on the future. Many family members identify that it is vital to support and care for their loved ones in this situation, and many family members take on these roles and responsibilities (Stajduhar et al., 2013). At the same time, they also cope with their loved ones' prognosis (Canadian Hospice Palliative Care Association, 2013).

Family members caring for loved ones at the end of life have identified both positive and negative aspects (Brémault-Phillips et al., 2016; Stajduhar et al., 2010). However, family members are generally not adequately prepared or supported in their caregiver roles. Family members can experience feelings of isolation and a degree of burden, and the challenges and unmet needs can result in fatigue, stress, exhaustion, and psychological distress (Morris et al., 2015). It is essential to acknowledge these experiences of family members who care for a loved

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[8] Associated with quitting or losing their job, unpaid leave, using vacation/holiday/special leave time (Genworth Financial, 2018; National Alliance for Caregiving, 2009).

[9] Includes prescription and over-the-counter medications, home care, and support equipment.

one with a life-limiting illness at the end of their life. As assisted dying becomes more widely accepted, broadening our understanding to include family members affected by this choice is essential. Particularly as assisted dying laws are modified and evolve in different regions, and governments provide direction for enacting adjustments to legislation and rules surrounding assisted dying.

Assisted Dying in the International and Canadian Context

When considering aid in dying, the experience of death and dying may become more complex or more manageable, depending on a loved one's condition and the involvement of family members (Gamondi et al., 2015; Gamondi et al., 2013; Holmes et al., 2018). Before exploring the specifics of assisted dying in Canada, the next section of the chapter provides a broad overview of the key aspects of assisted dying in the international context. Next, I provide a brief history of Canada's version of assisted dying, medical assistance in dying (MAID), and focus on aspects that could affect family members. I also describe legislative components, such as eligibility criteria, implementation measures, policy features, and regulatory measures (Bill C-14, 2016). Finally, I present federal data on the current context of MAID from a pan-Canadian perspective.

International Context of Assisted Dying

The following is a list of international jurisdictions in which some form of aid in dying is legal: Austria; Australia,[10] including all states[11] ; Belgium; Canada; Columbia; Germany; Luxembourg; Netherlands; New Zealand; Spain; Switzerland; and the United States, including

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[10] Voluntary assisted dying became legal for eligible individuals in New South Wales effective 28 November 2023.

[11] Although not all are yet in force.

the states of Oregon, Washington, Vermont, California, Montana, Colorado, New Mexico, New Jersey, Maine, the District of Columbia, and Hawaii (Canadian Association of MAID Assessors and Providers, 2022a). In each of these jurisdictions, legal and ethical guidelines provide a framework for assisted dying, offering a distinct perspective for comprehending the option and eligibility requirements (Emanuel, 1994; Emanuel et al., 2016; K. Wright et al., 2017). The language used in jurisdictional documents to describe the type of assisted dying is important as it identifies key elements, including the intentions[12] of the health care provider, the actions taken to aid[13] in the person's death, and whether the person's consent[14] is necessary (Emanuel, 1994).

The subject of aid in dying encompasses not just laws but also societal and cultural beliefs (Dees et al., 2013; Gamondi et al., 2015; Gamondi et al., 2018; Kimsma, 2010; Snijdewind et al., 2014). For instance, the Netherlands had widespread approval for the *Law on Termination of Life on Request and Assisted Suicide*, which occurred in 2002, with widespread support by the public and physicians for over 30 years before it was legalized (Emanuel, 1994). In Canada, over the past few decades, opinion polls have indicated that most Canadians were receptive to having some type of assisted dying as a legal option, with regional differences seen[15] (Angus Reid Institute, 2010). When the Supreme Court of Canada struck down the federal law that criminalized assisted dying in 2015, public support for assisted dying was on the rise, with physicians remaining divided about the option. Few[16] physicians at that time identified they

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[12] Include the intentional administration of the lethal medication or providing the lethal medication to the individual for self-administration

[13] Terms identified include active or passive

[14] Noted as voluntary or involuntary

[15] Quebec had the highest level of support (78%) and Alberta the lowest (49%) (Angus Reid Institute, 2010).

[16] In 2015, a significant minority of Canadian physicians, only 29 per cent, said they would be willing to assist a gravely ill patient who wants to end their life (Picard, 2015).

would be willing to assist with this choice (Forum Research, 2015; Picard, 2015). After 7 years into the legalization of MAID, attitudes toward assisted dying continue to evolve among individuals, health care providers, advocates, and society (Ipsos, 2022).

Canadian Context of Assisted Dying

Legalization of assisted dying in Canada resulted from several decades of advocacy, activism and reflection, and the legislative requirement for laws to comply with the *Canadian Charter of Rights and Freedoms*. Critical developments, including a ruling by the Supreme Court of Canada in the Rodriguez case[17] and several unsuccessful private members bills focusing on assisted dying, were crucial in the history of MAID in Canada (Martin, 2018). The turning point for MAID legalization, however, transpired in 2011 when the BC Civil Liberties Association filed a claim on behalf of Kay Carter, Hollis Johnson, and Dr. William Shoichet, who challenged the laws, and sought to allow "serious and incurably ill, mentally competent adults the right to receive assistance to hasten death under certain specific safeguards" (BC Civil Liberties Association, 2012, para. 1). Their claim was later amended to include Gloria Taylor (*Carter vs. Canada* (Attorney General), 2012). On June 12, 2012, the BC Supreme Court found the Criminal Code provisions against assisted dying to violate the rights of the seriously ill in *Carter vs. Canada* (BC Civil Liberties Association, 2012). Following this Decision in June 2014, the federal government applied to the BC Court of Appeal, prompting the BC Civil Liberties Association to appeal. The case then proceeded to the SCC.

While this case occurred at the federal level, a doctor-led movement around end-of-life care began in the province of Québec. It resulted in the introduction of legislation in the Québec

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[17] Decision came on September 30, 1993, with the Supreme Court judges' ruling in a majority 5-4 decision that section 241(b) was constitutionally valid and did not violate the *Canadian Charter of Rights and Freedoms*.

National Assembly in June 2013. By focusing on the provincial mandate to provide health care and care to the population, Québec politicians avoided attention to the Criminal Code playing out in federal court. Québec then became Canada's first jurisdiction to pass legislation allowing for choice around the right to die (Browne & Russell, 2016). The provisions in the *Act Respecting End-of-Life Care* came into effect on December 10, 2015 (Bill 52, 2014).

At the federal level, the unanimous SCC decision in *Carter v. Canada* (2015) prompted the legalization of assisted death on February 6, 2015. In its decision, the SCC declared that key sections of Canada's Criminal Code (1985) that prohibited assistance in terminating life infringed on the right to life, liberty, and security of the person by impacting the principle of fundamental justice (*Carter v. Canada*, 2015, Section 7). More specifically, the SCC identified that Sections 14 and 241(b) violated Section 7 of the Canadian Charter of Rights and Freedoms (*Constitution Act*, 1982) and declared that those sections

> are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. (*Carter v. Canada*, 2015, para. 127)

At the time of the decision, the SCC issued a 1-year extension to the federal government (followed by an additional 4 months) to allow time to address potential legislative changes (*Carter v. Canada*, 2015).

It was during this time that the government created the Special Joint Committee on Physician-Assisted Dying to develop the framework for MAID legislation. The committee sought input from various stakeholders, including interest groups, professional organizations, government representatives, community members, and regulatory bodies. The report titled *Medical Assistance in Dying: A Patient-Centred Approach* (Ogilvie & Oliphant, 2016) by the Special Joint Committee on Physician-Assisted Dying played a crucial role in shaping the final MAID legislation. Most of the committee's key recommendations became incorporated into the legislation, which also amended other federal Acts[18] (Bill C-14, 2016). MAID became permitted in Canada on June 6, 2016, but only a legal option once it received royal assent on June 17, 2016.

MAID Legislation

When MAID through Bill C-14 was legalized in June 2016,[19] eligibility criteria and safeguards were included to assure that critical elements surrounding MAID were present for individuals desiring this choice; and to protect potentially vulnerable individuals, regardless of the Canadian jurisdiction. Eligibility requirements outlined in Bill C-14 (2016) MAID legislation included that an individual have decision-making capacity and (a) be eligible for government-funded health care; (b) be at least 18 years old; (c) have a serious and incurable illness, disease or disability;[20] (d) are in an advanced state of irreversible decline in capability; (e) that the illness, disease, or disability or state of decline must cause enduring physical or psychological suffering that is intolerable to them and that their suffering cannot be relieved under conditions that they themselves consider acceptable; and (f) that the individual's natural death had become

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[18] Other acts were amended to ensure that no financial or other losses would result for individuals who chose MAID.

[19] Bill C-14 (2016), also known as Medical Assistance in Dying (MAID) legislation, is the foundation of assisted dying in Canada. Legislative changes through Bill C-7 (2021) are now recognized; however, at the time of this study, only Bill C-14 impacted study participants.

[20] Mental illness as the sole underlying reason for a request for MAID is not currently permitted. This will change as of March 17, 2024.

reasonably foreseeable (Bill C-14, 2016; Government of Canada, 2022).[21] Within the legislation (Bill C-14, 2016), an individual was expected to give their informed consent to receive MAID after having all information including the medical diagnosis, available forms of treatment, and options to relieve suffering, such as palliative care. The legislation (Bill C-14, 2016) addressed concerns of influence and coercion by stating that the request for MAID must be voluntary and not due to external pressure (Bill C-14, 2016; Government of Canada, 2023a).

Another feature of the legislation (Bill C-14, 2016) is procedural safeguards. The inclusion of safeguards was designed to balance the protection of choice and autonomy while protecting vulnerable individuals[22] and avoiding potential abuse (Bill C-14, 2016). Safeguards in MAID legislation (Bill C-14, 2016) include that an individual's request be made in writing,[23] was done so in the presence of two independent witnesses and occurred after being informed that their medical condition, disease, or disability is grievous and irremediable (2016). Following a request, an individual must undergo independent assessments by two MAID practitioners to determine that all the eligibility criteria are met, with each assessor providing their assessment results and decisions in written form. Medical assistance in dying legislation through Bill C-14 (2016) outlined a requirement for "at least 10 clear days between the day on which the request was signed … and the day on which the medical assistance in dying is provided" (Safeguards section, para. 10); however, if there was concern from both MAID assessors that an individual

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[21] In March 2021, Bill C-7 modified this criterion into two categories or tracks. There was only one-track option in this study and the participants, "reasonably foreseeable natural death" through Bill C-14 (2016).

[22] Vulnerable individuals include the elderly and people with disabilities.

[23] The request must include the individual's signature and a date.

may lose capacity during the waiting period or that the individual’s death was imminent, the legislation allowed for the 10-day waiting period to be waived (Bill C-14, 2016).

Late-stage consent was also a safeguard contained in the legislation (Bill C-14, 2016). This criterion specified that an individual requesting MAID must have the capacity to decide about ending their life at the time of their MAID eligibility assessments and at the time of the MAID provision. The legislation also outlined that regardless of the phase in the MAID process, even on the day of the planned provision, the individual could stop proceeding toward an assisted death (Bill C-14, 2016).

The legislation also articulated a safeguard related to access, specifically indicating that various forms of communication can and must be utilized for those working in MAID roles to ensure that communication does not become a barrier (Bill C-14, 2016). Medical assistance in dying legislation articulates that everyone, including MAID practitioners, are liable if they fail to comply with the requirements and safeguards outlined in the legislation (Bill C-14, 2016). If found guilty, the legislation states that the punishment could include imprisonment for up to 5 years (Bill C-14, 2016).

MAID Legislation and the Canadian Health Care System

In addition to amending the Criminal Code, Pension Act, Canadian Forces Members and Veterans Re-establishment and Compensation Act, and Corrections and Conditional Release Act, the federal government also made a “commitment to uphold the principles set out in the Canada Health Act” concerning MAID (Bill C-14, 2016, p. 2). This obligation was necessary given that decriminalizing aid in dying through MAID legislation directly affected end-of-life options and, as a result, practice and health care across Canada.

The *Canada Health Act* (1983) is the legislation that establishes principles and conditions that guide health plans in provinces and territories across Canada. This legislation allows jurisdictional decisions based on a local understanding of the five principles (universality, accessibility, comprehensiveness, portability, and public administration) as criteria for provinces and territories to frame health care (Armstrong & Armstrong, 2016). It is also a requirement for provinces and territories to qualify for federal health funding (Armstrong & Armstrong, 2016).

When MAID became legalized and brought into the purview of health care, provincial and territorial governments were given the authority to implement MAID as they determined. Some provinces used the parameters outlined in the legislation to establish guidelines and modified existing legislation[24] within their jurisdictional context (Canadian Nurses Association, 2017b; Health Canada, 2017b; Rivard et al., 2018). These amended provincial Acts addressed actual or potential MAID-related issues.[25] Additional matters have been evident in areas across Canada with demands from families, the public, advocacy groups, and scholars to develop standards, procedures and principles, or modify legislation, to address concerns and ensure that the principles of the *Canada Health Act* (1985) are upheld (Downie, 2018; Health Canada, 2017a; Mertz, 2018). For example, there are reports from across the country that provincial governments have continued to permit institutions to refrain from allowing access to or providing MAID or that provincial health authorities still need to enforce their mandates requiring MAID provision in facilities (DeRosa, 2023; Gilbert, 2020; “Group Opposes Forced Transfer,” 2022; Jones & Cousins, 2020; Russell, 2018a).

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[24] For example, the Province of Ontario’s *Medical Assistance in Dying Statute Law Amendment Act* (*Bill-84*) received assent on May 10, 2017, amending several provincial Acts relevant to the MAID context.

[25] For example, the protection of identifying information about providers and the coroner’s role in MAID.

The Organization and Implementation of MAID

After the passing of Bill C-14 in 2016, MAID implementation was widespread in the health care system throughout Canada, and how it was provided and experienced varied across the country (Dying with Dignity Canada, n.d.; A. C. Wright & Shaw, 2018). “Ambiguity” and “limited guidance” (Silvius et al., 2019, p. 398) were cited as some of the barriers to preparation at that time. The context of not anticipating or being prepared for individuals requesting MAID, including during the exemption period, created particular challenges for those individuals and their family members waiting for the changes to the Criminal Code to follow the SCC decision (Valentich, 2021). Although MAID has been legal for only 7 years, the legislation (Bill C-14, 2016) has already undergone one amendment (Bill C-7, 2021), and we anticipate further adjustments, leading to ongoing discussions about balancing the rights of individuals, health care providers, and institutions, as well as protection of vulnerable Canadians.

Implementation. MAID implementation was determined at provincial, territorial and regional levels (Ball et al., 2018; Feldstain et al., 2016; M. Li et al., 2017; Taylor, 2018). The range in implementation has been broad, with individuals accessing MAID services either by speaking with their primary care provider, accessing information via telephone, email, or through a provincial or territorial website which health care professionals monitor and respond, or, in jurisdictions where they exist, directly contacting MAID care coordination teams (Canadian Association of MAID Assessors and Providers, 2022b; Dying with Dignity Canada, 2021). Over the past 7 years, care coordination services have become more common as the primary resource for individuals seeking help with, receiving guidance on, or accessing MAID (Canadian Association of MAID Assessors and Providers, 2022b; Dying with Dignity Canada, 2021). In some jurisdictions, clinicians identify themselves as MAID practitioners[26] and can be contacted directly by individuals or family members when they want to access MAID. Often no referral is required. Once an individual submits a request for MAID to the appropriate point of contact in their jurisdiction, the MAID process[27] is activated.

MAID care coordination teams not only interact with individuals and family members, but they also support health care professionals and organizations in identifying appropriate care, facilitating patient transfers, and connecting individuals with MAID practitioners (Canadian Association of MAID Assessors and Providers, 2022b; Dying with Dignity Canada, 2021). Although care coordination teams nationwide provide similar services, each is implemented differently and comprises different interprofessional health care providers[28] (Clark et al., 2018). For example, in at least one jurisdiction, a speech pathologist is a team member and joins when beneficial for the patient or at the request of a MAID practitioner (Dunsford & Wiebe, 2018). Spiritual care practitioners are also involved with some MAID care teams (KI-14).

With nuances in MAID implementation identified across Canada, there is consistency in that MAID is provided by a diverse group of professionals working in collaboration to facilitate choice within the framework of MAID legislation and policy. The objective of MAID teams and practitioners is to appropriately address the needs of an individual choosing MAID; however,

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[26] In British Columbia, this is the case, with Island Health (n.d.), for example, listing clinicians' names and contact information on their website. As of April 17, 2022, 17 MAID providers were on the Island Health site.

[27] This may mean follow-up by a MAID team member for information gathering and the scheduling of two independent MAID assessments.

[28] Including physicians, nurse practitioners, registered nurses, social workers, and spiritual care practitioners.

how MAID implementation and provision may impact the experiences of family members or their bereavement has only begun to be uncovered.

Policy. The decriminalization of aid in dying and the subsequent introduction of MAID legislation was a paradigmatic policy shift in Canada (P. A. Hall, 1993). In preparing the legislation, the federal government did not enter into provincial or territorial domains to address how the implementation of this end-of-life option should unfold. Following royal assent, jurisdictions and institutions developed their MAID policies, which included operationalizing processes such as MAID access, inquiries, assessments and provision. Scant literature, and of this primarily in media reports, have outlined the degree to which elements of operationalization and policies have been a factor in the experience of individuals and their family members in the MAID context (Adams & Ogbogu, 2018; Goldberg et al., 2021; Grant, 2018).

In some provinces and territories, faith-based medical and long-term care institutions can decide whether to conduct assessments or offer MAID in their facilities (De Bono, 2017; Gilbert, 2020; Grant, 2018; McPhee, 2018). In some cases, MAID care teams, individuals and their family members have had to make adjustments and difficult decisions about how to gain access to MAID (DeRosa, 2023; Grant, 2018; “Group Opposes Forced Transfer,” 2022; Markusa, 2017; Rieger, 2018) including where to complete the MAID request form while residing in a faith-based institution or facilities that have chosen to refrain from allowing MAID (Russell, 2018d). At the same time, in an objecting facility, a MAID practitioner may only be permitted to initiate the eligibility process and assess the individual if the patient or resident relocates (Russell, 2018b). Other individuals admitted to objecting facilities may require family and friends to assist and facilitate access, or MAID practitioners may choose to violate the institutional policy and assess individuals onsite (Vikander, 2021).

Another group of individuals impacted are those not allowed to receive MAID in their home-like, objecting institution (DeRosa, 2023). In these scenarios, the individual who has qualified to receive MAID must be transferred to another facility or residence or not have access to MAID (Patterson, 2023). Individuals may be unaware that their access to MAID may be impacted by where they are admitted or live.[29]

In some rural and remote communities, there is also the reality that the only option for health care services is at a faith-based, MAID objecting institution. To provide context, Alberta Health Services (AHS), the single, integrated health authority in the Province of Alberta, provides all acute care services and a few palliative care beds in the South Zone of the province. In contrast, Covenant Health[30] facilities contain almost all palliative care beds in the South zone, including the hospice in Lethbridge and Medicine Hat and long-term care facilities (Dr. Dionne Walsh, Palliative Care Physician, personal communication, April 18, 2022). In order to consider the effects of non-provision facilities and their policies on individuals seeking MAID, navigators in certain zones of AHS aim to avoid admitting individuals to hospice or palliative care while they are in the process of MAID. Instead, they try to find an available bed in a secular hospice or setting that allows MAID access on-site (Dr. Misty Watson, Medical Lead–Medical Assistance in Dying Calgary Zone, personal communication, April 19, 2022).

Sometimes, people who want to receive MAID may have to move to a different facility outside their community to receive their choice (Adams & Ogbogu, 2018; Gilbert, 2020; Grant, 2018; McPhee, 2018; Rieger, 2018). Reports suggest that policies and processes not only impact individuals seeking MAID, but anecdotal information also reveals that family members can be

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[29] Faith-based residential or long-term care institutions, for example.

[30] This contracted partner is a healthcare organization led by Catholic values (Covenant Health, 2019).

affected during the assisted dying process and into bereavement (Grant, 2018; Russell, 2018e; Willick, 2018). Currently, there is minimal research on how these policies may affect the experiences of family members, their roles and responsibilities, or their grief and bereavement.

In the multi-methods study by Hales et al. (2019), surveys, focus groups and unstructured interviews were conducted with 11 family caregivers (five spouses/partners, three sons/daughters, two brother/sisters; one friend) to “identify opportunities for improvement in the delivery of MAID in [their academic] hospital setting” (Hales et al., 2019, p. 5). Potential participants were family members or friends of an individual who had accessed MAID services from this single site. They received MAID in the hospital’s inpatient or palliative care unit between July 2016 and June 2017.[31] The family members who participated in this study expressed that the MAID process caused them to feel anxious and negative as their loved ones went through it. They found the process to be complex, which added to their stress. They felt that they needed more information about important aspects of the MAID process, such as the involvement of health care professionals and how the eligibility criteria were determined (Hales et al., 2019). This research from a single centre was the first published study in Canada that highlighted that there may be aspects of MAID legislation, including eligibility criteria and components of MAID processes, that may influence the experience of family members. This study provided foundational knowledge for understanding how these aspects may impact family members and since this study was published, other research reveals similar findings (Oczkowski et al., 2020; Smolej et al., 2022; Thangarasa et al., 2021); however, conducting more extensive

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[31] Twenty-one patients received MAID from 27 eligible participants during this period. Researchers sent 23 invitations to participate. The response rate was 48%.

research with a broader jurisdictional focus is vital, given the variability identified across regions in Canada.

Regulation. The practice of MAID in health care is regulated by criminal law, making it unique in the Canadian health care landscape. MAID legislation outlines key regulatory elements, including eligibility and provision, safeguards, monitoring and oversight regulations, and death certificate guidelines (Bill C-14, 2016). Early in implementation, some of these regulatory elements were particularly burdensome for individuals seeking a MAID death, but also for their family members who may be supporting their loved one and have an active role in the process. Some of the contentious elements became addressed with amendments in Bill C-7 (2021).[32]

MAID legislation (Bill C-14, 2016) outlined that federal guidelines were to be published by the federal Minister of Health related to medical death certificates for individuals who received MAID. The medical death certificate is necessary to record an individual’s death and vital statistics for health policy purposes and to deal with an individual’s estate, insurance claims, pensions, and genealogical purposes (Brooks & Reed, 2015; Swain et al., 2005). Terms used on medical death certificates are significant from a legal and epidemiological perspective, but also from a personal view as they may stigmatize some family members or relatives of the deceased (Brown et al., 2018).

Medical death certificate guidelines for MAID were available in April 2017 for use by provinces and territories. According to the guidelines, when reporting a death resulting from MAID, it is necessary to specify that the cause of death was drug toxicity. Additionally, the

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[32] This dissertation research does not cover aspects of Bill C-7. However, you can find relevant information at: https://www.justice.gc.ca/eng/csj-sjc/pl/charter-charte/c7.html

primary medical condition that led to the MAID death be identified as the primary reason for the death, with MAID noted as a contributing factor (Health Canada, 2017b, 2023). According to federal guidelines, medical death certificates should specify the type of MAID provided and acknowledge the manner of death as ‘natural.’ (Health Canada, 2017b, 2023). These federal guidelines are non-binding elements, with some provinces and territories adopting a different approach to this oversight mechanism (Brown et al., 2018).

In 2018, an environmental scan by Brown et al. revealed variability in classifying the manner of death in MAID cases, including it being noted as ‘natural,’ ‘unnatural’ (including suicide and unclassified), and ‘MAID.’[33] According to the research, four jurisdictions followed the federal government’s directions, but none wholly adhered to the guidelines (Brown et al., 2018). Using stigmatizing or inaccurate terms on a medical death certificate could affect the reflections of family members of MAID recipients, impacting their memories of their loved one in the future and their overall after-death experience (Bridges, 2017; Taylor & Bridges, 2018). There has not been a study that reveals how the completion of these certificates may have impacted bereaved family members; there has only been anecdotal information from bereaved family members whose loved ones’ medical death certificates reported suicide following their MAID death in media reports (Taylor & Bridges, 2018).

Medical assistance in dying legislation (2016) also mandated the federal Minister of Health to regulate the collection and reporting of information related to requests for and the provision of MAID. Regulations in the original MAID legislation (Bill C-14, 2016) enforced mandatory reporting by physicians, nurse practitioners, and pharmacists on the assessment and provision of MAID (Health Canada, 2022a). With the passage of Bill C-7 on March 17, 2021,

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[33] This is evident in at least one jurisdiction in Canada.

however, amendments were required to align the regulations with the new legislation (Health Canada, 2022b).

Current Data on MAID

In jurisdictions where assisted death is permitted, monitoring is crucial. Public reports provide a clearer understanding of how legislation works and its impact. In Canada in 2018, monitoring regulations outlined in MAID legislation (Bill C-14) were enforced, mandating medical professionals involved in MAID to collect and report specific information (Health Canada, 2022a). Health Canada (2022b) prepared each report[34] in consultation with provinces and territories to ensure that the federal report aligned with those jurisdictions.

According to collected data, since 2016 there have been more than 44,958 Canadians who have chosen to end their life with MAID (Health Canada, 2023). The number of MAID provisions continues to grow steadily each year. In 2022, there was a 31.2% increase in total MAID provisions compared to the previous year, and overall there was an increase in MAID deaths seen across all jurisdictions. Within these percentages, however, there are regional differences noted in the uptake of MAID. In 2022, for example, Québec, Alberta, Newfoundland and Labrador, Ontario, and BC had the highest percentage of year-over-year increases, with rates of 45.5%, 40.7%, 38.5%, 26.8%, and 23.9%, respectively. Nova Scotia (11.8%), Prince Edward Island (7.3%) and Saskatchewan (4.0%) had lower rates.. Since the introduction of MAID legislation in 2016, the highest number of MAID cases have been reported in Ontario (13,732), Québec (14,578), BC (9,219), and Alberta (2,937; Health Canada, 2023).

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[34] The fourth year of data collection following the implementation of these regulations occurred in the latest report from 2023.

MAID deaths accounted for 4.1% of all deaths in Canada in 2022, an increase from 3.3% in 2021,2.5% in 2020 and 2.0% in 2019 (Health Canada, 2023). In 2022, all provinces except Manitoba and the Yukon continued to experience increases in the number of MAID provisions as a percentage of total deaths, ranging from a low of 1.5% (Newfoundland & Labrador) to a high of 6.6% (Québec). Québec and BC experienced the highest percentage increase of MAID as a proportion of all deaths within their jurisdiction in 2022 (6.6% and 5.5%, respectively). This trend was fairly consistent with 2020 and 2021 and reflective of the socio-political dynamics of these individual provinces. Coronavirus disease 2019 (COVID-19) was seen tocause some variation in the overall numbers of deaths in 2020. Despite the rise in deaths in 2020 due to COVID-19, however, Canada's percentage of MAID deaths remained unchanged[35] (Health Canada, 2022b).

Monitoring data shows the geographic location of MAID recipients remained consistent in 2022 compared to prior years, with the highest proportion of deaths through the practice of MAID in urban areas in Alberta and BC (84.3% and 82.4%, respectively; Health Canada, 2023); and enacted relatively equally between males (51.4%) and females (48.6%)[36] (Health Canada, 2023). According to Health Canada, in 2022, the average age of individuals who received MAID was 77.0 years old, slightly higher than in 2021 (76.3) and 2020 (75.3). Females had a higher average age of 77.9 years compared to males who had an average age of 76.1 years. There is no information at this time on the approximate gender or age of family members who were involved in the MAID process with their loved ones.

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[35] Health Canada (2022b) noted this was because the number of MAID provisions is relatively low compared to the total number of deaths in the country.

[36] This is consistent with 2021 (52.3% of males vs 47.7% of females) and 2020 (51.9% males vs 48.1% of females; Health Canada, 2023)

Most reported deaths among MAID recipients are associated with cancer-related diagnoses, comprising 63.0% of cases (Health Canada, 2023). This is consistent with statistics from other countries. The subsequent most common underlying health conditions are cardiovascular conditions at 18.8%, respiratory conditions at 13.2%, neurological conditions at 12.6%, organ failure at 7.7% to 8.6%[37] , with multiple comorbidities[38] and "other condition"[39] consolidated in reporting for 2022 and comprising 22.6% of individuals receiving MAID.

Individuals requesting MAID may have more than one underlying medical condition that can be reported for monitoring purposes, and in 2022, 25.6% of those receiving MAID had two or more underlying conditions[40] comprising 24.6% to 26.7%[41] of cases (Health Canada, 2023). These figures are similar to those reported in 2020 and 2021 and are in line with the country's most common causes of death (Health Canada, 2022b, 2023).

According to international studies, the location of an assisted death impacts the experience and bereavement of family members (Swarte et al., 2003; Wagner, Müller, et al., 2012). In Canada, private residences remain the top location for MAID provision, accounting for 39.5% of event locations, which is down from 44.2% in 2021 and 47.6% in 2020, which may have been a result of addressing public health measures due to COVID-19 (Health Canada, 2023). In 2022, just 30.5% of people who received MAID were in hospitals (Health Canada, 2023). This percentage is higher than 2021 and 2020 (28.6% and 28.0%, respectively; Health Canada, 2023). It is important to continue to monitor the reporting on these two settings for

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[37] Males and females.

[38] It encompassed various diseases or conditions, including frailty, diabetes, chronic pain, and autoimmune conditions.

[39] It encompassed osteoarthritis, osteoporosis, fractures, vision or hearing loss, dysphagia and falls.

[40] This percentage is consistent with data in 2021 (23.7%; Health Canada, 2023).

[41] Females and males.

MAID deaths given the trend of moving towards more familiar and desired environments for patients' deaths (Funk et al., 2022). In 2022, 20.8% of individuals who underwent MAID did so in palliative care facilities, slightly more than in 2021 (19.6; Health Canada, 2023). This percentage has increased from 17.2% in 2020 but is comparable to the levels observed in 2019 (20.6%; Health Canada, 2022b).[42] The percentage of provisions in residential care facilities were up in 2022 (7.6%) and other settings like medical offices, and clinics or funeral homes remained consistent at 1.5%(Health Canada, 2023). There is no published data on whether individuals seeking MAID, their family members, health care providers or policy requirements impacted the location of MAID provisions. Few Canadian studies have been published that aim to comprehend how the setting of a MAID event might affect the experiences of family members whose loved one receives MAID (Hales et al., 2019; Hashemi et al., 2021; Oczkowski et al., 2021).

To qualify for MAID, an individual must endure unbearable physical or psychological suffering due to their medical condition or deteriorating state, and this suffering is not alleviated in a way that the individual finds acceptable (Bill C-14, 2016). According to 2022 reporting, the most commonly cited source of suffering of an individual requesting MAID was their loss of ability to engage in meaningful activities (86.3%), followed by difficulty in performing daily tasks (81.9%) and inadequate or concerns about pain control (59.2%; Health Canada, 2023). These findings are similar to those from 2019 to 2021, suggesting that the type of suffering that prompts an individual to request MAID has remained unchanged over the past 4 years.[43] Data were only collected on the individual requesting MAID, there was no data on the family

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[42] This increase may be related to the easing of COVID-19 restrictions (Health Canada, 2022b).

[43] The 4 years include 2019, 2020, 2021, 2022.

members impression of their significant others' suffering or how the suffering impacted them as family members, friends or caregivers in federal monitoring data (Health Canada, 2022b).

According to reporting from MAID practitioners, in 2022, most MAID recipients (77.6%) had received palliative care (Health Canada, 2022b). This is down from 80.7% in 2021 (Health Canada, 2022b, 2023). Of those who received palliative care services in 2022 (49.9%) did so for at least a month, which is similar to the results in the previous 3 years (Health Canada, 2022b, 2023). Of the MAID recipients who did not receive palliative care (19.6%), 87.5% had access (Health Canada, 2023). These data are consistent with the results from 2019, 2020, and 2021 (89.6%, 88.5%, and 87.5%, respectively), indicating that palliative care was available and accessible to individuals (Health Canada, 2023). This reporting, however, lacks data on the quality and adequacy of the available and provided palliative care services.

During the MAID assessment, practitioners evaluate whether the individual requesting MAID needed and had access to disability support. This includes how long they received such support or whether they utilized any disability support. These data help to shape the circumstances and supports available to individuals with disabilities who seek MAID. In 2022, MAID practitioners identified that 36.8% of the individuals who received MAID needed disability support services, down from 43.0% in 2021 (Health Canada, 2023). MAID practitioners also reported most (89.5%) of those individuals received the support they needed (Health Canada, 2023). Of these individuals, 39.8% received these supports for 6 months or less, and 38.4% received services for longer than 6 months (Health Canada, 2023). For 21.9% of individuals, it was reported as 'unknown' how long the disability support was received. Unfortunately, a percentage (4.1%) of people who reported needing disability support services did not receive them; reporting suggests that 75.0% of these individuals had access to the services. These results are similar to those from the last 3 years of monitoring data (Health Canada, 2022b, 2023). It is important to note that the current MAID reporting requirements do not ask practitioners for detailed information about the type, length and acceptability of disability support services received by MAID requesters (Health Canada, 2022a).

Starting January 1, 2023, enhanced data collection requirements began to address the Regulations for Monitoring amendments within Bill C-7 (2021). In 2024, Health Canada will provide more comprehensive information in the Annual Report, based on the full year of data collected in 2023 (Health Canada, 2022b). These data include more detailed information on the type and location of palliative care services, as well as, more detailed reporting on the specific types of disability support services provided (Health Canada, 2022a).

Summary of Assisted Dying in the International and Canadian Context

Assisted dying is an option in several international jurisdictions, with Canada legalizing MAID in June 2016. Following royal assent, provincial and territorial governments implemented MAID in their jurisdictions resulting in variability identified across the country. Over the past 7 years, over 44,958 Canadians have accessed MAID, with a steady increase in MAID provisions continuing each year (Health Canada, 2023).

Key features of MAID legislation (Bill C-14, 2016), implementation processes, policies and health system factors have potentially impacted the experience of family members during the MAID process and into bereavement (Adams & Ogbogu, 2018; Downie & Chandler, 2018; Goldberg et al., 2021; Leeder & Grant, 2018; Patterson, 2023). At this time, however, there has yet to be a published study that has taken a broad perspective on how these elements may influence the experiences of family members who have had a loved one participate in MAID.

Family Members Experiences with Assisted Dying

To gain insight into the experiences and perspectives of family members throughout assisted dying, I conducted a literature review using a comprehensive list of search terms[44] in MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO databases. I also reviewed the list of published research on the Canadian Association of MAID Assessors and Providers website. The studies I found were a mix of qualitative and quantitative research, with most from Europe[45] and the United States. Of the studies, most only included one family member of the recipient of assisted dying instead of multiple members or family units. The majority of participants were female spouses of the assisted dying recipient. The primary diagnosis of the loved ones of many of the study participants was cancer (M. Li et al., 2021). The Canadian studies on MAID and family members mainly focused on one setting or region, usually at a large academic hospital in Ontario. Primarily nominated sampling strategies were employed and the studies had small sample sizes. The time from a loved one’s death to study participation ranged from months to years, resulting in varied lengths of bereavement of family members.

Although the literature on family members of assisted dying recipients is limited, the information I gathered was instrumental in shaping my understanding of this area of study and my dissertation research. I have categorized the following section into three parts for clarity. The first part explores the current understanding of the roles and involvement of family members in assisted dying. The second part focuses on the experiences of families whose loved ones have

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[44] This included physician-assisted death, medically assisted death, MAID, family members, family caregivers, grief, and bereavement.

[45] Primarily Switzerland.

undergone assisted dying. Lastly, I discuss the literature on the grief and bereavement experienced by family members after a loved one has received an assisted death.

Roles and Involvement of Family Members in Assisted Dying

The involvement of family members and individuals close to the MAID recipient may be critical in an individual's journey toward assisted death (Gamondi et al., 2015; Holmes et al., 2018) with research highlighting that family members are generally not surprised by requests for assisted dying by their loved ones, as they had expressed or alluded to this choice prior. However, family members who oppose aid in dying acknowledge that they found it challenging to discuss the option when their loved one brought it up (Harvath et al., 2006).

The experiences and involvement of family members during the assisted dying process are seen to differ depending on the location and stage of the process (Goldberg et al., 2021; Hashemi et al., 2021; Kimsma & van Leeuwen, 2007). Studies described that the location of an assisted death may impact the experiences and bereavement of family members (Goldberg et al., 2021; Hashemi et al., 2021; Swarte et al., 2003; Wagner, Keller, et al., 2012) including the policies of locations and settings that may prevent full access to MAID (Patterson, 2023). In most jurisdictions, the stages where a family member may be involved in the process include when a loved one requests this option and (if desired) discloses the request to a family member(s), during assessment and eligibility determination, when the planning and scheduling of the date of death occurs and during the reflective waiting period, during the administration of the lethal medications, and in the after-death period (Gamondi et al., 2018; Goldberg et al., 2021; Wu et al., 2018).

Two primary forms of support identified in the literature are emotional and practical or instrumental (Buchbinder et al., 2018; Ganzini et al., 2009; Holmes et al., 2018). Several factors seem to influence family members' involvement and support during their loved one's process, including the type of assisted death chosen,[46] their loved ones' capacity, family relationships, individual beliefs, and interaction with health care professionals and right-to-die advocacy groups (Buchbinder et al., 2018; Frolic et al., 2020; Thangarasa et al., 2021). In jurisdictions were assisted suicide is the option for chosen death, family members describe their involvement as a complex and burdensome undertaking because it requires them to prepare the lethal medications and assist with ingestion (Buchbinder et al., 2019; Buchbinder et al., 2018; Gamondi et al., 2018; Srinivasan, 2019). Given the burden and emotional challenges that seem to be experienced by family members when they provide support (Dees et al., 2013; Gamondi et al., 2015; Ganzini et al., 2002; Smolej et al., 2022; Thangarasa et al., 2021), it is important to consider the form of assisted death, as well as the degree and type of family member involvement and support when a loved one proceeds (Buchbinder et al., 2018; Gamondi et al., 2018; Snijdewind et al., 2014; Thangarasa et al., 2021).

During the process of assisted dying, family members had different levels of involvement and varying responsibilities, ranging from being passive to actively engaged (Gamondi et al., 2015). The level of participation by family members appears to primarily be a decision made by the individual family member, resulting in increased demands on them (Gamondi et al., 2018). In a secondary data analysis of the Vermont Study on Aid-in-Dying, Buchbinder et al. (2018) analyzed data from 19 semi-structured in-depth interviews (that had occurred between 4-30 months post-death) with family members and friends who were present at the assisted-suicide of their loved one. The family members and friends who participated in the assisted death process

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[46] Some of the practical tasks include preparing and administering lethal medication, and problem-solving adverse events.

were significantly involved, and the findings suggest that they felt deeply implicated, both socially and morally. Study participants also indicated that they had to suppress their emotions during the process to focus on their loved one and during specific periods when others in the family unit needed support (Buchbinder, 2018). It was noteworthy that family members who experienced this type of loss seemed to express minimal regret about the level of support they provided (Buchbinder et al., 2018; Ganzini et al., 2009; Kimsma, 2010; Starks et al., 2007). Studies indicate that involving family members in this type of supportive role may help reduce potential stress if they do not feel coerced or pressured (Gamondi et al., 2013; Holmes et al., 2018; Snijdewind et al., 2014).

Although family members do not have formal roles in the assisted dying process, they may be present during important periods such as the request, assessment, and death. Snijdewind et al. (2014) used this as the foundation for their research and studied the complexity of the assisted dying process from the time of the request until the death of a loved one from the perspective of family members. Twenty-six relatives[47] of 24 patients who had explicitly requested assisted dying participated. Sampling was primarily nominated, through physicians, with purposeful sampling[48] also employed. Of the family members interviewed, 19 loved ones died in the manner they had requested. In contrast, the remaining patients died through other means, such as suicide (*n* = 2) and palliative sedation until death (*n* = 30; Snijdewind et al., 2014).

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[47] Participants included 22 females and four male relatives; Connection to the deceased: 11 spouses, nine children, one parent, one sibling, one cousin, three others (including neighbour and friend).

[48] Study recruitment notices with right-to-die organizations enabled family members to self-identify.

According to Snijdewind et al. (2014), two main categories of complexity were identified in family members’ experiences: relational challenges and unexpected occurrences. Relational complexities, which typically occurred before an assisted death, were noted to involve miscommunication, uncertainty about the degree of suffering experienced by a loved one, and the time needed to come to terms with the situation (Snijdewind et al., 2014). In addition, poor collaboration and a lack of respect from those in health care seemed to make family members feel uneasy and further complicated their situations (Dees et al., 2013; Denier et al., 2010).

The second category of complexity, unexpected occurrences, is broader issues beyond relationships (Snijdewind et al., 2014). These include changes in the person’s health status or the need to transfer to a different setting on the day of their assisted death (Snijdewind et al., 2014). These factors seemed more likely to add complexity to the experiences of family members, who also feel anxiety and negative emotions due to ambiguous, unexpected, or poorly coordinated assisted dying processes (Hales et al., 2019; Oczkowski et al., 2021). Understanding the potential impact of these elements on family members, given the emotional ramifications, is important, especially in the context of governmental, organizational, and institutional policies and processes that may inadvertently create challenges and emotional unrest for family members (DeRosa, 2023; Buchbinder, 2018; Hales et al., 2019; Oczkowski et al., 2021).

Given the context that family members are often involved in the assisted dying process and their involvement may be crucial when family members chose to disengage, it was significant. The literature suggested this may be a result of moral tension or objection to the chosen option (Thangarasa et al., 2021); however, a clear understanding of why family members chose to withdraw from being involved is not well known (Gamondi et al., 2018; Ganzini et al., 2002, 2008; Snijdewind et al., 2014; Starks et al., 2007), nor is it known how their decision may impact their emotional state.

Experiences of Family Members in Assisted Dying

Assisted dying is a complex and emotional family experience (Dees et al., 2013; Srinivasan, 2019). Although it brings hope of ending their loved one’s pain and suffering, the sadness associated with the process can also be overwhelming (Frolic et al., 2020; Holmes et al., 2018; Srinivasan, 2019). These factors can cause an increase in emotional distress for family members (Hales et al., 2019; Holmes et al., 2018).

During the assisted death process, family members generally support and care for their loved ones just as they would for someone with a terminal illness (Gamondi et al., 2015). Research shows that sharing the same beliefs and values with their loved ones about end-of-life choices may facilitate active involvement and more significant inclusion and collaboration in the assisted dying process (Goldberg et al., 2021; Thangarasa et al., 2021). While support for assisted dying may be high among some family members, this attitude does not reflect an absolute willingness to participate (Emanuel et al., 2000; Frolic et al., 2020).

Engaging in the emotional work to determine one’s moral understanding and level of acceptance of an assisted death appears to be an essential responsibility for family members to undertake (Gamondi et al., 2015; Gamondi et al., 2018; Kortes-Miller, 2018; Holmes et al., 2018; Snijdewind et al., 2014; Starks et al., 2007). Studies highlight that moral dilemmas may be quite common for family members connected to aid in dying and that these dilemmas appear to be a result of tension between family members support of a significant other and their decision, and being morally ambiguous about the choice (Frolic et al., 2020; Gamondi et al., 2015; Ganzini et al., 2009; Harrison, 2018; Holmes et al., 2018). According to Gamondi et al. (2015), some family members also perceived their moral dilemmas as unrecognized by health care professionals, friends or other relatives.

Family members with passive involvement in their loved one's assisted dying process are more likely to experience moral dilemmas, according to Gamondi et al. (2015). In these situations, family members are more likely to report a significant burden associated with their moral tension (Frolic et al., 2020; Gamondi et al., 2015). According to researchers, family members appear to experience moral dilemmas during two main times in the assisted dying process (a) when a significant other contemplates assisted dying and (b) during the planning and administration phase of assisted dying (Buchbinder et al., 2018; Gamondi et al., 2018).

In situations where an advanced request for assisted dying is in place but their loved one is not capable of providing verbal consent at the time of death, experiences can become morally complicated (Variath et al., 2020). In these cases, research reveals that family members may be reluctant to adhere to the advanced request and through this, tend to experience distress (de Boer et al., 2011). Similarly, moral tension can occur when family members cannot observe and understand that a loved one is suffering, making it challenging for them to support their loved one's choice for an assisted death (Dobscha et al., 2004; Snijdewind et al., 2014).

While respect for autonomy and understanding the degree of suffering experienced by their loved ones appears foundational for supporting this choice of death (Dobscha et al., 2004; Frolic et al., 2020; Ganzini et al., 2008; Holmes et al., 2018; Snijdewind et al., 2014), the literature does not connect this with a resolution of family members' moral dilemmas (Gamondi et al., 2015). For some, their ethical conflicts may continue throughout most of the assisted dying process, with resolution tending to be identified in the immediate after-death period. For others, unresolved moral dilemmas may continue for months to years following the death (Frolic et al., 2020; Gamondi et al., 2015). Given this, it is vital to further understand the ethical conflicts that may be experienced by family members of recipients of assisted dying, and if or when these dilemmas resolve.

In the first published study in Canada focusing on family members and MAID, Holmes et al. (2018) used a qualitative approach to study the experiences of these individuals at a Vancouver, BC, clinic within the first 9 months following the *Carter v. Canada* (2015) decision. The researchers used convenience sampling, and 18 individuals participated. Through thematic content analysis, the findings revealed that although family members may not have been initially comfortable with their loved one's choice, they eventually came to support it. An element of this study that may have influenced family members' comfort and choice for MAID included that some interviews occurred soon after legalization, before royal assent of the legislation (Holmes et al., 2018). Other studies also describe that individuals with fewer religious beliefs and those with health concerns themselves may be more likely to support a loved one's desire for assisted death (Ganzini et al., 2006; Ganzini et al., 2008; Ganzini et al., 1998).

A multi-methods study by Hales et al. (2019) was the second Canadian study to be published related to family members and MAID. In this study, the researchers used structured surveys, focus groups, and unstructured e-mail and telephone conversations to understand MAID delivery from the perspective of family members at a large academic hospital in Toronto, Ontario. During the study period, 21 MAID deaths occurred and 11 family members participated. A qualitative descriptive approach guided the identification of themes with two broad categories acknowledged: operational and experiential improvements (Hales et al., 2019). Operational improvements connect to the complexity and lack of clarity with the MAID process and eligibility criteria resulting in increased anxiety and negative emotions among some family members. Unexpected challenges that potentially impacted the MAID event, such as rescheduling the date or location of death, were also distressing for some family members (Hales et al., 2019). These complexities are similar to those in international studies (Snijdewind et al., 2014).

This study conducted by Hales et al. (2019) is crucial to understanding Canada’s MAID landscape. There is an indication from this research that assisted dying legislation, policies, and processes may impact the experiences of family members. The findings also emphasize the need to explore various study settings and regions to consider other factors that may also complicate or alleviate the effects on family members.

In a qualitative study conducted by Gamondi et al. (2015), 11 family members of cancer patients who died through assistance were interviewed. The study discovered that family members faced moral and ethical challenges both before and after the death of their loved ones. Some participants reported feeling like they were going against cultural norms by assisting in their loved ones’ request for assisted dying, while others worried about being blamed for the death and facing social stigma. When confronting challenges, family members weighed factors such as the patient’s autonomy, degree of suffering, and the inevitability of death. Keeping promises to their loved ones and considering assisted death as an alternative to unassisted suicide were also considered. Unfortunately, some family members reported ongoing concerns about these issues years after their loved ones died (Gamondi et al., 2015). This study also revealed that many family members experienced feeling isolated because they feared judgement, stigmatization, or getting involved in moral and ethical conflicts with family members or friends.

According to Gamondi et al. (2015), some family members experienced isolation when trying to keep the type of death a secret. They created boundaries that prevented them from discussing their loved one's choices, making it difficult to process their experiences (Gamondi et al., 2015; Hales et al., 2019; Roest et al., 2019). Ciesielski-Carlucci and Kimsma (1994) conducted a study in the Netherlands with a focus on nondisclosure of an assisted death of a loved one. Researchers found that when physicians failed to disclose an assisted death, it caused complications and tended to make family members uneasy because of the secrecy about the type of death (Ciesielski-Carlucci & Kimsma, 1994). Other studies supported the findings that family members are more likely to encounter difficulties when they are unable to discuss their loved one's choice of death openly, leaving them with the impression that they should maintain secrecy about it (Brown et al., 2020b; Dees et al., 2013; Frolic et al., 2020; Gamondi et al., 2019; Roest et al., 2019). This burden of secrecy seems to impact family members' ability to process their experience while also causing stress and anxiety (Gamondi et al., 2015; Hales et al., 2019; Roest et al., 2019).

Establishing and upholding relationships can foster a positive experience for family members (Hashemi et al., 2021). Additionally, ensuring elements such as effective communication, collaboration, and mutual respect within personal relationships and those with the health care team seem to enhance the positives in family members' overall experience (Beuthin et al., 2018; Crumley et al., 2023; Dees et al., 2013; Denier et al., 2010). By incorporating these social elements, family members may also be better able to address the secrecy and isolation inherent in their experiences (Brown et al., 2020; Dees et al., 2013; Frolic et al., 2020; Goldberg et al., 2021; Roest et al., 2019; Variath et al., 2020).

Family Members' Grief and Bereavement

Experiencing grief after losing someone important is a common response (Swarte et al., 2003). According to the Canadian Hospice Palliative Care Association (2017), around five people are affected by grief for each death in Canada (Beuthin et al., 2021). As access to aid in dying increases due to legislative changes, shifting attitudes about assisted death, and provisions, a rise in the number of individuals who become bereaved following an assisted death is expected (Yan et al., 2022).

Throughout this section, I discuss several factors that can affect the experience and quality of grief of family members following the assisted death of a loved one. There is, however, limited research focused specifically on the grief and bereavement in this group of individuals. Of the studies published, only one has shown that family members present during assisted death had a higher occurrence of post-traumatic stress disorder and depression than the general[49] population (Wagner, Müller, et al., 2012). In this research, Wagner, Müller, et al. (2012) studied the experience of witnessing the assisted death through assisted suicide. According to their cross-sectional survey, 13% of the participants met the full post-traumatic stress disorder criteria, while 6.5% met the partial post-traumatic stress disorder criteria. Additionally, the researchers found that 16% of the participants had a higher prevalence rate of depression compared to similar groups. The prevalence of anxiety among participants was 6%. There were no significant gender differences among participants in diagnoses of depression, anxiety or general functioning. The researchers noted that 4.9% of the participants showed signs of complicated grief, which characterizes grief as separation distress, including being preoccupied with thoughts of the deceased, longing for them, and feeling lonely (Wagner, Müller, et al., 2012). The prevalence rate of 4.9% is similar to complicated grief after a significant bereavement (Wagner, Müller, et al., 2012).

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[49] Swiss population.

Additionally, traumatic distress was present, which involves feeling disbelief about the death, mistrust, anger, shock, and somatic symptoms. These symptoms caused significant impairment for some family members, leading to a clinical diagnosis (Forstmeier & Maercker, 2007). It is unclear whether the rates of post-traumatic stress disorder, depression, or grief in study participants differed from those experienced by bereaved family members who witnessed a loved one's natural death or death from another cause during the same time frame. Additionally, it is uncertain whether the level of connection and involvement with the individual and the assisted suicide process varied among bereaved family members, and if this could be a factor (Wagner, Müller, et al., 2012).

Conversely, other studies have shown no significant disparities in psychological factors, such as prolonged grief, depressive symptoms, or the need for mental health services following the death of a loved one through assisted means (Andriessen et al., 2020; Crumley et al., 2023; Ganzini et al., 2009; Hashemi et al., 2021; Laperle et al., 2022). Although psychological symptoms may also go unrecognized by health care professionals (Boivin et al., 2019; Brown et al., 2020a; Crumley et al., 2021; Gamondi et al., 2018), one of the first studies, and one of the first to focus on bereaved family members, included two groups of participants, bereaved family and friends of cancer patients who (a) died by euthanasia (*n* = 189) or (b) died from natural causes (*n* = 316). According to this cross-sectional study, family members involved in the assisted dying process seemed to experience fewer grief symptoms and post-traumatic stress reactions. Both groups had similar levels of depressive symptoms but family members of euthanasia recipients scored slightly better on general well-being compared to family members of individuals who died naturally (Swarte et al., 2003).

The level of agreement with the decision for a loved one to receive an assisted death can also impact the amount of grief experienced by family members or friends (Pronk et al., 2021; Srinivasan, 2019). Those who agree to support their loved one may feel guilty about being involved, which can complicate their grief (Beuthin et al., 2021; Crumley et al., 2023; Frolic et al., 2020). Even those who are only passively involved may feel uneasy (Buchbinder et al., 2018; Oczkowski et al., 2021). Researchers highlighted that encouraging families to enter into conversations early in the end-of-life process (Schutt, 2020) may be one way to improve the quality of their grief and bereavement when assisted dying comes into focus (Andriessen et al., 2020; Gamondi et al., 2019; Hashemi et al., 2021; Pronk et al., 2021).

When supporting a loved one through to an assisted death, having open and collaborative health care professionals in the process can ease the grieving of family members (Crumley et al., 2023; Yan et al., 2022). A systematic review of end-of-life care from the perspective of family caregivers found that family caregiver involvement and preparation tended to lead to better outcomes in bereavement (Nielsen et al., 2016). A Canadian study by Hashemi et al. (2021) also found that positive interactions between health care professionals and family members led to a better understanding of the MAID process and suggested a more positive bereavement experience. Hashemi et al. (2021) noted possible elements to foster this positive experience included a lack of perceived barriers to MAID, lack of judgement by health care professionals, including overt support for MAID, enabling caregiving and MAID provision in the home setting. Several other factors can lead to less grief, even less complicated grief according to the literature. These include knowing the date of their loved one’s death (Oczkowski et al., 2021), having open conversations before the death and possibly resolving any issues (Beuthin et al., 2018), and being able to say final words to their loved ones (Swarte et al., 2003). However, planning the day of death can cause emotional upheaval for some family members, which may continue into bereavement (Brown et al., 2020a; Holmes et al., 2018; Smolej et al., 2022).

Interactions with others, and relationships, may cause bereaved family members to have a complicated experience, particularly when a health care professional(s) or family member decides not to be involved in the process (Brown et al., 2020b; Crumley et al., 2023; Hales et al., 2019; Ho et al., 2021). When values conflict, either from a professional or personal perspective because of moral tension with the choice for an assisted death, boundaries and emotional distancing appears to occur (Crumley et al., 2023; Gamondi et al., 2019; Lowers et al., 2020; Thangarasa et al., 2021). Studies suggest the potential consequences of this are families experiencing increased stress and anxiety, and a higher risk of prolonged and complicated bereavement (Beuthin et al., 2021; Goldberg et al., 2021; Wagner, Keller, et al., 2012).

Inconsistent coordination and planning of an assisted death can also increase anxiety and distress during family members' grief (Hales et al., 2019; Smolej et al., 2022). Frolic et al. (2020) described that family members may be left with challenges during their bereavement period when discussing their experience candidly with others or when feeling that their loved one's death was somehow more stigmatized than other ways of dying.

In end-of-life care, the stigma surrounding assisted dying appears to be a significant issue. As discussed previously, some family members hesitate to disclose their loved one's decision to pursue assisted dying due to various concerns, many related to the issue of stigma and secrecy (Andriessen et al., 2020; Bruce et al., 2020; Frolic et al., 2020; Gamondi et al., 2015; Wagner, Keller, et al., 2012; Yan et al., 2022). These concerns may be in reference to the perceived societal stigma of the type of death (Hales et al., 2019; Srinivasan, 2019), worry about how relatives will react (Crumley et al., 2023; Hashemi et al., 2021; Oczkowski et al., 2021), or the controversial nature of the death (Yan et al., 2022). Unfortunately, these worries can cause added burden and distress, even during bereavement (Crumley et al., 2023). Mental health issues, specifically post-traumatic stress disorder and complicated grief, tend to be found to be more severe when disclosure about an assisted death is kept a secret because of a fear of disapproval (Wagner, Keller, et al., 2012). Research by Gamondi et al. (2015) also indicated that secrecy surrounding an assisted death, whether self-imposed or by request from a loved one, may result in fewer opportunities for family members to discuss their experience and reduced the circumstances where another could share in the death experience (Gamondi et al., 2018; Hales et al., 2019; Srinivasan, 2019). This made some family members develop a higher risk for post-traumatic stress disorder (Gamondi et al., 2015; Wagner, Müller, et al., 2012) and other psychological issues (Ganzini et al., 2009; Wagner, Keller, et al., 2012).

Some family members indicate that receiving support and talking about the assisted death of a loved one can positively impact their well-being, even during the grieving process and into bereavement (Gamondi et al., 2018; Hashemi et al., 2021). These insights complement the research by Ciesielski-Carlucci and Kimsma (1994), which suggested that disclosure and open communication about assisted death were ways of providing a more natural grief process for bereaved individuals.

Another feature of assisted dying is anticipatory grief. Although not unique to assisted dying, anticipatory grief is associated with expecting impending death (Yan et al., 2022). Since assisted dying allows an individual to choose a date of death and enables the preparation and planning for their end of life, anticipating a loved one’s death is an important part of a family member’s experience (Beuthin et al., 2021). Knowing the exact day of a loved one’s death can be both helpful and stressful for family members, as it removes uncertainty about when the death will happen (Frolic et al., 2020; Thangarasa et al., 2021). For some family members, they described experiencing anticipatory grief to a greater extent than grief following the death of their loved one (Hales et al., 2019). Setting aside their feelings so they can support a loved one to an assisted death (Buchbinder et al., 2018; Crumley et al., 2023; Gamondi et al., 2015; Gamondi et al., 2018; Lowers et al., 2020) appears comforting for some family members because of being able to fulfill their loved one's wish and see an end to their suffering (Hashemi et al., 2021; Holmes et al., 2018; Schutt, 2020; Srinivasan, 2019).

There is scant literature available that specifically addresses the impact of bereavement support on family members (Gamondi et al., 2013). In the studies where family members did receive psychosocial support, they suggested that these supports appeared crucial to their aftercare and bereavement experience (Smolej et al., 2022). Some bereavement studies also highlight that interdisciplinary bereavement support would ideally begin before the assisted death and into aftercare and bereavement (Brown et al., 2020a; Hales et al., 2019), with indications that the greatest need for support occurring close to and on, the day of death (Hales et al., 2019).

Connecting with individuals with similar experiences or perspectives during bereavement was noted in the literature as important (Smolej et al., 2022), as this appeared to lead to feeling less judgement (Gamondi et al., 2015). However, bereaved family members generally did not require specialized support services or more intensive aftercare than individuals bereaved by other forms of death (Laperle et al., 2022). The logistics of accessing bereavement support following the death tends to be challenging for some family members because of the emotional investment while attempting to return to their usual activities (Hales et al., 2019) and due to concerns of being judged or confronted by an individual who objected to their loved one's choice

(Bruce et al., 2020; Crumley et al., 2023; Yan et al., 2022). Overall, the literature indicated minimal consensus on which supports would be valuable for bereaved family members (Smolej et al., 2022).

Summary of Literature on Family Members and Assisted Dying

When assisted dying becomes part of the end-of-life trajectory for an individual, research suggests that family members may be vital for this type of death to proceed as desired (Gamondi et al., 2015). Having shared values about the type of death with a loved one may permit greater engagement in the process, but not necessarily (Emanuel et al., 2000; Frolic et al., 2020; Gamondi et al., 2015; Gamondi et al., 2013; Gamondi et al., 2018). According to the literature, family members seem to consider many factors in determining their level of involvement in the assisted dying process. Personal and broader factors influence this. Family members provide emotional and practical support during the assisted dying process (Ganzini et al., 2009; Hashemi et al., 2021), with positive aspects acknowledged within both categories (Holmes et al., 2018; Starks et al., 2007; Swarte et al., 2003). Regardless, family members can play a vital role in most instances of assisted suicide (Buchbinder et al., 2018; Gamondi et al., 2015; Gamondi et al., 2018; Snijdewind et al., 2014) and seem to be not well supported during their experience (Brown et al., 2020a; Gamondi et al., 2018; Holmes et al., 2018; Roest et al., 2019; Thangarasa et al., 2021; Trouton et al., 2020; Variath et al., 2020).

As this section outlined, family members can experience challenges related to their involvement in the assisted dying process, including feelings of guilt and isolation, the need for secrecy, and a sense of burden (Ciesielski-Carlucci & Kimsma, 1994; Crumley et al., 2023; Gamondi et al., 2015; Hales et al., 2019; Holmes et al., 2018; Swarte et al., 2003; Wagner, Keller, et al., 2012). Moral dilemmas may also emerge for family members. Unfortunately, the type and impact of psychological or other types of support are not well-detailed in the literature (Gamondi et al., 2015; Hales et al., 2019).

The available research has offered a suitable foundation for comprehending the experiences of family members when a loved one receives an assisted death. However, gaining more knowledge related to the Canadian context, one which builds on international findings, is necessary. This review suggests various aspects of MAID legislation could impact the experiences of family members. Additionally, understanding the possible influence of MAID policies, processes, and procedures on the experience of family members is also essential, particularly given the evolution and amendments to Canadian MAID legislation that has, and is, expected (Hales et al., 2019; Oczkowski et al., 2021). To gain an understanding of how different settings and locations affect experiences during the process and into bereavement, conducting studies beyond individual hospital units or settings would also be useful for knowledge development (Hashemi et al., 2021).

Chapter Summary

After the legalization of MAID, provincial and territorial governments had the authority to implement it as they saw fit. Health Canada (2023) reports an increasing number of Canadians choosing this option. However, their monitoring data focuses on the individual receiving MAID rather than family members or caregivers. Nevertheless, family members' support seems to be crucial when a loved one chooses assisted death, and their involvement may address complexities associated with this option (Buchbinder et al., 2018; Ganzini et al., 2009; Kimsma, 2010; Starks et al., 2007).

Also noted in the literature are that family members' roles and responsibilities during this time seem to impact their loved one's experience and themselves (Arnup, 2018; Stajduhar, 2003;

Stajduhar et al., 2010). Of published research, international jurisdictions where laws, society, and cultural perspectives differ from Canada are central locations of this knowledge. While there has been a notable increase in studies published on family members whose loved ones have chosen MAID within the past 7 years that contribute to our understanding of these experiences (Beuthin et al., 2021; Boivin et al., 2019; Brown et al., 2020b; Crumley et al., 2023; Frolic et al., 2020; Hales et al., 2019; Hashemi et al., 2021; Holmes et al., 2018; Laperle et al., 2022; M. Li et al., 2021; Schutt, 2020; Smolej et al., 2022; Thangarasa et al., 2021; Yan et al., 2022), a knowledge gap exists concerning how family members may be involved in the MAID process in different settings and what factors may have impacted their experiences, including bereavement. Some factors identified in the literature include legislation, policy, and procedures. Conducting an exploratory study in this area can offer pragmatic knowledge for MAID practitioners, health care providers, health care leaders, health and social care educators, and advocacy groups. The findings of this study may help improve MAID programs and supportive interventions for family members while prioritizing the individual requesting MAID, overall, leading to a more positive experience for family members during the assisted dying process and in their bereavement.

Chapter 3: Methodology

This chapter will first provide an overview of the interpretive description approach, including theoretical scaffolding, a synopsis of the theoretical framework, and relational ethics used to orient this research, including the rationale for my choice of methods. Then, I will outline the methodological considerations relevant to the study's design, including detailing the recruitment and sampling approach, data collection strategies, and the process I undertook for data analysis. Finally, I discuss the methods used to optimize the research integrity and will respond to anticipated and unexpected ethical considerations.

Interpretive Description

Interpretive description is a qualitative methodology developed by nursing scholars to address the challenges of using social science research methods in applied health fields such as nursing (Thorne et al., 1997). The interpretive description approach aims to address these challenges by implementing effective strategies during the research process, resulting in tangible benefits for individuals involved in or utilizing health care. The interpretive description methodology draws from various research approaches, including grounded theory, phenomenology, and ethnography (Thorne, 2014). Rather than having rigid elements, interpretive description condones a degree of flexibility that "search[es] out and explore[s] features… of a common issue" to understand and recognize the complexity of a phenomenon (Thorne, 2016, p. 83).

Undertaking interpretive description for this doctoral research enabled the identification of patterns and commonalities of the experiences of bereaved family members of MAID recipients while retaining individual variation that was meaningful and applicable (Hunt, 2009) in a phenomenon where diversity in implementation, policy and processes has been identified

(Health Canada, 2018, 2023). This research methodology also enabled the contextual understanding of the experiences of bereaved family members to be uncovered and for this knowledge to be presented in a meaningful way for MAID practitioners, nurses, health care administrators, non-profit leaders, and other health care providers (Teodoro et al., 2018; Thorne, 2008b, 2016; Thorne et al., 1997).

The process of scaffolding is a crucial feature of interpretive description that allows for incorporating disciplinary, theoretical and practical knowledge into the study frame (Thorne, 2008b, 2016). Scaffolding unfolds in two ways: through a review of the literature and theoretical foregrounding (Thorne, 2008b). In the previous chapter, the literature review focused on family members' experiences at end-of-life, a review of research and the current knowledge on assisted death in international and Canadian contexts, and a scan of MAID legislation, processes and policy documents. This review was one element in the scaffolding of this study and, through it, identified that family members' support in the assisted dying process was crucial and may be a way to address complexities associated with the assisted death process and that regardless of their level of involvement, some family members experience moral dilemmas. The literature review also highlighted that this study might be the first, within the Canadian context, to focus on how MAID legislation, policy, processes, and guidelines may have influenced the experience of family members whose loved ones received assisted death.

The second scaffolding element, theoretical foregrounding, entails explicating the researcher's personal, academic, and disciplinary understanding (Thorne, 2016). This feature is designed to help shape the study and determine the potential impact of the findings based on the researcher's knowledge (Teodoro et al., 2018; Thorne et al., 2016). Interpretive description research is philosophically underpinned by fundamental beliefs about knowledge and knowing, including its nature, different forms, and where it resides. As such, the theoretical stance and methods we adopt to guide the research influence these ontological and epistemological understandings and are explored in interpretive description research through theoretical foregrounding.

Epistemological and Foregrounding Orientation

How we conduct research is influenced by our beliefs about knowledge, such as what it consists of, what forms it can take, and who can possess it (Campbell & Bunting, 1999; Crotty, 1998). These beliefs are shaped by the theoretical views and methods we use to guide our research, and we choose theoretical perspectives and strategies based on our beliefs (Crotty, 1998). This section explores my approach to this study, including my epistemological and theoretical foregrounding and focus on relational ethics in the research process.

Theoretical Foregrounding

In the following section, I explain my disciplinary and philosophical standpoint and outline relational ethics, which influenced my perspective on this study. I will begin by discussing my position as a researcher, my chosen topic, and the principles that directed my research. Before proceeding with designing the study, I engaged in critical self-reflection to establish my initial position based on my knowledge and subjective understanding of the research topic for this study (Thorne et al., 2004). Reflecting on my researcher and clinical practitioner positioning, life experience, beliefs, and theoretical viewpoint, which were all crucial factors in designing this study.

Researcher Positioning

I have worked as a Registered Nurse for over 20 years, specializing in oncology and palliative care. I am an Associate Professor at a teaching-focused undergraduate university in

Western Canada, teaching in the Bachelor of Nursing program. My research is therefore grounded in the discipline of nursing.

When MAID became a legal option for individuals, it seemed to me that it might create moral challenges for family members, friends, health care professionals, and within health care institutions. As a nurse, I understand the importance of a broad understanding of the phenomenon of MAID, which includes knowledge about conscientious objection, death, dying, palliative care, family members and caregivers in the context of a life-limiting illness, end-of-life care, grief, and bereavement. This perspective was crucial in developing this study as it brought my attention to these experiences which may have been overlooked or given less attention in other research methodologies.

Disciplinary epistemology provides the intellectual structure for interpretive description methodology, with no requirement for positioning a formal theory within the design (Thorne, 2016; Thorne et al., 2016). Instead, interpretive description considers a discipline’s principles, elements, and assumptions, which form the basis of a study’s design (Hunt, 2009; Pesut & Johnson, 2008; Thorne, 2016). As a researcher, I focus on nursing’s disciplinary epistemology, which emphasizes the uniqueness of the individual human experience, its diversity, and how it can relate to knowledge in the context of larger populations (Thorne & Sawatzky, 2014). In this study, I considered the crucial role of the natural world in the lives of individuals and families and the context of their communities and the broader population, meaning the natural world’s influence, impact, and complexity are essential disciplinary epistemology elements for this research (Thorne & Sawatzky, 2014). As a doctoral researcher, I needed to recognize and acknowledge the significance of contextual factors to attain an understanding of the knowledge landscape related to MAID and foster meaningful learning. These factors encompassed social, political, structural, ethical, and cultural aspects, which all may potentially influence the experiences of MAID recipients' bereaved family members (Rodney et al., 2013).

Clinical Perspective

Through my experience in clinical practice, I have gained a unique perspective on cancer and end-of-life care. I firmly believe that health and social care practitioners can integrate palliative care and MAID within patient-centred approaches, despite there being tension between the two (Amies, 2018; Dierickx et al., 2018; Downar et al., 2023; Gamondi et al., 2018; A. C. Wright & Shaw, 2018). Some of the strongest advocates and voices in hospice palliative care have declared that "euthanasia and physician-assisted suicide are incompatible" with palliative care (Dierickx, 2018, p. 115), and prominent organizations released a *Joint Call to Action* that states that "MAiD is not part of hospice palliative care; it is not an 'extension' of palliative care nor is it one of the tools 'in the palliative care basket'" (Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, 2019, para. 2). I however, believe that the common principles of palliative care and MAID provide a strong foundation from which to provide patient-focused, family-centred care.

Palliative care is a specialized type of care to improve patient well-being, dignity, and quality of life by relieving suffering, including when an individual is diagnosed with a life-limiting illness (Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, 2019; Canadian Institute for Health Information, 2023; Sumner, 2017). Through quality palliative care, an individual's physical, psychological, social, spiritual, and practical concerns are inquired about, and efforts are made to address them (Canadian Hospice Palliative Care Association, n.d.). A palliative approach to care focuses on patient autonomy and broadly on the well-being, quality of life, and reduction of harm to families (Canadian Hospice

Palliative Care Association, n.d.; Hentelef et al., 2011; Stajduhar & Mollison, 2018). Access to and integration of quality palliative care in Canada varies from setting to setting and across jurisdictions (Reimer-Kirkham et al., 2016; Stajduhar, 2011). Health care professionals acknowledge that palliative care is consistently inadequately funded, creating challenges to providing quality care that eases suffering and supports dignity and quality of life (Canadian Hospice Palliative Care Association, n.d.; Canadian Institute for Health Information, 2023).

For practitioners involved in MAID, their focus is also on patient autonomy and on relieving the suffering of the individual (Canadian Association of MAID Assessors and Providers, 2020; Downar et al., 2023; Sumner, 2017). As outlined in MAID legislation (Bill C-14, 2016), which is foundational for health care professionals working in this practice area, an individual's right to self-determination and choice is essential. As the Canadian Association of MAID Assessors and Providers (n.d.) outline in their document on *End-of-Life Care and MAiD*, "MAiD should be included as an option in all end of life goals of care conversations with potentially eligible patients" (para. 5); "should a patient choose to pursue MAiD … all medical care, including palliative care if involved, should be continued" (para. 4). Meaning acknowledging and respecting an individual and their wishes, which may include an assisted death, is a core element in the work of MAID teams (Canadian Association of MAID Assessors and Providers, 2020; Woods, 2005).

There are common principles that palliative care and MAID share such as relieving suffering, upholding dignity, respect, and respecting an individual's right to make their own choice as they sometimes prioritize quality over quantity. These commonalities make them compatible with a person-focused approach during end-of-life care (Sumner, 2017).

Finding My Question

I was aware of the Supreme Court of Canada’s decision in *Carter v. Canada* (2015) related to physician-assisted dying; however, my awareness elevated when I attended a national oncology nursing conference in Toronto, Ontario, in 2015. I attended the conference before the implementation of Québec’s Act Respecting End-of-Life Care (2013) and during the Supreme Court of Canada’s 16-month suspension of the *Carter v. Canada* (2015) decision. In a workshop titled “Medically Assisted Death in Canada: Careful and Thoughtful Practice Directions for Oncology Nurses,” I listened to my nursing colleagues express their concerns about how MAID would affect their patients, family members, and nursing practice. Their worries changed my professional focus and research interest toward MAID.

I have actively sought knowledge about MAID and assisted dying since October 2015. This has involved connecting with individuals with firsthand experience with this option. Along the way, I have interacted with bereaved family members who have had a loved one receive MAID. Through these experiences, I have come to understand the diverse complexity surrounding MAID. For example, choosing MAID may conflict with the moral beliefs of a family member or the individual’s support community, such as a religious community. Before conducting this study, I learned about and from individuals and their family members who went through the MAID process and faced challenges, such as being estranged from loved ones or their community, accessing MAID, or issues of competency (e.g., when to receive MAID with the requirement for late-stage consent[50]).

One advantage of using interpretive description methodology is that I could use the knowledge I obtained from speaking with family members and health care professionals

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[50] The eligibility criteria and safeguard in Bill C-14 (2016) was late-stage consent.

involved in MAID and palliative care and the literature in the research design. This knowledge provided important foregrounding for this study and fostered the development of a credible and more meaningful study (Hunt, 2009; Thorne et al., 2016).

Philosophical Perspective

Knowledge, including nursing knowledge, is not discovered but rather is socially constructed (Creswell, 2014). The context and people involved influence and create the knowledge (Crotty, 1998; Lincoln et al., 2011). I recognize that there can be multiple realities within a single experience and that truth can be subjective. My perspective on individuals, families, nursing, and health care is shaped by a feminist and critical social justice perspective, allowing me to gain a more profound understanding.

Theoretical Orientation: Relational Ethics

I approached my research with a concern for the ethics shaping health care practices and moral values. Since health care and end-of-life care are complex and involve multiple perspectives (D. Wright et al., 2009), I used relational ethics as a foundation for this study. Through this, I recognize that every action, decision, and experience are interconnected and that individuals have layered understandings of experiences (Bergum & Dossetor, 2005), including the experience of bereaved family members of MAID recipients.

Relational ethics was developed by Bergum and Dossetor (2005) through a research project that aimed to identify the ethical commitments necessary for everyday health care situations (Keyko, 2014). This study resulted in a conceptualization of relational ethics emphasizing the importance of justice and a care ethic while also valuing autonomy through connection and recognizing the significance of ethical questions in our practice environments

(Austin et al., 2003). Additionally, the study highlighted the impact of practice environments on moral responses.

In relational ethics, which emphasizes the moral responsibility of nurses to understand and appreciate our patients’ unique perspectives and vulnerabilities, it is essential to prioritize building quality relationships with individuals, families, communities, and populations (Thiele & Dunsford, 2017). The foundation of relational ethics lies in creating a moral space, or relational space, where patients, family members, and health care providers in health care environments or society can come together and share experiences and perspectives (Bergum & Dossetor, 2005). By focusing on relationships, nurses can better ensure ethical action and compassionate care according to the relational ethics framework.

Bergum and Dossetor (2005) stress the importance of viewing relationships and moral space in health care from three levels: micro, meso, and macro. They contend that interprofessional interactions and broader factors, such as social and structural contexts and power structures within the health care system, intertwine with a patient or family’s experience at the bedside. These factors can impact individuals and families (K. Wright et al., 2017). Therefore, it is important to consider these factors comprehensively within relational ethics rather than from a narrow perspective. Bergum and Dossetor believed that this type of relational paradigm could advance the health of individuals in society (2005).

Relational ethics involves four main components: engagement, mutual respect, embodiment, and environment (Bergum & Dossetor, 2005). These aspects are essential to relational ethics and can be used to analyze the experiences of bereaved family members whose loved ones received MAID. The following section will provide an overview of these relational elements.

Environment. In a relational ethics framework, when considering ethical action in the relational space, the environment is seen to play a significant role (Bergum & Dossetor, 2005; Keyko, 2014). The environment is not just the individual or the system but a combination of both (Bergum, 2013). This perspective of the environment is called a “living system” (Doane & Varcoe, 2013, p. 129) and comprises various contextual factors that change with daily activities. It allows people to interact, understand, and address one another’s needs.

According to K. Wright et al. (2009), in palliative care nursing, the environment is a metaphor that helps us understand the complexity and interdependence of families. Illness does not just affect the individual - it also challenges family members and their relationships (Meiers & Brauer, 2008). This conception of the environment was an essential consideration in this study.

The environment also comprises the health care system’s effect on one’s quality of relationships with self, individuals, families, and communities. Bergum (2013) suggested this aspect of the environment is a complex, dynamic, and interdependent system that requires a nurse, or other health care professional, to assess, adjust, and readjust continuously to engage in respectful relationships. As an example, many health care and hospital policies reflect the importance of self-determination, autonomy, informed decision-making, and transparency as key values (Armstrong & Armstrong, 2016; T. Bryant, 2016) in policies and guidelines, yet they may conflict with the beliefs of some individuals or make it difficult for nurses and other health care professionals to build strong relationships with patients and families (Bearskin, 2011). These factors are essential to consider in the context of MAID.

Embodiment. According to Bergum (2013), the concept of embodiment acknowledges that the physical body and the objects around it are interconnected and equally significant. In the context of relational ethics, embodiment highlights that in the relational and moral space, objective and subjective awareness determine what is ethical (Bergum & Dossetor, 2005). These factors are a prerequisite for ethical action to occur.

Bergum and Dossetor (2005) suggest that the context of quality relationships and the importance of thinking about how our decisions affect others in those relationships establish a foundation for ethical action. It is relevant to consider this when looking at the experiences of bereaved family member participants in this study, as their beliefs and struggle with moral issues may come into play during the MAID process with their loved ones or in their grieving process (Thiele & Dunsford, 2017). To fully comprehend the effects of MAID, it was crucial to consider the perspective of grieving family members and how the implementation of MAID policies and procedures could affect their experience. This aspect was critical to understanding the complex nature of MAID.

Mutual Respect. In health care, mutual respect involves acknowledging and valuing differences in beliefs, knowledge, and relationship experiences (Bergum & Dossetor, 2005; Thiele & Dunsford, 2017). However, this can be challenging in cases with significant differences in opinion, values, or beliefs, such as the case of MAID. Mutual respect is an interconnected element in relational ethics, where respect for self and others is equally important (Bergum, 2013). By practicing mutual respect, ethical action can be initiated, resulting in improved understanding between each other, in part because of establishing a more balanced power dynamic in the relationship (Bergum & Dossetor, 2005).

In the context of this study, relational ethics also recognizes the significance of autonomy, personhood, and interdependence in building mutual respect (Bearskin, 2011). However, neglecting the viewpoints and concerns of family members may cause relational tension and lead to feelings of relational exclusion (Abma, 2005), ultimately affecting their experience. Hence, it was crucial to explore mutual respect when applying relational ethics as the theoretical lens in this study.

Engagement. Empathy and understanding toward others are essential in a relational ethic, especially in health care (Bergum, 2013). According to the literature on palliative care, engagement is crucial for developing a relational ethic and enabling compassion (D. Wright et al., 2009). Engagement occurs when a health care professional and patient or family member connect emotionally and approach a situation or experience together (Bergum, 2013; D. Wright et al., 2009). However, when nurses or other health care professionals seem disengaged, others can interpret this as being unethical. This ethical attention was critical in my study because it provided a foundation to make meaning from an experience with moral features (Bergum, 2013; Doane & Varcoe, 2013). I used relational ethics as a theoretical framework to explore how MAID policy and implementation, and critical process features, affected bereaved family members' relational engagement.

Overview

This section provides an overview of the research question, study aims, and methods used to answer the research question. It includes sample settings, the recruitment process, and participant characteristics. I outline the data collection strategies, analysis process, and quality measures used to maintain research integrity. I also review the ethical considerations.

Research Question and Study Aims

This study was designed to understand the following question: What are the experiences and perspectives of bereaved family members who have had a loved one end their life through MAID? In addition, I sought to address four aims:

1. Describe bereaved family members' experiences of having a loved one participate in MAID, including moral and ethical dilemmas associated with this choice.
2. Gain an understanding of the way in which the implementation of MAID legislation has influenced family members' experiences.
3. Provide direction for interventions designed to support family members.
4. Provide health care professionals, MAID practitioners, health care administrators, and advocacy groups who influence decision-making, with knowledge to inform policy directions related to bereaved family members and MAID.

Participants

This study featured two participant groups: (a) bereaved family members of MAID recipients and (b) key informants. While understanding the experiences of bereaved family members was the primary focus of this study, Thorne (2016) suggests that broadening the lens to include multiple perspectives may be necessary to comprehend a complex issue. To more fully understand the experience of bereaved family members and generate relevant findings, it was necessary to explore the perspective of key informants connected to the MAID process and experience. The inclusion of key informants in this study allowed the opportunity for MAID practitioners and other members of MAID teams, health care professionals working in palliative care, nurses, social workers, spiritual care practitioners, health care administrators, volunteer(s) with local chapters of Dying with Dignity Canada or other support organizations who have specific experience and knowledge about implementation, policies and processes related to MAID to inform the research. To maintain confidentiality when presenting data, I used participant codes beginning with FM followed by a digit for family members (e.g., FM-01, FM-02) and KI followed by a digit for key informants (e.g., KI-01, KI-02).

Study Setting

Although federal MAID legislation sets out basic requirements, it is up to the health authorities, regions and zones in each Canadian province and territory to develop implementation guidelines, policies, and services that comply with federal regulations. As a result, there has been variability in the structure of MAID services in each jurisdiction (Health Canada, 2022b, 2023), with some of the reasons for the diversity in implementation related to the geographic, regulatory and cultural distinctions (Health Canada, 2022b). This variation continues at this time. This variability and how it has influenced both the uptake of MAID and processes in provinces and territories led me to the decision to include two provinces in this study.

The settings for this study include jurisdictions in Alberta, with a primary focus on South, Calgary and Central Zones,[51] and BC, with a primary focus on Vancouver Island. Alberta has the fourth-highest total MAID deaths in Canada (Health Canada, 2021) and Vancouver Island has consistently reported the highest percentage of MAID deaths in Canada[52] (Courtney et al., 2022; Robertson & Beuthin, 2018). Also, Vancouver Island's proportion of MAID events that take place at home has been consistently higher than the national average since implementation (Health Canada, 2017a, 2018, 2019); and the nature of rural communities also makes this jurisdiction unique[53] (Robertson & Beuthin, 2018). Although my overall intent was not to do a comparative analysis, laying out the differences in the two identified study settings, including

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[51] This study focused on the Calgary, South, and Central Zones as they offered a mix of urban and rural healthcare access.

[52] Island Health, the Health Authority (HA) for Vancouver Island, noted that MAID accounted for 6.29% of all death in the HA in 2019 (Courtney et al., 2022, p. 14). In contrast, MAID accounted for 2.0% of all deaths in Canada during the same period (Health Canada, 2022b).

[53] Vancouver Island is geographically composed of multiple islands, remoteness, and it often requires individuals to travel long distances to health care facilities or providers.

how MAID implementation has unfolded, formed an important part of my interpretive description.

The Alberta Context. In the Province of Alberta, there is a single, integrated health authority called AHS. As the body responsible for authorizing health care in Alberta, AHS delivers health care and partners with other organizations (e.g., Covenant Health, Carewest) to deliver care to people living in Alberta, as well as in some areas of BC, the Northwest Territories, and Saskatchewan. Partner health care organizations in Alberta are managed independently and have their policies and procedures. There is, however, an expectation of some alignment with AHS and meeting deliverables (KI-02). At the present time, AHS comprises five geographic zones: North, Edmonton, Central, Calgary, and South (AHS, 2021a; Appendix A). According to AHS, the zones were established to improve local decision-making and provide improved responsiveness within regional communities (AHS, 2021a).

The Alberta MAID framework is AHS’s response to MAID legislation and the requirement to implement MAID in the province. The Framework is composed of (a) MAID policy (AHS, 2021b; Appendix B), (b) MAID clinical guidelines that outline the process of MAID (Wu et al., 2018), and (c) the AHS MAID Care Coordination Service (CCS; Silvius et al., 2019; Wu et al., 2018; Appendix C). The AHS MAID CCS is a single point of contact for patients, family members, and care teams (including consultants and pharmacists) within AHS’s geographic zones (Silvius et al., 2019). The AHS MAID program “support[s] patient-centred thinking” (Silvius et al., 2019, p. 400) while also “balancing the rights and values of a practitioner who may not be willing to participate” (p. 400). Physicians, operational leaders, and MAID navigators compose the AHS MAID CCS. The MAID navigators play a vital role in the overall process. MAID navigators,[54] therefore, address key elements of MAID legislation within the Alberta MAID framework, including being a conduit of information, responding to general inquiries, and facilitating the MAID process, including scheduling assessments and provisions. MAID navigators also facilitate patient transfers from conscientious objecting facilities or home settings if requested or required (Silvius et al., 2019).

MAID assessments are permitted in all facilities[55] within AHS zones, and assessments and provisions are permitted in all AHS facilities and on all AHS units.[56] Access to MAID services may vary depending on the authority given to non-AHS health care organizations and institutions in Alberta. These organizations have the authority to create their policies regarding MAID within their institutional framework. This may include the option to exclude MAID provisions on site (AHS, 2016; Covenant Care, 2016; Covenant Health, 2018; Appendix D).

The British Columbia Context. In BC, the Provincial Health Services Authority "oversees the coordination and delivery of provincial programs and highly specialized health-care services"[57] (Government of BC, n.d.-b, para. 1). Within the five regional health authorities (HAs) and the First Nations Health Authority that exists in BC, collaborative coordination occurs with the Provincial Health Services Authority. The regional health authorities provide health care to people living in BC and parts of Alberta and include the Fraser Health Authority, Interior

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[54] At implementation, there were two nurse navigators for the province of Alberta; at present, there are five nurse navigators (two for the Edmonton and North zone; two for the Calgary and Central zone; and one for the South zone)

[55] This was different when MAID legislation was enacted and implemented in 2016 (Covenant Care, 2016). Policies and processes have evolved, most notably within Covenant Health (2018), which now permits assessments at their facilities.

[56] In the first few years of implementation, however, some AHS units did not permit MAID provisions, for example, the Tertiary Palliative Care Unit at the Foothills Medical Centre in Calgary.

[57] This includes resource-intensive services such as cancer treatment, heart surgery, and transplants.

Health Authority, Northern Health Authority, Vancouver Island Health Authority (VIHA), Vancouver Coastal Health Authority and the province-wide First Nations Health Authority (Government of BC, n.d.-b; Appendix E).

At this time, multiple pathways exist to facilitate the MAID process in BC, including a MAID[58] program in each HA. The MAID program is the CCS for medical assistance in dying.[59] In addition to being the point of contact for patients, each MAID program within the HAs supports health care professionals and organizations to identify the care that is appropriate for individuals, as well as to facilitate patient transfers and connect individuals with MAID practitioners (Government of BC, n.d.-a). Some clinicians identify themselves as Island Health MAID providers and can be contacted directly by individuals or their family members when they want to access the MAID process.

Similar to Alberta, there are hospitals and long-term care facilities that are members of a denominational health care association, where an agreement is in place that permits opting out of providing care that goes against the faith tenets of organizations, including MAID. Within VIHA, the BC setting for this study, most facilities permit full access to MAID, with only a few facilities not permitting MAID provision on site (e.g., Baptist, Dutch Reform, and Catholic institutions).

The differences outlined in the two study settings during the time of data collection are essential to acknowledge. In some cases, they may have influenced the experiences of bereaved family members of MAID.

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[58] In BC, the acronym used for medical assistance in dying is MAiD. However, MAID will be used for consistency unless there is a direct reference to a document or title that uses a different version of the acronym.

[59] Within VIHA, the CCS for MAiD office is located at the Victoria General Hospital.

Sampling and Inclusion Criteria

The study utilized a qualitative approach, and its objective was not to draw statistical conclusions or control for variables concerning the experiences of bereaved family members. Hence, probability sampling was not suitable (Creswell & Poth, 2018). Instead, purposeful, theoretical, and nominated sampling was used (Patton, 2015).

Bereaved Family Member Participants

To understand the phenomenon of the experiences when a loved one proceeded through to MAID, I used purposeful sampling of bereaved family members in each study setting (Merriam & Tisdell, 2016). This strategy enabled information-rich data to be gathered, allowing for an in-depth understanding of the phenomenon (Morse, 1991; Robinson, 2014).

As there is little consensus in the literature on how soon to recruit bereaved individuals to participate in research, I did not select a particular time frame for recruitment after the death of a loved one (Beck & Konnert, 2007; Bentley & O'Connor, 2015). Studies suggest that some bereaved family members feel comfortable and volunteer to participate in research as early as a few days after the death of a loved one to several years post-death (Beck & Konnert, 2007; Bentley & O'Connor, 2015). A study conducted by Beck and Konnert (2007) on the opinions of bereaved adults on ethical issues, such as attitudes toward bereavement research and timing of recruitment, highlighted that bereaved individuals do not feel it necessary to wait more than 2 years after a death to be a study participant. Research conducted with victims of trauma also suggested that being a study participant in the bereaved period rarely results in re-traumatization (Collogan et al., 2004). As no formal guidance existed regarding an appropriate time frame for study recruitment and participation with this population, and drawing on studies that have examined and published in this topic area (Addington-Hall & McPherson, 2001; Beck &

Konnert, 2007), in collaboration with my supervisor, I determined that for this study, potential family members would decide for themselves when they were ready to participate. When I screened potential participants, if it appeared that discussing their experience would cause unanticipated risk, I discussed this with the individual and provided them with grief and bereavement resources. I also invited them to reconnect at a later time.

Guiding the purposeful sampling, I used the following inclusion criteria for bereaved family member participants: (a) was 19 years of age or older; (b) was able to speak and read English; (c) was able to give informed consent; (d) resided on Vancouver Island or throughout BC, in the Calgary, South, Central zones in Alberta or elsewhere in Alberta at the time of the study; (e) was a family member of an individual who enacted clinician-assisted MAID;[60] and (f) MAID provision occurred on Vancouver Island, elsewhere in BC, or in the Calgary, South, Central zones in Alberta or elsewhere in Alberta. Exclusion criteria included any bereaved family member whose loved one enacted self-administered MAID.

In order to obtain maximum sample variation, I attempted to include bereaved family members with varying attributes from each study setting. This included individuals of different genders with different connections to the loved one who received MAID, varying degrees of involvement in the process, and experiences with MAID policy and legislation.[61] I also aimed to include family members who experienced MAID in different locations, such as hospitals, homes, long-term care facilities, nursing homes, hospices, and other settings and those bereaved for different periods of time. Nominated sampling was employed when attempting to diversify the

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[60] Clinician-assisted MAID has been the primary mode of MAID in Canada since 2016 (Health Canada, 2021).

[61] For example, transfer of their loved one to receive MAID; reflection period waived.

sample. The foundational understanding of the experiences of bereaved family members gained through this sampling approach also enabled better-informed interview questions for the key informant participant group.

Key Informant Participants

Key informants were selected using a purposeful sampling strategy. To encourage maximum sample variation in the study, I included participants with varying knowledge and roles related to MAID, palliative care, and end-of-life care. This included MAID practitioners and team members, health care professionals in palliative care, nurses, social workers, spiritual care practitioners, health care administrators, and volunteers from organizations with experience in MAID implementation and policies. I also included participants of different genders and from various geographic regions within the study settings.

I utilized the following criteria for inclusion of key informants: individuals over 19 who could speak and read English, provided informed consent, and were connected to MAID on Vancouver Island or in the Calgary, South, and Central zones in Alberta guided the sampling strategy. In addition, participants should have critical knowledge about MAID policy, processes, and implementation, which may have included developing policies and guidelines, MAID practice, and end-of-life care in the study settings. They should also have supported family members during or after a MAID provision. I used nominated sampling when some family members connected me with a MAID practitioner. After analyzing some of the collected data, I used theoretical sampling to gain additional insights.

Sample Size

While there is no definitive answer on what constitutes an appropriate sample size for an interpretive description study, it is vital that the reasoning behind the chosen sample size is clear

(Thorne, 2008b). Concurrent data collection and analysis are iterative in interpretive description and inform the sample size. In some cases, data analysis reveals gaps and subsequent interviews may result in additional data that is vital in the analysis (Thorne, 2009; Thorne et al., 1997). Interpretive description acknowledges the complexity and the infinite variability of the human experience (Thorne, 2008b). It seeks to gain an understanding through exposure to variations in an area of study rather than saturation (Thorne, 2016). Based on the literature, gathering data from 15-30 individuals in each participant group in a study would lead to a solid understanding of an issue of interest (Sandelowski, 1995). The overall intent of this study was not to do a comparative analysis based on provincial or regional variation but rather to understand how health care and MAID implementation in each of the study settings potentially impacted the experience of bereaved family members of MAID recipients. Considering the nature of my research question and aims, I anticipated a sample size of 15 to 20 bereaved family members and 10 to 15 key informants from each study setting.

Recruitment Strategy

Recruitment for this study started in April 2020 but had to be postponed after the COVID-19 pandemic announcement on March 11, 2020[62] (Appendices F and G). The study recruitment resumed in June 2020 after obtaining approval of amendments from both study settings (Appendices H and I). The recruitment process continued until February 2021.

Depending on the participant group, I used different methods to recruit participants. The primary group comprised bereaved family members of recipients of MAID. I advertised to this group through social media platforms like Facebook and Twitter. A script for social media and

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[62] World Health Organization Director-General declared the COVID-19 pandemic at a media briefing on March 11, 2020 (World Health Organization, 2020).

online recruitment through Facebook was employed (Appendix J), as was a script for social media and online recruitment for Twitter (Appendix K). A brief recruitment notice was attached to the online script regardless of the social media platform. The online recruitment notice extended an invitation to bereaved family members of MAID recipients. The notice provided details about the study's purpose, the requirements for participants, the eligibility criteria, and how to contact the researcher via email or phone for more information or to express interest in participating (Appendix L). Recruitment of bereaved family members also occurred directly through organizations likely to have contact with this group of individuals, including the Victoria, BC, and Calgary, Alberta, Chapters of Dying with Dignity Canada, Wellspring Calgary (Wellspring Cancer Support Alberta, n.d.)[63] and through the Institute on Aging and Lifelong Health at the University of Victoria. These organizations distributed recruitment notices in their newsletters(s), email, and websites.

When an individual showed interest in the study, I talked with them either over the phone or on Zoom, based on their preference. During the conversation, I addressed their queries, examined if they met the eligibility requirements, and elaborated on the study, including the data collection procedures. When individuals contacted me, I offered them a more extensive version of the recruitment document to accommodate various learning styles and ways of retaining information (Appendix M). Thirty-four individuals within the bereaved family member group contacted me about the study.

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[63] Wellspring Calgary amalgamated with Wellspring Edmonton in 2022. This charitable organization is now called Wellspring Alberta (n.d.).

When a bereaved family member met eligibility and agreed to participate after this interaction, they received the consent form[64] specific to their study setting (Appendices N and O). I encouraged all potential bereaved family member participants to review the consent form and followed up with the potential participant 2–3 days after if they had yet to contact me.

Due to COVID-19 public health restrictions during study recruitment (and data collection), I obtained verbal consent from all participants by asking the questions at the end of the consent form, which the participant would typically sign. I recorded their verbal consent.[65] Of those individuals who indicated interest and received the consent form, 32 bereaved family members provided consent and became study participants in the primary participant group. I documented when I obtained consent and the process used.[66] I reminded all participants that they could withdraw their consent at any time with no consequences. One bereaved family member participant withdrew from the study after providing consent.[67] They did not provide a reason for their withdrawal of consent to participate.

Following the sampling strategy, I sent a recruitment letter that outlined the study, my reason for seeking their participation, and details on how they could contact me if they wanted to gain further information or participate in the study to potential key informant participants (Appendix P). After a potential key informant participant contacted me, I explained the study further, answered any questions, and determined if they met the eligibility criteria. When a key informant agreed to participate or indicated an interest in additional information, the consent

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[64] I offered to send the consent form electronically via email or hard copy by mail through Canada Post. All potential participants requested that the consent form be sent electronically.

[65] Recording was done via Zoom or audio-recorded if the participant preferred to use the phone.

[66] Zoom or audio-recorded.

[67] Prior to data collection.

form corresponding to their study setting was sent electronically via email (Appendices Q and R).

Potential key informant participants were encouraged to connect with me with any questions or concerns or to seek clarification. Once there has been an agreement to participate, I obtain verbal consent from key informants by asking the questions at the end, which the participant would typically sign. I recorded their verbal consent. In total, 16 key informants contacted me about the study and consented to participate. I documented the date and time of the verbal consent and the process used to obtain consent for each key informant participant. I also reminded participants in this group that they could withdraw their consent without consequences. One key informant participant withdrew consent before data collection, citing workload issues due to the pandemic.

Data Collection

In order to foster a holistic and in-depth understanding of bereaved family members' experiences, five collection strategies construct data for this study. As stated, data collection commenced in June 2020. Data sources included the following:

- demographic questionnaire (one specific to bereaved family member participants, one specific to key informant participants),
- in-depth, open-ended interviews with bereaved family members participants,
- open-ended interviews with key informant participants,
- documents and artifacts, and
- supplementary memos and field notes.

Once a participant provided consent, I collaborated with them and scheduled their interview day and time. I then sent them the demographic survey and told them to complete and return it to me before their interview.

Demographic Questionnaire

Before each interview, I verified that each participant had completed their demographic questionnaire. The demographic data from bereaved family member participants included gender, age, ethnicity, the highest level of education, marital status, employment status,[68] relationship to the deceased, year, month, and date[69] of the MAID event, underlying medical condition of their loved one who received MAID, location of the death (e.g., hospital, home, long-term care/nursing home, hospice, or other) if the MAID event was in the desired location or setting,[70] what health care providers were present at the MAID event if palliative care services were involved prior to MAID,[71] where the bereaved family member lived in relation to where their loved one resided in the period before the death, if the bereaved family member saw the medical death certificate of their loved one and whether it used terms they expected (Appendices S and T). The key informant demographic survey questions included gender, age, their highest level of education, their profession or occupation, their role related to MAID and end-of-life care, and when they became connected to MAID (Appendix U). This data collection strategy allowed for a description of both participant groups.

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[68] Both at the time of filling out the questionnaire and throughout the MAID experience.

[69] Date was only collected from family member participants from the province of BC.

[70] If not, there was space on the form to indicate why not.

[71] If not, there was space on the form to indicate why not.

In-Depth, Open-Ended Interviews With Bereaved Family Members

This data collection strategy allowed for fluidity and the generation of rich data while also seeking “deep” information and understanding from participants (Johnson & Rowlands, 2012, p. 101; Roulston, 2012). As the researcher, I embedded myself in bereaved family members’ perspectives and their experiences, explored the broader context, challenged my perspectives and assumptions, and uncovered multiple views through this strategy (Johnson & Rowlands, 2012).

I used an open-ended interview format to guide this process (Appendix V). I employed a conversational approach during each interview, allowing flexibility and reducing any power differential between participants and myself (Patton, 2015). This approach also allowed participants to be comfortable expressing their positive or negative perspectives. During the interviews, I also asked participants to describe, explain further and elaborate on responses when their narrative had me wondering (Merriam & Tisdell, 2016). When thought-provoking descriptions and perspectives occurred, I noted them and recorded them in my supplemental notes for later self-reflection (Johnson & Rowlands, 2012). When needed, I also redirected questions and sought clarification from participants.

This study incorporated the concept of a first and second round of interviews. The initial first round of interviews with bereaved family members began on June 21, 2020, during which I focused on core questions from the interview guide. After conducting 16 interviews, I paused to undertake more in-depth data analysis (see the “Data Analysis” section for more detail). The pause at this juncture enabled future data collection to be augmented and additional questions identified. The second round of interviews with an additional 14 bereaved family members began on September 21, 2020. All bereaved family member participants’ interviews were completed by

January 15, 2021. This process, including the pause for data analysis, enhanced the study's validity and extended my understanding of the experience of bereaved family members of MAID recipients.

Regardless of whether the participant interviewed through video-conferencing or telephone, I recorded each interview. I stated the identification number assigned to the participant at the beginning of each interview recording. Interviews lasted between 0.45-3.0 hours. The interviews, at times, were highly emotional; and it was necessary to "capture[s] the mood and affective components" in my supplemental field notes so I could relate these data to the context during data analysis (Butler et al., 2019; Yin, 2018, p. 84). The transcriptionist transcribed every audio recording word-for-word and removed personal details from the transcripts, including the names of health care providers, hospitals or care facilities.

I sent a thank-you email to each family member participant following their interview. In the email, I attached a document listing available resources and support for bereavement and grief both online and in their area (Appendices W, X, Y, and Z). In that email, I also stated that I would check in with them again in approximately 5 days to see how they were doing and that if they had any questions or concerns, to contact me.

In-Depth Key Informant Interviews

Key informants' interpretations of MAID implementation, policy, and processes, as well as their understanding of broader factors that may influence the experience and perspectives of family members of MAID recipients, were essential to highlight through questions in the interview guide (Appendix AA). After conducting interviews with bereaved family members, I refined key informant interview questions based on the insights gathered. I used the first and second-round interview process with the key informant participant group. The first round of interviews with key informant participants began on September 30, 2020, and during this time, I focused on core questions from the interview guide. After conducting six interviews, I stopped to engage with these data (see the “Data Analysis” section for more detail). Following this, I enhanced data by developing additional questions identified during analysis and identified areas requiring follow-up or additional probing. I re-engaged with key informants beginning November 25, 2020. The second-round interviews with participants were completed by February 4, 2021. This process of first and second-round interviews with key informants again enhanced my understanding of these data.

Each key informant interview was audio recorded (Patton, 2015), and I noted the identification number assigned to the participant at the beginning of each interview recording. Interviews lasted between 0.45-1.5 hours. Each audio recording was transcribed verbatim, and the transcriptionist removed all identifying information from transcription documents.

Documents and Artifacts

The purpose of constructing data through documents and artifacts[72] was to provide context to the experience of bereaved family members. These data are considered secondary sources and important for data triangulation (Miller & Alvarado, 2005). Documents such as MAID implementation guidelines, policies, and processes that framed and may have influenced the experience of bereaved family members comprise these data. Public documents made available by federal or provincial governments; and organizational and institutional guidelines, mandates and policies (e.g., policy and program documents, guidelines, and frameworks) were also examined (Patton, 2015). I purposefully selected information-rich and appropriate data

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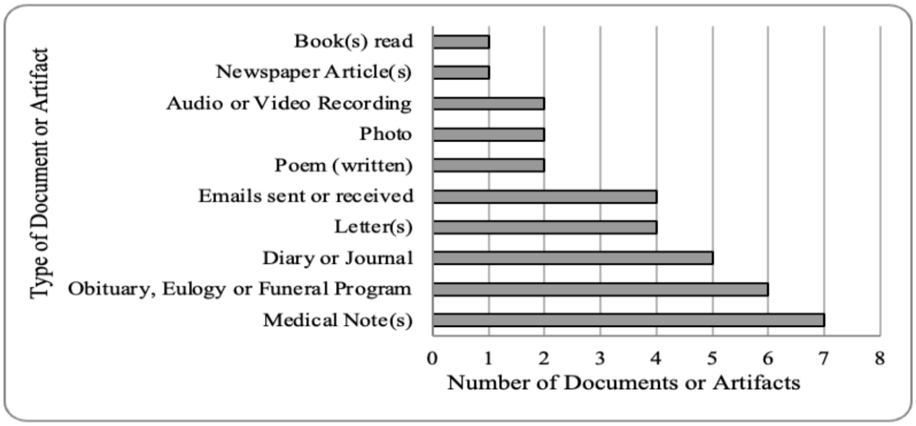
[72] Artifacts are considered “objects in the environment that represent some form of communication that is meaningful to participants and/or the setting” (Merriam & Tisdell, 2016, p. 162).

sources relevant to the aims of this study. Theoretical selection of documents was also conducted based on insights and preliminary analysis from bereaved family members and key informant interviews (Miller & Alvarado, 2005). Thirty-six documents were collected and reviewed (Appendix BB). By including these data, they increased the comprehensiveness and validity of this study (Miller & Alvarado, 2005).

Data collected included personal documents and artifacts. The purpose of reviewing these documents or objects was that they were considered a "good source of data [relating to] a person's attitudes, beliefs, and view of the world" and could provide another account of the participant's experience (Merriam & Tisdell, 2016, p. 166; Polkinghorne, 2005). If bereaved family members offered them, I considered excerpts from diaries and journals, along with letters, videos and photos, personal notes and reflections, medical notes, email exchanges, announcements and obituaries, and physical objects in these data. In total, 13 bereaved family member participants provided personal documents and artifacts connected to their experience as their loved one journeyed to an assisted death (Figure 1).

Figure 1

Type and Number of Personal Documents and Artifacts submitted by Family Members



Note. This figure represents the type and number of personal documents and artifacts submitted as data by bereaved family member participants.

Supplementary Field Notes and Memos

This strategy aimed to add more rigour to the study by ensuring I regularly recorded my thoughts, feelings, and observations after every interview (A. Bryant, 2014; Patton, 2015). I recorded operational information about the interview (e.g., date, time, setting/location) and assumptions and observations that could establish a context for interpreting and meaning-making. Following each interview, I reflected on and expanded upon my observations. This allowed me to identify potential emerging themes and connections to existing literature, which helped me form initial analytical impressions (Patton, 2015). Recording of subjective and objective information gathered from interviews is crucial to the interpretive description research process (Thorne, 2016).

After each interview, supplemental field notes and memos were recorded in a typed fashion (Patton, 2015). During interviews, I made mental notes, and following the interview, I wrote personal memos, including particular phrases and keywords that resonated and engaged my memory. Recording personal memos and supplementary field notes (Appendix CC) was facilitated by purposefully scheduling time to allow for long uninterrupted periods when reflection and the notes could be composed. I recorded 46 memos, which corresponded to the number of study interviews. Taking the time to compose the memos allowed me to connect with possible insights from the interviews, and I could note any questions or curiosities that arose. (Patton, 2015).

Description of the Sample

The size of the sample for this study was 46. Thirty-one bereaved family members comprised the primary participant group, and 15 key informants comprised the secondary participant group.

Bereaved Family Member Participants

Of the 31 bereaved family member participants, 19 were from Alberta, and 12 were from BC. The family members had ages ranging from 28 to 81 years old, with an average age of 63.06 years and a standard deviation of 13.99 years.

As Table 1 presents, 26 bereaved family members were female, and five were male. Examples of ethnic origin were not provided in the study questionnaire; as a result, bereaved family members self-identified their ethnicity and cultural identity. Some participants provided a single-ethnic or cultural response, while others indicated multiple ethnicities and cultural identities (Statistics Canada, 2016). Twenty bereaved family members reported their ethnic origin or cultural identity as Canadian/Caucasian/white, three family members indicated a European ethnic origin, three reported a European-Canadian origin, one of Chinese origin, one Croatian, one Jewish, one German Canadian and one bereaved family member participant reported as Métis.

Table 1

Demographic Characteristics of Bereaved Family Member Participants

	Frequency
Province of the participant (*n* = 31)	
Alberta	19
British Columbia	12
Gender (*n* = 31)	
Female	26
Male	5
Ethnic or cultural background (*n* = 31)	
Canadian/Caucasian/white	20
European	3
European-Canadian	3

Chinese	1
Croatian	1
Jewish	1
German Canadian	1
Métis	1
Highest degree of schooling (*n* = 31)	
Baccalaureate degree	12
Post-graduate degree	8
College diploma	5
High school diploma	4
Below high school	2
Marital status (*n* = 31)	
Widowed	14
Married	11
Common-law	3
Single	1
Separated	1
Engaged	1
Relationship to the deceased (*n* = 33)*	
Daughter	12
Wife	8
Sister	5
Son	4
Mother	1
Husband	1
Sister-in-law	1
Best friend	1
Employment status when loved one had MAID event (*n* = 33)*	
Retired	18
Full-time employment	8

Part-time employment	3
Self-employed	3
Casual/contract	1
Unemployed	1
Semi-retired	1
Current employment status (*n* = 31)	
Retired	18
Full-time employment	6
Part-time employment	3
Self-employed	1
Casual/contract	1
Unemployed	1
Semi-retired	1

Note. This table outlines the characteristics of the sample of bereaved family members.
*Two participants had two loved ones who were MAID recipients.

Most bereaved family member participants stated that their highest level of education or schooling was a baccalaureate degree (*n* = 12). Eight had a post-graduate degree, five had a college diploma, four had a high school diploma, and two did not have a high school diploma. At the time of study participation, 14 bereaved family members were widowed, 11 were married, three were in a common-law relationship, one was single, one was separated, and one was engaged to be married. Twelve were the daughter of the MAID recipient, eight were the wife, five were the sister, four were the son, one was the mother, one was the husband, one was the sister-in-law, and one was the best friend of the MAID recipient. At the time of their loved one's MAID event, 18 of the family member participants were retired. Eight were working full-time, three worked part-time, one was self-employed, one worked casual/contract, one was unemployed, and one considered themselves semi-retired. The employment status of bereaved family members at the time of study participation included 18 who were retired, six who were employed full-time, three on a part-time basis, and one who was unemployed. Three indicated ‘other’ employment (one was self-employed, one worked casual/contract, and one considered themselves “semi-retired”; see Table 1).

In addition to demographic information about bereaved family member participants, the demographic questionnaire also focused on characteristics related to the MAID recipient and their death (see Table 2). Twenty MAID deaths occurred in Alberta and 13 in the Province of BC. Sixteen bereaved member participants lived in the same city but in a different home as their loved one before the MAID event, ten lived in the same home, four family members lived in the same province but another city as the MAID recipient, one participant relocated to the same city as the MAID recipient, but to a different home. One family member relocated to the same home as the MAID recipient, and one bereaved family member lived in a different province. Twenty-three bereaved family members reported that palliative care services were involved before their loved one received MAID, and nine highlighted that palliative care was not involved. One family member participant did not know or recall if their loved one had received palliative care. Of those who indicated their loved one did not receive palliative care before their death, one stated there was a conversation, but their loved one “did not qualify.” One family member noted that home care was involved but did not perceive it as palliative home care. The remaining participants, who indicated palliative care was not engaged in care, did not comment further.

Table 2

Characteristics of the Loved Ones of Bereaved Family Members Participants

	Frequency
Province of the participant (*n* = 33) *	
Alberta	20
British Columbia	13

Lived/resided in relation to MAID recipient (*n* = 33)	
Same city but in a different home	16
Same home	10
Same province, different city	4
Relocated to the same city, different home	1
Relocated to the same home	1
Lived in different province	1
Palliative services involved prior to MAID event (*n* = 33)	
Yes	23
No	9
Do not know/cannot recall	1
Year of MAID death (*n* = 33)	
2018	8
2019	8
2020	8
2016	5
2017	4
Underlying medical condition of MAID recipient (*n* = 33)	
Cancer-related	18
Neurological	10
Cardiovascular	2
Other[73]	2
Respiratory	1
Where the MAID recipient died (*n* = 33)	
In their home	20
Hospital	8
Long-term care facility/nursing home	3

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[73] 'Other' medical conditions included untreatable diarrhea (*n* = 1), liver cirrhosis (*n* = 1)

Hospice	1
Other[74]	1
Location/setting of MAID event chosen by recipient (*n* = 33)	
Yes	27
No	6
Professional/provider present for MAID event**	
Physician	35
Registered Nurse	32
Other	5
Nurse Practitioner	3
Spiritual care provider	3
Social worker	2
Reviewed medical death certificate (*n* = 21)	
Yes	12
No	9
Cannot recall/unsure	0

Note. This table outlines the characteristics of the MAID recipient, as recalled by bereaved family member participants.

* Two participants had two loved ones who were MAID recipients.

** Participants could indicate as many professionals or providers as were present.

Eight of the bereaved family members' loved ones died through MAID in each of 2018, 2019, and 2020, five died in 2016, and four of the loved ones died in 2017. Only 11 bereaved family member participants reported their loved one's death date.

As outlined in Table 2, the primary medical condition of the MAID recipients whose family members were participants in this study was cancer (*n* = 18). The next most common conditions were neurological (*n* = 10), cardiovascular (*n* = 2), other (*n* = 2), and respiratory

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[74] Physician's office

(*n* = 1). According to the collected demographic data, the number of MAID team members and health care professionals present at the MAID event ranged from 1 to 7 (M= 2.42). A physician was the most common health care professional present (*n* = 35), followed by a registered nurse (*n* = 32), then ‘other’ (*n* = 5), nurse practitioner (*n* = 3), spiritual care provider (*n* = 3) and social worker (*n* = 2).

Twenty of the bereaved family member’s loved ones received their MAID event in their home. Eight had MAID at hospital, three in a long-term care facility or nursing home, one in hospice and one at another location.[75] Of the MAID event locations, 27 bereaved family members indicated that the place was of the loved one’s choosing. Of these, three participants highlighted that the location of their loved one’s MAID event had been chosen but also had required relocation because of COVID-19 public health measures and the desire to have family members and support systems attend the death. Six bereaved family member participants indicated that the location or setting of the MAID event was not of their loved one’s choosing. Table 3 outlines the reasons and explanations provided by bereaved family members participants for why the participant’s loved one did not choose the location or setting for MAID.

Table 3

Reasons and Description for the Location or Setting not being Chosen

*Participant	Reason	Explanation
1	Forced transfer (policy)	They were in hospice, but the hospice did not support MAID. Therefore, they had to transfer to home on the day of the MAID event.
2	Forced transfer (policy)	At the time, their loved one wanted to go to a hospice but was told that no hospice would accept someone whose choice was MAID. So, the future MAID recipient went home, but then

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[75] Physician’s office.

*Participant	Reason	Explanation
		returned to hospital less than a day later because of a broken hip (cancer metastases).
3	Forced transfer (policy)	Moved off their regular unit to a different unit in hospital on the day of the MAID event. This policy was not discussed with the MAID recipient or family. The family found out when they arrive at the hospital on the day of the MAID event.
4	Required level of care	Preferred to be at home but the palliative care unit was needed due to symptoms.
5	Forced transfer and resources (policy)	Preferred to be at home but no provider could be found to accommodate the MAID assessment and provision. Required to fly to a different province so that MAID could be obtained. No home-like setting was available at the time.
6	Forced transfer (policy)	The MAID recipient's preference would have been to have his death in the long-term care facility in which he lived; however, the facility would not allow MAID to be provided there.

Note. This table outlines the reasons recalled by bereaved family member participants about why the location or setting for the MAID event was not the one chosen by their loved ones.
* Participant study ID was removed to maintain confidentiality.

Following their loved one's MAID event, 12 bereaved family members indicated that they reviewed the medical death certificate, with nine participants reporting no issues with the document completion. Nine bereaved family members reported they had not reviewed the medical death certificate. From this sample (*n* = 21), two bereaved family member participants indicated seeing unexpected details on the medical death certificate (Table 2). In the narrative section of the questionnaire, one participant explained,

> The medical death certificate listed cause of death as the four intravenous medications mom was administered at the time of her death. To me it is technically accurate, but cancer was actually the cause of her death and not secondary. The medications she was administered at the end helped her die from cancer. And it distressed my dad who was worried about collecting life insurance subsequently. He was able to submit the funeral home certificate and a letter from the family doctor, so that worked out okay. My

> husband is a retired police officer/lawyer, so I understood the “WHY” of it all, and why it was written like that. I just didn’t like it feeling so “criminalized.” He tells me that I can request to have it amended. I haven’t done that step. (FM-13)

Another bereaved family member reported, “It has the cancer on the document, but also the medical assisted dying – my Mom was upset about that” (FM-25).

Key Informants

Of the 15 key informants who comprised the sample of the secondary participant group, 13 were female, and two were male. Key informant participants ranged in age from 33 to 75 years (*M*= 51.2 years, *SD*= 11.5 years). As Table 4 outlines, the most frequent level of education or highest degree noted by this group was a post-graduate degree (*n* = 7), followed by a baccalaureate degree (*n* = 4), Doctor of Medicine (*n* = 2), college diploma (*n* = 1), and one participant noted having two post-graduate degrees.

Table 4

Characteristics of the Key Informant Participants

	Frequency
Gender	
Female	13
Male	2
Highest level of education	
Post-graduate degree	7
Baccalaureate degree	4
Doctor of Medicine	2
College diploma	1
Two post-graduate degrees	1
Profession/occupation	
Registered nurse	5
Physician	4
Nurse practitioner	2
Social worker	2

Spiritual health practitioner	1
Licensed practical nurse	1
Role related to MAID and end-of-life care	
Only a MAID service team member	8
Member of palliative care and MAID service	4
Facilitator of psychosocial support services	2
Only a member of palliative care and hospice service	1
When became connected to MAID	
Before implementation (prior to June 2016)	7
During first year of legalization (July 2016 to June 2017)	4
At the time of implementation (June 2016)	3
Since July 2018	1

Note. This table outlines the characteristics of the sample of key informants.

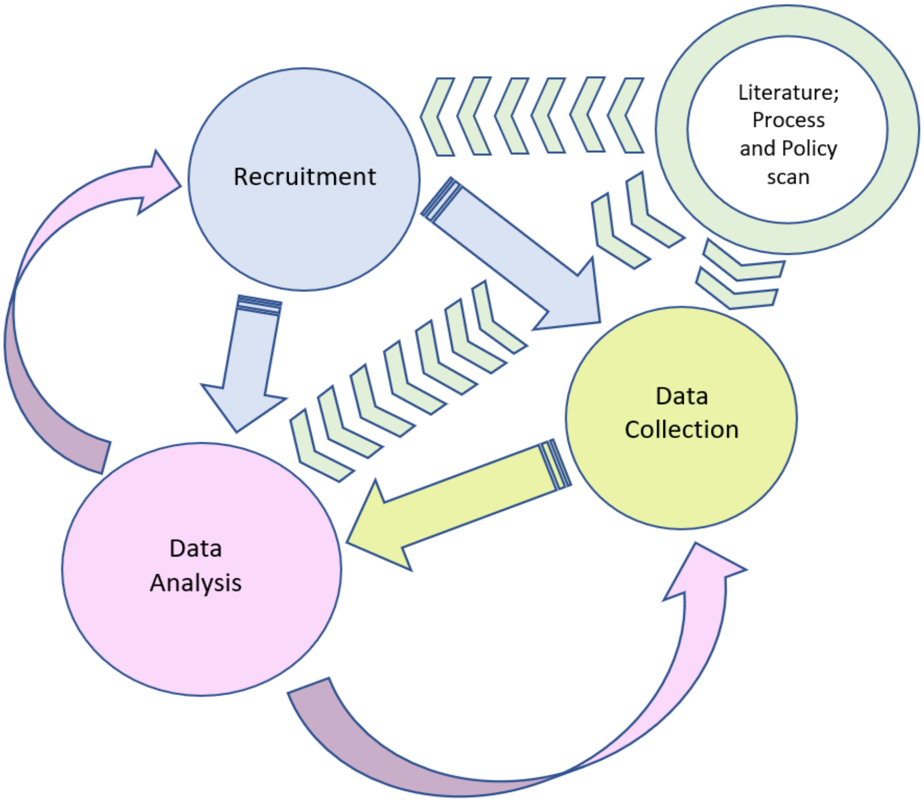
Nine key informant participants were from the Alberta study setting, and six were from BC. Five key informant participants were registered nurses, four physicians, two nurse practitioners and two social workers, one spiritual health practitioner and one licensed practical nurse. The role of these key informants in relation to MAID included eight who were only a MAID service team member, four who were a member of the palliative care and MAID service, two participants were facilitators of psychosocial support services for individuals seeking MAID or family members of MAID recipients, and one key informant was a member of a palliative care and hospice service. Seven key informants noted they became connected to MAID before implementation (before June 2016), four during the first year of legalization (July 2016 to June 2017), three at the time of implementation (June 2016), and one had become involved with MAID since July 2018 (see Table 4).

Data Analysis

Data collection and analysis occurred concurrently and iteratively, as expected within the interpretive description approach. Doing this allowed for the refinement of interview questions and reflection on the research process (Thorne et al., 2004). During data analysis, knowledge was sought at both the individual and broader contextual levels to ensure relevance. This involved examining the "context beyond the obvious" (Teodoro et al., 2018, p. 2; see also Thorne, 2016; Thorne & Sawatzky, 2014; Figure 2). The fluid and emergent nature of a naturalistic inquiry, such as interpretive description, meant there was no proper distinction between data collection and data analysis. I immersed in these data from the beginning of the study, from the point of personally collecting these data (e.g., demographic survey and interviews), and recorded my insights and reflections in personal memos following each participant interview. My immersion continued as I reviewed, reflected on, and engaged with personal documents and artifacts from bereaved family member participants. Circling back to the literature, policies and processes, and data continued throughout the data analysis process. At the same time, I worked towards inductively building a coherent picture of the experience of bereaved family members (Thorne, 2016). This iterative process of data analysis began at the time of data collection with the first participant (FM-01) and concurrently as I collected data from subsequent participants (Patton, 2015).

Figure 2

Concurrent and Iterative Process for Data Analysis in Interpretive Description



Note. This figure is a representation of the concurrent, iterative processes of recruitment, data collection, and data analysis in this interpretive description study. The diagrammatic depiction also conveys the role of literature, as well as process and policy scans which aided in comprehending the phenomenon of bereaved family members' experiences of MAID.

As outlined previously (see the "Interpretive Description" section in this chapter), current health care systems consist of social and structural influences, including power structures, relationships, and practices that have the potential to impact individuals and families (Krawczyk et al., 2019; D. Wright et al., 2018). In the context and complexity of MAID, I anticipated some of these influences and interconnections to be evident. Given this, I decided to employ a multilevel analysis that would assist in distinguishing between micro-, meso- and macro-level considerations that may have impacted the experience of bereaved family members of MAID recipients (Krawczyk et al., 2019).

As discussed, all interviews were audio recorded and transcribed verbatim by a professional transcriptionist. Identifying information was removed from each transcript. To ensure that transcripts were correct and personal details were removed (e.g., health care provider's or facility's name), I read each transcript and compared them to their audio recording. By engaging with the interview transcripts and audio recordings at this juncture, I began to sort and organize data while continuing to establish some early comprehension of the perspectives and experiences of bereaved family members (Appendix DD). If additional reflections or impressions arose when I re-engaged with these data, I would note them on the associated memo document for the individual participant.

I carefully read the transcripts and personal memos multiple times to gain an early understanding of these data (Morse, 1994). In an open process, I then organized these data using broad, vague terms to identify what seemed significant[76] (Lofland et al., 2006; see "Continued Comprehension & Early Synthesis" in Appendix DD). As I became more familiar with these data, I made sure not to evolve into a process of coding because of the potential to "detract from the mind's inherent capacity to see patterns, follow intuitions, and retrace a line of logical reasoning among and between pieces of data" (Thorne et al., 2004, p. 14).

As I continued analyzing and organizing, I used descriptive labels instead of vague terms (Braun & Clarke, 2019). During this phase, I followed Thorne's (2016) suggestion to sort codes into areas of commonality or patterns to allow for the consideration of relationships amongst

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[76] I would do this by asking questions such as "What are these data saying?" and "What is going on here?" (Lofland et al., 2006).

patterns while also remaining focused on the research question. As I centred on the phenomena, I grouped ideas and patterns and committed to doing constant comparative analysis. In doing so, I compared all study data (e.g., policy, interviews, documents, codes) so that I could understand the similarities and differences as well as identify possible relationships amongst these data (Creswell & Poth, 2018; Zamawe, 2015; see ‘Synthesis” in Appendix DD). As I began identifying credible patterns and developed groupings (Thorne, 2016), I was mindful of being flexible in how I labelled, coded and uncoded data (Lofland et al., 2006). As patterns emerged, I compared and contrasted them, shifting from individual to whole sets of data, from groupings of similar to particular differences that seemed relevant, and comparing them to existing data (Patton, 2015; see “Theorize and Conceptualize” in Appendix DD). I maintained descriptive memos that outlined meanings and underlying assumptions about these data, the patterns and relationships, and noted ideas and interconnections among and about patterns and relationships (Patton, 2015; Zamawe, 2015). I also reflected on this in my journal. Decisions about creating or collapsing categories were noted (Merriam & Tisdell, 2016).

Additional insights and reflections occurred as the patterns and relationships that seemed relevant to the bereaved family members’ experiences became more apparent (Morse, 1994; Thorne, 2016). Articulating how the gained knowledge contributed, including expanding or extending the knowledge about bereaved family members’ experiences, was essential at this time; and came about by interrogating the patterns and relationships (see “Reconceptualization” in Appendix DD). Reconceptualizing the patterns and relationships was a way to ensure that the research question was the focus and that the analysis was exhaustive and addressed all relevant data. This allowed insight and sensitivity into the nature of knowledge for the MAID phenomenon (Merriam & Tisdell, 2016).

I engaged in reflexive discussions with my supervisor throughout the data analysis process. These discussions and the guidance I received were vital as I continued to interrogate these data and conceptualize and reconceptualize the patterns, themes and relationships related to the research question and study aims. Being able to make sense of the findings and locate them in a meaningful way within current knowledge (Thorne, 2016) was the final part of the analysis. All members of my doctoral committee were engaged in this part of the process.

Data Management

I used the data management system, NVivo, to organize all the data collected in this study. During the data analysis phase, I utilized NVivo as a management tool to aid me in the process without replacing my immersion in data analysis (Morse & Field, 1995)

All personal documents, artifacts, memos, and physical documents collected from the data collection strategies were stored electronically. For this study, I stored the audio recordings and transcripts on a computer that I exclusively used. To ensure their safety, I protected the files with a password (Flick, 2014). Once I confirmed the transcript accuracy, I destroyed the audio recordings.

Research Integrity

To conduct a credible interpretive description study, I looked to the literature for recommendations and carefully considered strategies to ensure this study was rigorous (Creswell, 2014; Thorne, 2016; Thorne & Sawatzky, 2014). Thorne (2008b) suggests four strategies to enhance the quality and integrity of qualitative research, including (a) epistemological integrity, (b) representative credibility, (c) analytic logic, and (d) interpretive authority. To begin, I will discuss the epistemological integrity of the study (Dowling, 2006; Merriam & Tisdell, 2016).

Epistemological Integrity

A logical and coherent approach must be followed to maintain epistemological integrity in interpretive description research, from the research question to the interpretation of the study's findings (Thorne, 2016). In my study, I ensured epistemological integrity by carefully developing the research question with guidance from my supervisor and selecting a sampling strategy that focused on potential participants with knowledge about the phenomenon of interest. This strategy aimed to ensure enough detail and diversity among the participants (Morse et al., 2002; Thorne, 2008b). I also employed multiple data collection strategies that would provide a variety of data from which to engage in analysis. While working on the research design and process, I reflected on my experience as a nurse; thoughtfully evaluating how my background could impact the study's development and my analysis of these data.

Representative Credibility

The measure of representative credibility in interpretive description studies refers to consistency in the knowledge links between the outlined theoretical claims, the research topic, and whether the study can be substantiated based on the sample of participants (Thorne, 2008b). This measure assumes that health research findings are more likely to be applied or implemented if they appear meaningful (Thorne, 2014). During the study, I ensured credibility by collecting and analyzing data. I also ensured that there were clear links between the claims, the process of inductive reasoning, and the findings supporting those claims (Maxwell, 1992; Thorne, 2008b).

The transcripts of participant interviews were carefully reviewed multiple times during the analysis process to ensure I contextualized data excerpts correctly. In order to have a better understanding of MAID, I also considered my personal experience, education, and perspective, while remaining alert to my assumptions' influence (see the "Researcher Positioning" and

"Clinical Perspective" sections in Chapter 3). This is known as contextual awareness (Thorne, 2016).

Throughout my dissertation, I considered the study's objectives and how the findings might be interpreted by bereaved family members, and in a clinical context by nurses, and other health care professionals, including MAID practitioners. This approach helped me maintain credibility in my analysis, reporting, and discussion of the data.

Analytic Logic

Analytic logic refers to the ability of researchers to demonstrate their decision-making process throughout their study. In order to provide assurance to both the research process and the findings and to establish credibility as a researcher, I maintained an audit trail (Thorne, 2016). In the audit trail for this study, I provided a clear description of how the research process unfolded, key decision points and the reasoning behind them, as well as the process of data analysis. This measure of integrity contributed to the validity of my qualitative study (Lincoln & Guba, 1985).

Interpretive Authority

Ensuring a reliable and genuine representation of participants' experiences in a study, rather than being biased by the researcher's personal views, is known as interpretive authority. I practiced transparency through reflexive journaling to ensure consistency in the research process (Dowling, 2006; Lincoln & Guba, 1985; Merriam & Tisdell, 2016). Reflexive journaling involves remaining alert to and explicitly stating my experiences and viewpoints that may impact how I interpret data (Patton, 2015). In this process, I shared my beliefs, thoughts, and choices and documented any obstacles during data collection and analysis and their resolution (Dowling, 2006; Merriam & Tisdell, 2016). During meetings with my supervisor, I communicated my thoughts and reflections that evolved from my reflexive journal. This practice allowed me to articulate my understanding, insights, and perspectives, especially during data analysis. I received questioning, which enhanced my reflexivity.

Reflexivity is a crucial practice whereby the researcher reflects on their personal views, assumptions, biases, and abstract thoughts that could impact the research process and results (Patton, 2015). This process requires more than just a brief acknowledgement; it is engaged in by the researcher throughout the entire process, including study design, data collection, analysis, and writing. Reflexivity involves identifying and addressing any barriers, power imbalances, and ethical concerns that may exist throughout the research process. I engaged in critical self-reflection, self-understanding, and ownership of my perspective and preconceptions throughout the research process to foster interpretive authority (Patton, 2015). To understand the factors that possibly affected my internal and external reactions, I carefully examined my knowledge and experience. I approached data collection with mindfulness and reflection and considered my biases and assumptions during data collection and in relation to MAID legislation, implementation, policy, and processes. I remained alert to the ways my beliefs and perspectives could influence my results and interpretations. For example, after each interview, I reflected on the content and process of the interview, then, when re-engaging with the audio recording as I reviewed the transcripts, I took the time to listen and critically reflect on how I interacted with each participant. This prompting of self-reflection assisted me in becoming more aware of my perspective and possible preconceptions that could impact data collection. It also aided in framing subsequent interviews in some cases. This process was essential if I encountered participants who expressed surprising or divergent views or beliefs from my own, as it could impact data collection, data analysis, and study findings. By practicing reflexivity, I could conduct this research more effectively, contributing to the research's integrity (Band-Winterstein et al., 2014). Including rich data excerpts to demonstrate the themes and patterns in the findings was an additional measure to promote interpretive authority in this study (Mauthner & Doucet, 2003; Maxwell, 1992; Thorne, 2008b).

Ethical Considerations

This study received ethical approval from the Harmonized University of Victoria Health Research Ethics Board (REB), the Health Research Ethics Board of Alberta- Community Health Committee (HREBA-CHC), and the Human Research Ethics Board at Mount Royal University.[77] In conducting this study, it was necessary to adhere to ethical standards such as obtaining informed consent, being mindful of participants' possible emotional and physical reactions, and safeguarding participants' confidentiality.

Potential participants received a copy of the consent form for their reference and review to address any potential concerns about informed consent. After reviewing the consent form, they were encouraged to contact me with any questions or to seek clarification. This practice promoted the autonomy of bereaved family members by allowing them adequate time to review, discuss, and understand what participation in the study involved. Before and during the data collection process, participants re-confirm their consent. I also reinforced to participants that participation in the study was entirely voluntary, that they had the right not to answer a question on the demographic questionnaire or during the interview, and that they could cease the audio recording at any time during the interview.

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[77] This was a requirement for grants that I received from Mount Royal University. This study received ethical approval from the Harmonized University of Victoria Health Research Ethics Board (REB), the Health Research Ethics Board of Alberta- Community Health Committee (HREBA-CHC), and the Human Research Ethics Board at Mount Royal University.

As outlined in my discussion on the sampling criteria for bereaved family members, seeking this group of individuals as participants was feasible and acceptable (Beck & Konnert, 2007; Butler et al., 2019; Whitfield et al., 2015). From an ethical perspective, there was no substantial evidence to suggest that being a study participant during the bereaved period resulted in re-traumatization (Collogan et al., 2004). The literature notes that individuals feel positive about participating in bereavement research; however, opinions about timing and recruitment method for bereavement studies vary (Beck & Konnert, 2007). Regardless, I was mindful that the focus of this research could have potential risks to participants.

Due to the personal, private and possibly intense experience of MAID, bereaved family members could experience difficulties if they chose to participate in this study. There was the potential that family member participants could feel emotional or physical responses ranging from "mild discomfort to significant psychological distress" (Butler et al., 2019, p. 228; Elmir et al., 2011; Sque, 2000) as a result of retelling their experiences. Published literature indicates, however, that bereaved individuals identify being "grateful for the opportunity to tell their story and… find increased self-awareness, empowerment, emotional relief and a sense of healing" (Butler et al., 2019, p. 228).

Throughout data collection, the priority was on each participant's well-being rather than solely on the study or data. Given the potential distress that could result from participation in this study, I provided a list of resources for family member participants following their interview (Appendices W, X, Y, and Z). I also had a plan if a participant demonstrated or articulated distress or their safety was questioned[78] I reconnected with each participant approximately 5

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[78] I would ensure they connected with their healthcare provider and were safe.

days after their interview to see how they were doing and to contact me if they had any questions or concerns (Butler et al., 2019).

As noted earlier in the dissertation, I maintained confidentiality in several ways in this study. To ensure the confidentiality of participants, I implemented a pseudonym identification system. This system used the participant group's initials (e.g., FM, KI) and the order of their study participation (e.g., FM-01, KI-01). I maintained spreadsheets that connected the identification system with participant information. I kept the spreadsheets in a password-protected folder on my computer that was separate from other files.

Data were collected using the University of Victoria hosted Zoom conferencing service primarily due to the health-protection measures in place due to the COVID-19 pandemic. As a result, I notified participants that Zoom servers, located outside of Canada, stored users' names and usage data outside of Canada. Also, Zoom stored no other information outside of Canada, and no Zoom servers stored recordings of meetings. The following measures were employed to provide increased security and confidentiality during video conference interviews: I was the host for each meeting or interview with a participant; a pre-meeting ID was established and exclusive to every single interview and meeting; I provided the pre-meeting ID to each participant; the waiting room feature was enabled in the Zoom program so that I could identify who was attempting to join the interview or meeting before access was permitted; I ensured that the 'join before the host' function was disabled in Zoom settings, as well, that screen-sharing for non-hosts, remote control functions, all file transferring, annotations and autosave features for chats were also disabled. Once the interview began, the Zoom conference locked outsider visitors. I informed participants that they could protect their identity and increase the protection of their personal information if they used a nickname or substitute name, rather than their real name, while on Zoom. I told participants they could turn off their cameras while on the Zoom conference for additional security.

The audio recordings of the interviews were sent to the transcriptionist via email in a password-protected data file. Only the transcriptionist and myself had the password for the data file. As discussed, the transcriptionist removed all identifying information at the transcription time, and I destroyed data files after confirming the accuracy of the transcripts. At no time were specific comments attributed to any participant unless there was prior agreement. Any hard copy documents with contact information or documents produced during this study were in a locked cabinet in a private office, at Mount Royal University. These documents will be stored as such for 5 years, after which time the researcher will destroy them through confidential shredding.

Chapter Summary

Interpretive description is a valuable research method in nursing research and practice-driven inquiries. Understanding the complexity surrounding MAID required collecting detailed and comprehensive data. I used five data collection strategies including demographic questionnaires, documents and artifacts, supplementary field notes and interviews with bereaved family members and key informants connected to MAID to address the research question and study aims. This study included a sample size of 46 participants, consisting of 31 family members and 15 key informants. I conducted data analysis in a concurrent and iterative process to gain a better understanding of the experiences of bereaved family members whose loved one was a recipient of MAID. The study design and processes were carried out with quality criteria to ensure the findings’ trustworthiness.

Chapter 4: Findings

In this chapter, I present the findings of my study. To provide an understanding of the experiences of bereaved family members, I have divided my findings into two main sections. In the first section I identify three contextual factors that seemed to frame the experiences of bereaved family members as a loved one moved through the process of choosing and receiving MAID. In the second section, I describe my gained understanding of the experience of bereaved family members using three overarching themes that emerged from the study data. I conclude with a summary of the complex nature of the experience of family members.

Throughout this chapter, I include excerpts from participants' interviews to illustrate the findings. As outlined in Chapter 3 (see the "Ethical Considerations" section), I implemented a pseudonym identification system to ensure the confidentiality of participants and I have used this throughout this chapter. Participant identifiers FM-01 to FM-32 (excluding FM-15, as they withdrew) were used when citing material from family member interviews, and identifiers KI-01 to KI-16 (excluding KI-08, as they withdrew) when quoting key informant participants.

Understanding the Context for Family Members

During this study, family members shared emotional and impactful descriptions that shed light regarding their experiences as well as illuminating contextual factors that created tension and complexity to these experiences (Patton, 2015) and seemed to have significant impact on the bereaved family members. Three factors emerged as key contextual considerations for family members of MAID recipients: knowing the perspective of their loved one, being aware of their loved ones' suffering, and the family members' personal beliefs about assisted dying. These contextual elements appeared crucial to gaining an understanding of the experience of family members as they moved through the MAID journey with their loved ones.

Knowing the Perspective

Many family members revealed they knew their loved one’s views on death, dying, and assisted death. However, I discovered the timing at which they gained this knowledge differed and impacted their experience. Some shared that their loved ones had already expressed their comfort with the idea of assisted death before it became legal in Canada. It was not uncommon for family members to anticipate their loved ones’ choice for MAID as an option, as this daughter shared,

> Medical assistance in dying, it was always on our radar, because of my mother, she had MS [multiple sclerosis]. Long before it [MAID] became legal, she had talked about it and mentioned that this would probably be something that she would deal with. It was through her that I came to know about it. As soon as it became legal, she was right on it and said this is what she wanted to do. (FM-17)

A loved one’s perspective on MAID also came into focus following the diagnosis of a life-limiting condition. They expressed that this life event sometimes prompted their loved ones to share their viewpoints about assisted dying. Others spoke of their loved ones openly discussing their outlook on death and how they wanted to die for many years before any health issues arose, much like the father of this participant:

> My dad had always expressed ages ago that if he was ever terminally ill, that that would be his choice even before it was legal in Canada. He commented he would fly overseas. That would always be his choice, particularly if it was a terminal illness. (FM-25)

As this daughter described, her father’s declaration occurred before any diagnosis of a life-limiting condition or illness, yet the sharing of his beliefs seemed to provide a foundation for later understanding. For other bereaved family members, their knowledge of their loved ones’ perspective about death and assisted dying came to be known gradually over time, as this son explained,

> She had been an advocate for MAID. I remember her forwarding me things from Dying with Dignity [a national human-rights charity focused on protecting end-of-life rights] to write MPs [members of parliament] about. During these 6 years she would have the conversation with me about when she is hospitalized and when the medical directives are updating changes; she would [laughing], she would set up treasure hunts for me to find around the house where different important documents were. She was actively participating in planning for her own death and way more actual planning when we get to MAID. (FM-22)

Although some family members were aware of their loved one's perspective, other family members expressed that knowing this perspective did not necessarily make their experience less profound or easier to manage.

Some family members also expressed they were surprised that their loved ones' beliefs were compatible with MAID or that their loved ones would even consider it. When their loved ones then expressed their desire to begin the process for MAID, these family members were taken aback and expressed that they were not mentally or emotionally prepared for it, as described by the daughter: "At that time … I felt like I had been hit by a ten-tonne truck" (FM-05). Not knowing that a loved one would consider MAID also intensified the experience for some family members. As one participant recalled, her brother-in-law "cried and cried" (FM-32) when her sister brought up that she wanted MAID, he had no idea that she would contemplate an assisted death, but as this family member recalled, the husband gradually "got more used to it as the time when on" (FM-32). The contextual factor of knowing a loved ones' perspective on assisted dying appeared to be an important element in the experiences of bereaved family member participants.

Being Aware of the Suffering

For the most part, family member participants understood the suffering of their loved ones, and recognized that suffering had a negative impact on their loved ones. Family members seemed somewhat prepared when their loved one announced they were pursuing MAID in the context of being aware of the suffering. Some family members also acknowledged that through this recognition of suffering, feelings and discussions about their loved one's situation and circumstances occurred, as this wife articulated,

> We were talking a lot and talking about it and discussed our feelings about it and kept coming back to he's suffering so much, and he was getting worse every day, and this was a way to end that, and this was the best thing. He was a shell of a human. (FM-16)

There was variability in when family members came to realize the suffering of their loved ones and its impact on their loved one's life. When a loved one had been diagnosed with a progressive, life-limiting condition, family members seemed to more easily confront the idea of suffering of their loved one, as this daughter recalled,

> My family already talked, and we all supported Dad a hundred percent and told him that right from the start. The Parkinson's he was dealing with, and it was a very fast onset, rapid progression, we were all one hundred percent behind him, whatever he wanted. (FM-26)

Being aware of their loved one's suffering tended to influence the context of family members' experiences, as this wife recalled "seeing the rapid progress of his disease and knowing that his suffering would be over. That was a big thing. That was central" (FM-27). For some, like this wife, it meant they had to be honest about what they saw and the challenges their loved one was experiencing:

> Seeing someone like [my husband] suffer and struggle like, you could physically, viscerally see it and witness it. It was awful and the worst thing I have ever witnessed, So, trying to dissipate that but being unable to was hard. (FM-16)

When family members did not observe their loved one's deteriorating health or understand the degree of suffering, this seemed to establish a more intense experience for family members. When a family member lived far away and was not able to see the changes in their loved one's health firsthand, this seemed to occur more frequently, as this mother reflected,

> The closer people were, the more they saw the need for it [MAID]. The person who had the most resistance, that's the wrong word, the person who had maybe some feeling of dismay, was my daughter. She is far away and doesn't see him very much. She hadn't seen him for a year. A lot changed in a year. (FM-28)

This mother seemed to indicate that her daughter's situation was more complex than her other children's, as it was dependent on the time spent with her father. At times, family members needed to witness the suffering their loved one was going through to understand and more likely accept their situation. In a particular case, a mother remembered her son's reluctance to consider MAID as an alternative for his father: "He didn't believe [his dad] was dying" (FM-23). She explained how her son started spending more time with his dad, even staying overnight because "he didn't believe it" (FM-23). Sometimes, conversations also made family members aware of their loved one's suffering. For some, these discussions helped them acknowledge the suffering and formed the foundation of their understanding:

> We talked about what was important to [my husband], particularly about what he wanted the remainder of his life to be. I know that he was pretty firm in his belief that MAID was the right decision for him. To prolong the torture, he was going through was not quality of life at all; it was just endurance. (FM-07)

This participant found that her husband's conversations about his experience and feelings helped his family better understand what he was going through. Despite knowing that he was suffering, his family still experienced intense emotions, as this same participant described, "As we waded through the process [of MAID], [it] was just horrific to know this" (FM-07).

Personal Beliefs

It became evident to me during this study that family members' moral and ethical beliefs seemed to be a crucial contextual element to their overall experience. Many described how they worked through their perspective about MAID, including this son who spoke of his worldview that framed his perspective around assisted death:

> I am a former geologist, so I am a scientist. I am atheist, agnostic so I am not bound by those conventions. I have had many pets over the years. Taking care of an animal makes you realize you have this obligation to minimize suffering, and I understand that the medical profession going all the way back to do no harm, yada, yada, yada. That is very narrowly interpreted a lot of times. The question is, are you actually doing more harm by prolonging an existence as opposed to a life when you are ending it? We [he and his family] had that discussion many times about how we treat our animals and the way we treat our ageing parents and it was a pretty easy conversation to have. My sister and I were on the same page. My brother needed to come to terms with it. (FM-01)

For the most part, family members appeared to try to balance their personal, moral and ethical perspectives about MAID with the choice of their loved ones, as this daughter described,

> That human beings should have that opportunity. Morally without having it a part of my life or thinking too deeply about it, yeah, that makes sense, why wouldn't we? Our dogs and our animals get sick and we euthanize them and so on and so forth. I always agreed with self-determination in that respect. When he said it, it kind of shocked me, I didn't really feel ready for that in the moment, but then I realized he's been waiting for this for years and his time is here [pause], then ethically, there's no way I would have put any seeds of doubt in his mind, not that we could have. I just felt like this opportunity was here, this is what he wanted. He clearly had been thinking about this. (FM-06)

Many family members shared this common experience of reflecting on their personal beliefs and interpreting what MAID meant to them, within the framework of their loved one's desires. A daughter recalled that she "always held back a little bit about how [she] felt" as "it [was] definitely what mom wanted" (FM-17).

In reflection on family members' personal, moral, and ethical beliefs it appeared to me most significant when the choice for MAID was incompatible with their beliefs. In coming to terms with her mother's (the aunt's sister) choice for MAID, this daughter recalled that her aunt had asked if a friend could speak with her mother in hopes of obtaining a different outcome:

> At one point, my aunt had a lady that she played bridge with, and the lady was quite religious, and my aunt asked my mom if this lady could come and talk to her. My mom said, "Sure, why not." This lady came and tried to, a stranger, in essence, tried to convince my mom that she was going against God and going against, just pulled out every religious card in the book. I was disgusted to hear this. Then my mom told me, she

> said, “You would be proud of me.” I guess my mom listened to the lady and did a lot of nodding, my mom was a really good listener, and when the lady started on the religious bent, my mom just said, “I understand your opinion, but I truly believe if God did not want me to have this right then He would not have allowed our Canadian Government to put it into practice.” (FM-11)

As another family member recalled, her sister’s religious perspectives conflicted with her father’s decision to enact MAID, which became an element to the contextual background of their experience in the weeks before their father’s death. After several discussions and encouragement from the sister, the family member decided to engage with her father before his death:

> I couldn’t be mad at my sister either; that was something she struggled with. She didn’t agree with it. That was hard for her, and part of what she had to go through. Within a couple of weeks coming up on the event, I did finally tell her, “If you don’t go talk to him, you will regret it. Go take the kids in to see him. You will regret it for the rest of your life. You will be unhappy with yourself about this one thing, so you have to go at least and see him and say goodbye.” It was about a week before and she and her family went in and spent a Saturday with him. Did all the things I would normally do with him there. (FM-25)

Key informant participants suggested that family members and friends, even though they seemed uncomfortable with MAID due to personal, religious or moral reasons, often demonstrated support for their loved ones. For the most part, family members managed to get through to the MAID event, as this wife of a MAID recipient highlights,

> He asked [others] to leave the room and he [the best friend] was with [her husband] and tried to talk [her husband] out of it, one last time because he said, “I won’t get to see you

> in the after-life because this is a sin based on my religion." [Her husband] said, "You know what man, I love you, you are my best friend, but I am doing this for me, and I believe we will meet again some time." (FM-16)

This wife recalled that her husband's friend "believed so strongly [against the decision for MAID] that he tried one last time" (FM-16) to alter the decision. Her husband did not reverse his choice but replied, "thank you, I respect you, but no, there's no way [I will change my mind]" (FM-16). The friend stayed and supported the MAID recipient and afterwards told the recipient's wife that "he was going to do a lot of praying [for her husband]" (FM-16). In this wife's experience, she was not personally impacted by what occurred or the inclusion of this individual's beliefs into the experience because her husband was so confident in his choice but it seemed to establish an element to the contextual framework as the family gathered in the room before the MAID event. However, other participants suggested they experienced more intense emotional conflict regarding their choice to participate in supporting their loved one, as this husband shared,

> It's murder. She doesn't die, she's killed by us. I'm being very careful to separate my relationship with [my wife] and how comfortable I am with that and how comfortable I am with her decision. I'm talking about me in that moment, in abstract. I don't know if you could prepare anyone for that. I don't know how you do that. (FM-02)

Although this perspective was not frequent among the study participants, it indicates that the moral, religious and personal perspectives of a family member could impact their overall experience.

Summary of the Contextual Elements of the Experience of Bereaved Family Members

The stories coming from bereaved family members suggested three contextual considerations: (a) knowing the perspective of their loved one, (b) being aware of their suffering, and (c) the family members’ own personal beliefs. Each of these factors appeared to impact and influence bereaved family members’ experiences throughout the assisted dying process. Although it was not easy to hear, most family members spoke of knowing their loved one’s perspective on assisted dying and generally were not surprised when they chose MAID. For those unsettled by a loved one disclosing that the MAID process would begin, it appeared that having prior knowledge of their loved ones’ perspective influenced the context of family members’ experience. Acknowledging the suffering of a loved one seemed important for many family members in that it provided context to their experience; most notably for those who were physically distant or unprepared to accept that their loved one was suffering and preparing to die. Family members’ perspectives, including their religious, moral and personal beliefs, also tended to influenced the context of family members’ experiences. Most family members worked through their perspective about MAID, understanding and balancing their beliefs about MAID to support their loved one’s choice. Even though some family members had unresolved conflicts with this choice, it was my observation that most chose to set aside their apprehension and supported their loved ones, regardless.

Understanding the Experience of Bereaved Family Members

Beyond the individual and personal experiences, family members seemed to describe broader system and policy factors that impacted them during this time in their life. The interconnections between these considerations added layers and complexity to the experience of bereaved family members. I have described these as three overarching themes: (a) they want

MAID, now what, (b) prepared but maybe not ready, and (c) evolving understanding of this type of death. Several subthemes further illuminate the perspectives of bereaved family members and how their experience with MAID impacted them.

They Want MAID, Now What?

Family members were affected in varying degrees by their loved one's choice to receive MAID. According to most family members, once their loved one indicated they wanted to pursue MAID, they responded by supporting them, and some felt they needed to become actively engaged to enable their loved one's choice. I also found that there were several external (meso-level) elements why and to what degree a loved one became involved to navigate the process. The three that I identified are (a) how health care organizations and provincial and territorial jurisdictions responded to MAID legislation, (b) how challenging it was to access information about MAID, and (c) how integrated MAID was in the system. In addition, the philosophy of palliative care services in relation to MAID, and the intersection between palliative care and MAID programs seemed to factor into family members' involvement. These meso-level considerations seemed influential in the experiences of family members as their loved ones proceeded to MAID.

Navigating Access. Family members described varying degrees of involvement, support and responsibility as their loved ones pursued their choice for MAID. Some family members did not have to do much, or anything at all, once their loved one expressed their desire for MAID (FM-03; FM-23; FM-26; FM-27). In these situations, the process towards MAID appeared to be seamlessly integrated into the system with accessible health care professionals who were knowledgeable and able to assist and guide individuals through the process, as one sister recalled,

> She said, “What do I need to do to have, to be allowed to go [have MAID]?” And that hospital was absolutely stellar. I’m so glad she was there. The staff were absolutely the most amazingly compassionate, empathetic people I have ever met. They have witnesses right on staff. (FM-18)

When this level of integration and collaboration occurred, the family members seemed to report the overall experience as being positive. However, regardless of the level of integration of MAID services, when a loved one declared they wanted MAID, many family members reacted to this by accessing and gathering information on their own:

> Being able to help my dad get what he wanted. That was the huge thing.… When my dad said, “This is what I want,” it was like, “I wish you hadn’t said that but okay. What do we need to do?” (FM-25)

For some, like this daughter, their involvement seemed to be by choice because they wanted to have some responsibility; for others, their engagement appeared to be related to whether their loved ones could determine how to access information and initiate the MAID process independently (FM-01; FM-02; FM-04; FM-21; FM-23; KI-09). This wife described that the “most challenging” part of her experience was “getting it [MAID] activated [initiating the process” (FM-29):

> We said right up front, he wants to be able to register for it [MAID]. If somebody had taken ten minutes to say, this is the paperwork, this is the process. Repeatedly having to push for information, to [get her husband] registered. If you look at the documentation, you need to have two people [witness the signature]. [He] couldn’t just do the documentation [himself]. The doctor told me to download it and to [get my husband to] sign it and drop it off at the [doctor’s] office. (FM-29)

This wife went on to express,

> It would be helpful at the front end, if there was a bit more hand holding … and here is someone to talk to you about what the [MAID] option is. You try to research stuff and try to figure it [the MAID process] out, so you can give the best support you can on the journey. We finally got the paperwork done but that was months after we had initially instituted the inquiries. (FM-29)

Some family members identified there was a lack of clarity on how to obtain information about the MAID process, program, and services which made their experiences a little more complicated (FM-07; FM-12; FM-13; FM-14; KI-09). As this wife remembered, “Trying to figure out the paperwork. Just getting it organized and lined up. It’s hard to find, first of all” (FM-12). When health care professionals, even those who did not know the MAID process, engaged with family members, sought out the information needed and openly shared it with family members, this tended to help ease the tension during this part of their experience (FM-11; FM-12; FM-14; KI-09). As this daughter recalled, her interactions with this health care professional made a difference for her:

> I had talked to the palliative nurse before, and said, “Listen, my mom wants MAID. What do I do? Can you help? Because nobody at the hospital was helping.” It was that uncertain time and people still didn’t know what the heck they were doing. She said, “I don’t know, I’ll have to talk to my supervisor and get back to you.” So, then she called me the next morning, she basically walked me through it. “This is what you need to do to apply for MAID, for your mom to apply. You need to go to the website. You need to go to this place; you need to download the form. You need to find witnesses, fill out the form and send in the form.” I needed somebody to verbally walk me through the steps. I

> was just thankful that she told me because I needed somebody to actually say those words. (FM-14)

When family members confronted unexpected impediments to information about MAID, it typically was surprising and appeared to cause stress for some during an already anxious time (FM-10; FM-13; FM-20; FM-21; FM-25; KI-07). In her interview, this wife recalled, “At that time, the hospice would not give me any information. Any of their personnel would not answer any questions or give me any direction” (FM-13). This wife went on to note how she “expected better at the hospice” (FM-13) and described how she handled the lack of access: “My sister and I were causing angst among some of the nursing staff because of our questions and because of our assertiveness and what we expected” but as a result, she “got called to the principal’s office [the Director of the hospice] a couple of times” because of her persistence (FM-13). When family members suggested that a MAID program was not well integrated into health care or organizational systems, this appeared to influence their level of involvement and, for some, their experience (FM-01; FM-07; FM-10; FM-13).

Variation in access to MAID, including provisions, were also described by some family member participants as a memorable part of their experience (FM-11; FM-13; FM-16; FM-17; FM-19; FM-22; FM-28). Meso-level elements, including organizational policies and processes, tended to be perceived by some to get in the way and potentially inhibit their loved one from accessing some or all aspects of MAID. This could include providing information and education about MAID, permitting members of the MAID team to enter the facility for the purpose of discussing aspects of MAID, allowing MAID assessments onsite and allowing a MAID event to occur in a facility or organization or on the unit. In some organizations and institutions, policies seemed to have evolved since implementation in 2016 (KI-02; KI-06; KI-13), but others have continued to refrain from allowing complete access to MAID, possibly resulting in loved ones having to be relocated for access to MAID to occur (FM-19; FM-21; KI-03; KI-09; KI-10). For some family members, the restrictive policies did not seem to impact their experiences (FM-19; FM-24); while others found this challenging (FM-16; FM-25; FM-28).

Where restrictive institutional policies existed, they seemed connected to faith-based organizations, a specific unit, or facilities where palliative care was the principal focus (KI-03; KI-09; KI-10). When in place, these policies refrained from permitting full access to MAID and sometimes resulted in family members needing to take more responsibility, including potentially bringing their loved one elsewhere for MAID to occur (FM-13; FM-14; FM-19; FM-25). As this daughter recalled, “The assessment took place at my sister’s place. He [her father] told the Lodge he was going to my sister’s house. Everything took place at my sister’s place. We just knew that’s where it would be” (FM-19). For this daughter, she knew the institution where her father lived was “staunch[ly] Catholic” (FM-19) and adapted since MAID could not occur there.

When unit or institutional policies restricted full access to MAID, including the above-mentioned provisions, many family members felt the burden of this as this daughter recalled,

> They wouldn’t [allow MAID provisions] at the facility. So, we had to take him over to the hospital which was just a block away. [We] got all of his room cleared out. Bundled him up because it was cold out. Took him to the hospital. The hardest part of this was that it was in the outpatient area of the hospital. It was really sterile, it was just weird. He didn’t want to do it at home because he didn’t want mom to go back to it afterwards. (FM-25)

For some of these family members, when their loved ones lived in a home-like institutional setting[79] for many years prior, and relationships had been established, bereaved family members appeared to be more tolerant of restrictive policies[80] (FM-19; FM-25; FM-27). Alternatively, family members tended to be impacted by policies that affected access when their loved ones were admitted before MAID occurred (FM-13; FM-16; FM-17).

When family members confronted unexpected impediments to information, such as, when MAID was being considered in the context of legalization and implementation, it appeared to create tension during an already stressful time (FM-10; FM-13; FM-20; FM-21; FM-25; KI-07). Family members who met knowledgeable and supportive health care professionals more likely spoke of a positive experience in these cases, even if there had been challenges with gathering information and access initially (FM-05; FM-11; FM-12; FM-14; FM-18; FM-26; FM-27; KI-09). When information about MAID could be accessed easily, and the process was understandable, family members suggested a positive experience. There also seemed to be an impact on the experience of bereaved family members when organizations and health care institutions prohibited full access to MAID, as defined in their policies. However, the degree to which this impacted them seemed possibly dependent on the prior relationship with the organization, the leaders and health care team.

Appreciating Palliative Care. As presented in Chapter 3 (see the “Description of the Sample” section, “Bereaved Family Member Participants” subsection), most bereaved family member participants recalled that their loved ones received palliative care before their MAID death. As this husband reflected, “She [his wife] qualified for palliative care the moment she was

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[79] A lodge, assisted-living facility, or long-term care institution.

[80] Restrictions include not permitting access to MAID or requiring a forced transfer.

diagnosed with ALS [amyotrophic lateral sclerosis], right from Day 1, as soon as there was a formal diagnosis" (FM-02). While most family members recalled conversations about palliative care for their loved ones, some family members remembered these conversations being "scary" (FM-16) because of the negative connotations they had associated with palliative care, as this wife recalled,

> They provided him with extra pain meds that would help but said, otherwise, wait for your meeting with the oncologist Monday. That's when we saw both oncologists come into the office and that was another big red flag and they said they wanted to admit him into the Palliative Care Unit because he had a lot of unmanaged symptoms.… That was very scary hearing that word. (FM-16)

It appeared that due to preconceptions about what a palliative approach to care means, family members seemed uneasy regarding this type of care. Several family members thought that palliative care was provided only to eminently dying individuals (FM-05; FM-20; FM-29), which they were not prepared to admit, as described by this wife,

> I had a misunderstanding of, as many people do I believe, about palliative care. I thought that automatically meant end of life, which it does not. They were very great in trying to alleviate some of his pain and suffering and doing everything possible to make him the most comfortable, which was wonderful. (FM-16)

As a result of misunderstanding and miscommunication, the consequence seemed to be a delay in access to palliative care for some of the loved ones, as the wife of a MAID recipient described,

> I didn't know what the significance was of being on palliative versus not being on palliative. There was confusion. We got the nurse to come so my son and his wife came so they could hear what the nurse had to say, and that's when some of the right questions

> got asked. She said, “You refused hospice.” I said, “We don’t want to put him in a hospice. I thought that meant that he had to go into a care facility.” He wanted to be at home. I didn’t realize that hospice care meant a level of caring in the home or access to support or other things. (FM-29)

After starting palliative care, some family members regretted not advocating for a change in their loved ones’ care level sooner (FM-13; FM-27). As this wife, a former palliative care professional, described,

> If I had one regret, he was palliative in the broad sense of palliative, the whole time he was there. If I have any regrets, I wish I had pushed for that earlier. Then, it was a total change. I’m not criticizing… I don’t know why I didn’t push for that [palliative care], but I wish I had. I was so caught up in this COVID virus and they wouldn’t let us in [to the assisted living facility where my husband lived]. It was still early days in terms of trying to figure out what to do with family and COVID. (FM-27)

Although this husband did receive palliative care, what resonated for this participant was that she felt it was her responsibility to advocate for her husband’s change in care as his condition deteriorated (FM-27).

Once palliative care was in place for their loved ones, some family members reflected that this did not mean it alleviated their experience or challenges, especially when MAID was chosen by their loved one. One son described his experiences as “compartmentaliz[ation]” (FM-30) of palliative care as MAID came into focus, with “little fluidity” between the two services (FM-30). Several other participants suggested palliative care and MAID services as poorly intersected, as this son continued to describe,

> There are multiple branches of the process … not just with MAID, but palliative care. It's all compartmentalized and doesn't really flow into one, and it's like, "We are going to do early palliative care. Oh, you will do this part, and now you have been determined that your cancer is terminal and now we will go onto here." There's very little fluidity to it all. It's all broken up. (FM-30)

When MAID was involved, several family members indicated that the continuity of care for their loved ones receiving palliative care at home through community-based services felt compromised, resulting in fragmentation of care. This tended to result in some family members engaging or re-engaging in caregiving activities (FM-07, FM-13, FM-21, FM-30).

In further reflecting on his experience, this participant wondered if the quality of palliative care services provided might have been a factor in the timing of his father's MAID death, "If he [his father] had been more comfortable and [it had been] easier, maybe he would have held off a little bit longer [before getting MAID]?" (FM-30). However, there seemed to be little more that many family members felt they could do other than continue supporting their loved one's choice and providing care as needed. This impression that individuals may choose assisted death due to inadequate care is a concern also heard in society and among health care professionals and disability advocates (Miyasaki, 2021; Raycraft, 2022).

I noted that access to palliative care prior to the choice for MAID seemed to be one component of the experiences of family members. Like faith-based institutions, however, when MAID became legalized, some hospice programs also chose to refrain from providing MAID, thus separating palliative care services from MAID programs, as this palliative clinician described,

> When the MAID legislation was first enacted, I was working on the hospice unit. It was really clear that hospice palliative care was separate from MAID. There was a lot of effort to distance that this wasn't our work—this isn't what we do. I feel like within our hospice, it wasn't a religious based one. We felt like this is a choice that people have, but it certainly wasn't part of our program. It was very separate. (KI-10)

Certain family members observed a difference in the provision of palliative care after their loved ones decided to pursue MAID, and their eligibility confirmed. As this wife recalled, "At the beginning, I had this idea that MAID would be linked with palliative care. I realized as time went on, that wasn't the case. It shocked me" (FM-27). Some family members seemed to feel that professionals on palliative care teams overlooked their loved ones once MAID was in focus (FM-07; FM-13; FM-16; FM-22), as this wife described, "Basically the Palliative team disappeared once [her husband] applied for MAID" (FM-07). From this wife's perspective, even though her husband had been receiving palliative care before MAID became his choice, he continued to experience poor pain and symptom control, and she was having trouble coping; the care did not seem as the same quality. This wife[81] also described,

> It saddens me. It came as a shock to me. I can be naïve. I didn't work when MAID was happening. I just assumed that MAID would be hand in hand with palliative care and that they would work together. When I started hearing bits and pieces, [I thought], "Oh my God." (FM-27)

In instances where palliative care services did not seem to support MAID, and the patient was in inpatient palliative care, this sometimes required a move to a new facility for the MAID provision, which added challenges during an already difficult time, as this daughter described,

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[81] This wife had worked as a palliative care professional.

> Even when my husband's mom and dad passed away, they were still in the palliative care rooms at the hospital or the long-term care facility. You were still there and able to stand by the bed and hold their hand. That didn't happen here [with her father]. (FM-25)

Key informants corroborated the identified benefits for family members when intersections between palliative care and MAID services were made (KI-01; KI-02; KI-06; KI-10; KI-12; KI-14; KI-15; KI-16). As this MAID practitioner reflected,

> It's really nice when I do work with the palliative care nurse because they make sure that they have given them all the grief support, the family, all the grief support. They offer to stay and wait for the funeral home with them. If it's another nurse, you don't get that usually. (KI-11)

When family members suggested a disconnection between palliative care and MAID services, it gave the impression that access to both care options was not optimal for individuals and their family members. The influence of program and policy decisions by organizations and institutions appeared to be challenges for family members during the MAID process and into their grief and bereavement (FM-07; FM-13; FM-27; FM-29; FM-30; KI-07; KI-14; KI-16). Some of these challenges included having to take on additional caregiving responsibilities and potentially seeing more suffering of their loved one when the fragmentation of care resulted in less adequate pain and symptom management.

For the most part, palliative care was in place prior to a loved ones' request for MAID (FM-02; FM-03; FM-16; FM-21; FM-23). Some family members wondered if palliative care was accessed by their loved one, or if the quality of the palliative care had been better, would their loved one have chosen to delay their MAID event (FM-07; FM-13; FM-23). Some family members seemed to feel that when their loved one chose MAID, there was a fragmentation experienced between MAID and the palliative care services that had previously been in place. This sometimes required that they take on additional responsibilities. Few family members felt as though they, personally, had received adequate support from the palliative care service as their loved one proceeded through to MAID (FM-02; FM-05; FM-26).

Prepared but Maybe Not Ready

Once their loved one opted for MAID, most family members valued being actively involved, although this closeness sometimes resulted in tension. Even when family members seemed to feel prepared for their loved one to receive MAID, the mental impact of this experience, mainly coming to terms with the fact that their loved one was going to die and, possibly, that they had supported them in achieving MAID still had to be dealt with. Family members also appeared to experience living in a state of suspension while waiting anxiously to hear if their loved one would be eligible and proceed to MAID. When their loved one decided on MAID and scheduled their day of death, the impression was that this was a significant part of the experience of family members as they confronted that their loved one was going to die. This part of their experience appeared to impact some family members throughout their grief and bereavement, as well.

Reconciling Involvement. Family members provided diverse perspectives on their experience of involvement. Some were already caregivers for their loved ones; for others, pursuing MAID seemed to prompt them to relocate or have their loved one move closer to be with them. With these changes, different responsibilities arose. Some family members spoke of being engaged with their loved ones in the time leading up to the request for MAID, with many noting they became most involved when MAID came into focus. Of those who spoke of their involvement with their loved ones before MAID was in focus, most talked about caregiving, providing transportation, and seeking additional treatments for their loved ones. Within these discussions, an acknowledgement of guilt appeared to frame their experience during this time, as this daughter recalled,

> From my perspective I felt guilt. I felt that if I could have done something more, maybe might have been able to visit more often [crying], or if I had been able to [pause, crying], have her live with me. Her family was everything to her, it was very important to her. I know it's ridiculous and I can't take that on, but that's something that I felt. (FM-17)

Several family members mentioned feeling exhausted before their loved ones decided to have MAID. Afterwards, family members sometimes expressed uneasiness in thinking about that time, as this wife described,

> I often wonder if he would have chosen to live longer, but he knew that I was exhausted. He knew the family were tired too. I have never been that tired in my life. Even when he was in care. I was there [at the long-term care facility] every day and if there were issues with his pump, I wasn't able to go to the cabin. I wasn't comfortable leaving him. (FM-27)

When MAID was requested, these family members wondered if they had been more involved, would their loved ones have chosen to live longer, as this daughter remembered, "I keep having to remind myself that I did my best. [My mother's friend] said to [me] that [my mother] knew that [I] didn't know how much [I] was actually doing for her". This daughter shared that it was good for her to hear this "because that meant it's true [that she was involved enough and her mother appreciated it]" (FM-20). In working through their grief, some family members like this daughter spoke of reconciling that they had been involved as much as possible and had done enough for their loved ones, indicating a perspective that their level of involvement did not determine why or when their loved ones chose MAID. As a key informant participant also described, “[It] is fairly universal in the people that are left behind. The question is, did I do enough? If I didn’t do enough, is that why they chose to end their life?” (KI-14). All participants who shared their experience gave the impression that they were aware that they were not responsible for their loved one’s choice for MAID and that they had done enough in caring for and supporting them. However, coming to terms with this realization appeared essential in the overall experience of family members.

When MAID became the option for loved ones, the level of support and degree of responsibility family members assumed varied. Despite differences in experiences, most family members mentioned they centred their attention around their involvement and connection so their loved ones could receive MAID. Many described a need to reconcile their involvement within this context. For some family members, there was little they needed to come to terms with (FM-01; FM-03; FM-04; FM-06; FM-28), but for others, this was not an easy part of their experience (FM-02; FM-17; FM-22). Illuminating that in some experiences, although family members were engaged and supportive, they may have had reservations about their involvement in facilitating access to MAID and, thus, their loved one’s death. The impact of this tension seemed to continue into bereavement for some family members.

After accessing information about MAID following a request from her father, this daughter spoke of sharing her learning with him:

> The first conversation I had with him [her father] about the MAID thing after I had explored, I told him what the process would be… I made up a document and gave him a simplified one about what would happen and what had to happen. (FM-28)

This daughter seemed to describe that being actively involved in this way was crucial to her experience: “I was unwavering because I knew why I was doing this. I would never not have done this. I felt this was the last but very significantly good thing I could do for my dad” (FM-28). Knowing what she needed to do and being prepared seemed comforting; others also described it eased their experience as their loved one made their choice.

Not all family members, however, expressed having a choice whether they engaged when their loved one brought up MAID as an option. Since requesting MAID involved certain regulatory and procedural aspects, including completing documents, finding independent witnesses, and submitting the request, some family members and friends felt they needed to be involved in completing the requirements. As one son remembered, their family experienced challenges from the beginning while they attempted connect their father with the MAID option:

> At [the hospital], nobody seemed to know what the process was. We went around, and you have to get two people and two doctors they know and then you have to get witnesses and they are all volunteers and they are hard to find. It struck me as being a convoluted process. I had a moment of frustration with the Minister of Health, “What’s going on here?” I ended up speaking to someone in their office, whose parents had gone through the process, and they were sensitive to my cause, things started to happen fast after that. It was just a question of getting it organized. (FM-01)

Without this son’s involvement and advocacy, it seems that his father’s pursuit of MAID may have been much more challenging; and the wife whose husband was told to simply sign the form and have it dropped off at the doctor’s office also noted difficulties in initiating the MAID process and felt that she needed to “speak for him a lot. Just because he [was] tired” (FM-29).

When a loved one had limitations or symptoms affecting their ability to complete the requirements or tasks to initiate MAID, their family members recognized the need to be involved. This seemed to happen most often with family members who were in caregiver roles. For example, this husband recalled that his responsibility in initiating the MAID process was necessary because of his wife's physical condition: "[She] couldn't control her hands anymore. She could use her keyboard but couldn't control a pen. I was involved in the administrative part of it completely, and I would make the phone calls" (FM-02). It appeared that some family members did not see they had a choice in being involved when their loved ones expressed wanting MAID, and when confronting this, they seemed to prioritize their loved ones. Although they did not express it in this manner, as an interviewer I wondered whether they were signalling a feeling that they had abandoned their loved ones if they did not assist and support them.

For some family members, their involvement affected them deeply. Most often, for these individuals, it seemed that the greatest impact was when it was close to when their loved ones would die and after the death. This son recalled that, after providing information on accessing MAID, his mother got approved. His perspective was that his mother might not have considered MAID if he had not given her the information, leading him to feel strongly about his involvement in the situation:

> Once she was approved, I tried to not display my reticence, I didn't feel very confident about [pause], I was scared because she was approved, then maybe she would be influenced, like she was influenced by me to get approved. I was worried she would be influenced to go ahead with it. I remember feeling a lot of turmoil inside. (FM-22)

This son described reconciling his level of involvement once his mother delayed her MAID event by about a month. She had been experiencing significant symptoms at the time she was approved, and following the easing of some of her suffering, she postponed her death. The son said he felt more comfortable about his involvement once his mother made a “very sober” (FM-22) decision about her date for MAID.

While many family members generally reconciled their involvement and their feelings and emotions about their connection to their loved ones’ MAID journey, others struggled. For some, their discontent and uneasiness continued into bereavement, as this husband discussed,

> We were supportive, we were comfortable that [she] was comfortable that she wished to do and did. Setting that aside, the actual act of killing her, which is what it is, was a total shock to me. Nothing in my experience had prepared me for that reality…. It’s the actual act itself. I am not an accessory after the fact, I am a participant. (FM-02)

Family members had different viewpoints about their involvement. Many individuals shared that when their loved ones began discussing MAID, this began a level of involvement in care that they had not anticipated; others spoke of being engaged beforehand. Many of these family members discussed coming to terms with the fact that they had done everything they could to help their loved ones before MAID became their loved one’s choice. Most family member participants spoke of coming to terms with their involvement and supporting their loved ones through the MAID process.

Primarily, family members reflected that they found positive elements to ensuring their loved one received MAID, which helped them reconcile their uneasiness in their experiences. For some, however, this part of their experience continued to cause unrest into bereavement.

Living in Suspension. Regulatory processes, guidelines and procedures evolved from legislation and policy and framed the time from when a loved one contemplated MAID to their event. According to some family members, the elements in the regulations and guidelines that required a pause in the MAID process caused family members to sometimes feel apprehensive and nervous while they waited for things to proceed (FM-07; FM-11; FM-20; FM-21; FM-25; FM-28; FM-31). Some family member participants also gave the impression that organizational and institutional policies and processes created a sense of loss of agency because of waiting periods as their loved ones sought MAID (FM-01; FM-04; FM-06; FM-11; FM-13). These periods seemed to result in family members being in a holding pattern, tending to have difficulty doing anything beyond waiting, nor did they give the impression that they could prepare for the potential that their loved ones may die because they may not qualify for MAID. This daughter described this part of her experience as an anxious and stressful time: “That was the stuff that was the most stressful. The most difficult was waiting to hear” (FM-11). Recall that many of these experiences were from the family members’ perspective of supporting and being involved with their loved one’s choice.

Many family members seemed describe feeling stuck in a state of uncertainty until their loved one received approval or the MAID event date was determined. Several family members articulated being unable to move forward psychologically, that their loved one may die through assistance, as this daughter described,

> What we really needed them to do was set up those assessments. Mom’s assessments took almost a week to set them up and they were 3 days apart. Her last assessment was 3 days before she died. It was like Day 8, in the 10-day waiting period I’m talking. We didn’t know [that the loved one qualified] until it was close to the end of the 10 days. (FM-14)

Interviews with several key informants highlighted that they seemed aware that the suspended waiting time that tended to be inherent in the journey towards MAID in the early days of implementation and through Bill C-14 was experienced differently by family members versus those within the health care system:

> Time runs on a different scale. Waiting for contact time, meaning, sending a message to coordination, or coordination saying, I need to look for an assessor. Any of those process related waiting times, I think for the family it's like five or 10 times longer than the actual clock time. (KI-05)

When a loved one opted for MAID, regulatory requirements (Bill C-14, 2016) seemed to cause family members to feel like they were in limbo at times, primarily because of safeguards and eligibility criteria noted in the legislation.[82] Additionally, organizational and institutional challenges seemed to lead to similar experiences. Some family members felt that the health care team's understanding of institutional MAID procedures and policies, especially during the first few years of MAID implementation, appeared to make things difficult. According to this daughter's recollection, the health care team on her father's unit admitted to being unsure how to proceed when her father requested MAID:

> They commented that they weren't, they were trying hard [pause], but this was new to them too, so sort of "bear with us while we try to figure this out." Of course, my dad is done with this and wants to get the process going. There were a couple of days there where it was stressful where everyone tried really hard to figure out what to do next. The comment was made, if these were the other hospitals [in the city], they are more familiar with this [MAID], and it would have gone more smoothly there. (FM-04)

Like this daughter, other family members tended to experience periods of anxious waiting due to factors that paused progression. It seemed that when this was related to a lack of knowledge

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[82] Some of the safeguards and criteria have since been modified in Bill C-7 (2021).

about crucial elements of the MAID process by those in the health care system, family members also felt they were living in suspension. In this son’s case, there were complications when a health care professional requested a suspension in the progress of his mother’s MAID request until she underwent additional assessments:

> Another challenge, my mom was diagnosed in Germany. Her full diagnosis was all written in German. [I got the documents] professionally translated and certified. That’s what we provided to the MAID navigators. The person who was doing the scheduling [of the MAID assessments], made contact with us, and she said that they wanted mom to be diagnosed in Canada. I felt like because [the MAID team member] was unsure, we got a little bit lost in the system. [The MAID navigator] then called me back finally and said, the doctor who will be assigned to your mother’s MAID case, is the neurologist from the ALS clinic and he insists on a diagnosis in Canada and his soonest available appointment is two months away. I lost my shit. My mother doesn’t want to die six months down the road, no. This is imminent and especially with something where she can lose her capacity to consent. (FM-20)

Waiting for supplementary requirements created a highly stressful experience for this family member as they witnessed their loved ones suffering and wondered if the delay would affect their opportunity for MAID. Such occurrences also seemed to make the psychological preparation of family members more challenging. These family members seemed to experience an emotional upheaval in these situations, as this son recalled, “The emotion for me was more tumultuous. When we finally got that [approval], it was tears of joy, and we don’t have to worry anymore” (FM-20).

In some cases, family members also gave the impression of living in a state of suspension as organizational leaders modified existing policies to permit access to MAID. Through this, as a daughter recalled, "there was a lot of back and forth" (FM-11) until progress was possible on access. Family members noted that when this occurred, it was unnerving to wait to find out if their loved one could access their choice in their location (FM-11; FM-12; FM-13; FM-14; FM-21; FM-26).

After the death of a loved one, some family members recalled that the feeling of living in suspension seemed to recur as a result of system and organizational factors they encountered. This created challenges for some family members and appeared to impact their experiences during grief and bereavement. As this wife recalled,

> They gave us some time with [my husband] and then the kids and I left the room. At that time, the individual had to be transported to the Coroner's Office, but no transportation had been arranged. It was hours, and they were trying to find somebody to transport [my husband]—[pause] it was uncomfortable because here there were strangers in our house and they were trying to make phone calls and sort out how [my husband] was going to be transported and who was going to do that. The kids and I went down to the creek and waited down there for an hour. They finally found someone. (FM-07)

Her husband's body remained at home for approximately 5 hours and there was nothing she could do about it. The lack of control that this wife had, in her home, after the MAID death of her husband seemed to be a factor in her experience. This situation appeared to significantly impacted her at the time, in grief and into bereavement. This participant recalled that she "can't shake that experience of where we waited, where we sat, what we did" (FM-07). At the time of the interview, she had listed her house for sale.

Waiting during the MAID process had disparate aspects and was interpreted differently by family members in their experiences. During the MAID process, some family members appeared to experience living in a state of suspension, particularly when involved with their loved one’s request. This caused many family members to feel anxious, apprehensive, and in emotional unrest. Some family members also seemed to articulate that this pause impacted them in preparing earlier for their loved one’s death because they were uncertain if MAID would occur. It is important to note that not all family members felt that when the system, an organization or regulatory requirements resulted in a period of waiting, it negatively impacted them (FM-11; FM-17; FM-25).

Realizing the End. Although many family members supported and were actively engaged with their loved ones as they proceeded to MAID, it seemed to be met with mixed emotions when it was official that their loved one would receive MAID. These feelings connected to their experience were generally not about the assisted death itself but rather that their loved ones’ life was ending, and they knew the date and time when it would happen. As this son described, “Death is always a random thing. When you say, the 18th of October, then it’s not random anymore. It’s very tough” (FM-30). This spouse also articulated this poignant aspect: “[It] puts a pin in your heart” (FM-29). Knowing the day of death placed concrete parameters around their loved one’s life length. It became more tangible and felt “unnatural and like [their] brain could not process it,” as one wife recalled (FM-16).

Although most family members understood their loved one’s wishes and supported them, it seemed from interviews that they might have put their feelings aside and focused externally on their loved ones while they pursued MAID. In doing so, and because of other experiences in the process, such as the periods of waiting, family members may not have fully addressed or reconciled their own emotions and feelings about their loved one’s death until decision on the date of death. This final realization was an aspect of their experience that many family members seemed to identify as requiring much more of them than they anticipated. It was intense, as this wife shared,

> Honestly, I didn’t take it [going through the process and qualifying for MAID] that seriously because we weren’t there yet; it [MAID] wasn’t something we had to seriously consider. I almost, I wouldn’t say I ignored it, but I didn’t give it [that her husband initiated the MAID process] much attention.… Maybe he just wants to have the idea, the option in the back of his mind, just in case, because things are pretty unbearable right now, but perhaps if they can get a better handle on everything, it won’t be necessary. I don’t know, in my mind I am obviously trying to justify any way to keep him around with me longer because, how could this be happening? (FM-16)

Once MAID was scheduled, as this daughter recalled, it was accompanied by a sense of disbelief in knowing this:

> It was really strange. For the next couple of weeks, oh my God, this time next week, dad’s not going to be here. How can I be thinking that? I don’t know when he’s going to die. Yeah, I do know when he’s going to die. So strange. (FM-19)

Family members seemed to find knowing the exact date and time of their loved one’s death to be an almost overwhelming aspect of their overall experience. When they were involved in determining and organizing the date, the reality of the situation appeared even more apparent. Despite the emotional and influential nature of the decision, most family members did not hesitate to participate in deciding the date, according to one daughter’s recollection,

> I said, “What about the summer? Why don’t we wait until July?” Of course, the kids weren’t in school because of COVID. Dad said, “Summer is the time for the kids to be at the lake. I want the kids to be at the lake” [crying]. (FM-26)

It was not only knowing the date that had them confront the realization of their loved ones’ pending death, but it seemed the process of deciding the day was also impactful in family members’ experiences. As this husband discussed, he found it jarring how the decision about his wife’s MAID event came about:

> So, we call the doctor, and she [the doctor] is in her own headspace because she [the doctor] can stand MAID for 6 weeks at a time and then she takes 6 weeks off to keep from burning out. She says, “I’m around for a couple of weeks, then I’m taking 6 weeks off.” [His wife] looks at that and says, “I have already decided to die, what difference does it make?” [It was] like being hit in the head with a two-by-four. They discussed it back and forth, and from her initial comment that “I am going to die at the end of November” to dying was 11 days. Like booking a pizza; there’s the discussion, which is how it feels, of setting a time. Like we are talking to an airline booking agent or something like that. No, that flight is not available, there’s another one leaving at such and such. Yes, it came as a deep shock to me. (FM-02)

He indicated that the conversation could have been more personal, relational, and not so mechanistic. He suggested that discussing something as important as the day his wife would die should not feel so casual and unfeeling.

Once the day of the MAID event arrived, it did not mean that some family members’ emotions had settled. This son remembered that the arrival of the MAID team nurse caused him to feel anxious and upset all over again because the end had arrived:

> We played her favourite music that she wanted playing, and what did surprise me was that the nurse who was assisting the doctor arrived like a half hour early. Which, when it happened, I was like, “No, no, no, no! Please leave. You said twelve o’clock.” That bothered me a bit, because [pause] I didn’t want to feel rushed, and, in that moment, I felt a bit rushed. (FM-20)

There were poignant times in the experiences of family members, often when they confronted the realization of their loved ones’ death. For many, internal tension seemed to surface when they realized the MAID death of their loved one was inevitable. Knowing the exact date and time their loved ones would die seemed to be an important part of their experience and grieving process. When family members were involved in the decision-making about the MAID event, this tended to make the reality of the situation more tangible and shocking for some.

Evolving Understanding about this Type of Death

Given the nature of assisted dying, for family member participants, MAID seemed to allow them a different death experience, including an opportunity for families to remember, honour and bid farewell to their loved ones. While emotional, having the time to reminisce and celebrate their loved one’s life appeared to help prepare family members as they grieved. Being able to say goodbye while their loved one had the capacity to do so tended to be a positive part of their experience.

When it came to the MAID death of their loved one, some family members expressed concern about sharing knowledge about the death. My findings illuminated that, for various reasons, many family members selected to keep the type of death private. For some individuals, maintaining privacy about the choice for MAID continued into bereavement and appeared to cause their experience to be stressful.

Enabling Celebration, Reminiscing, and Saying Goodbye. Although the impending death of their loved one was a difficult time, many family members described their experience as a time to celebrate, reminisce, and say goodbye to their loved ones. They recognized a desire to make memories not only for themselves but also for their loved ones and other members of the family. There seemed to be an acknowledgement of the feelings associated with the connection that came through these practices and how it influenced their overall experience. As one wife recalled, “The only way I can describe it is, it was basically a love orgy of the five of us all together” (FM-30).

Due to the MAID experience, many family members seemed encouraged to connect with their loved ones and create memories because they were aware of their loved one’s capacity and expected time of passing. This was described by one son who experienced the benefits firsthand:

> The night before she passed, my fiancé arrived, and we had a little engagement party because my mom wouldn’t make it to the wedding. It was me and my mom and my fiancé and my mom’s friend. My mom wrote a toast to us, … with my mom’s no-bullshit attitude.… The weeks leading up, we looked through boxes of photos and her telling me stories. I was recording stories and recording conversations with her, learning family and her history. (FM-22)

Giving attention and spending time, sharing favourite foods, reminiscing, or recalling fond memories (e.g., slideshows, presenting photo albums, a memoir) were just some of the elements described during this period. These interpersonal interactions and activities tended to be meaningful to family members. As this daughter recalled, they also marked a time that enabled reflection, connection, and togetherness:

> So, [our family friend] drove for us. It was my brother and his wife. My sister and her partner. My husband and I, my mom and my good friend all went on this final bus ride. He wanted to go for this big, long bus ride and [our family friend] said, as long as he wants to go, we are going to go. Mom, the practical one [said], he is going to need to be back to have lunch in time for the nurses to come at three. We had to rein him in a bit. We did this lovely tour. He [dad] didn't point out a single [thing]. He was at the very back of the bus and he told us afterwards that just seeing us [crying] that he had forgotten the [things he wanted to talk about], watching us was enough. (FM-26)

Another daughter reflected that having the opportunity to say goodbye and engage with family traditions was a memorable part of her experience:

> By this time, it was more intimate. People who weren't closely connected to him did not participate on this day, which meant it was his family and [his partner's family]. They were all people he was close to, and a few other people showed up. The plan was, we would have that room available as our base because we couldn't crowd around his room the whole day. People would go up and down and had what they knew was their last visit. Then he had lunch. This was a funny thing because what we were going to do afterwards was, we were all going to go to our house and have European wieners and a dinner around European wieners—he loved them. We were planning on doing that and have a meal that he might have had prepared. We need to be together for a bit. We can't have this happen and then go on our own way. We picked them [the wieners] up and had them in the car; it was February, so it was cold. My husband and I were there when he [her dad] was having lunch and he wanted to know what we were going to do later, so we told him about our European wiener dinner, and I thought he would like that idea. We were

> carrying on his traditions. He just heard that we had European wieners in the car. I had to go get a package and get a couple out and had to figure out how to heat them up. They had a kitchen with a microwave, so he had some European wieners and French's mustard for his last lunch. (FM-28)

Some family members suspected their loved ones did not care about what happened in those days leading up to their death, the celebrating and reminiscing. These family members felt that, in some way, their loved one had placated them. It seems these actions were more about what family members needed, as this daughter described,

> Our youngest son would come up there with his daughter and she would jump on grandpa's bed, and she brought him a Build A Bear, and I think he would have been fine if that didn't happen, but I don't know. He would eat the food that everyone brought. I think he was trying to make us happy too. My niece came up with her iPad and watched a baseball game with him, which he couldn't see or hear, brought him hot dogs, tried to keep him happy, I guess, and I think he tried to keep us happy too. I'm not sure that we were keeping him happy as much as we were making ourselves happy. (FM-04)

Saying goodbye and reminiscing was not without sadness, however. The realization that the connection, actions, and activities were occurring because of the known, pending death of their loved one was difficult for many:

> [My husband] also talked to his sister and her now husband on Facetime, and that was also very strange and odd, and they were talking about and bringing up different childhood memories and laughing and crying. (FM-16)

Final preparations varied among family members, but most described this time as one to embrace each other, remember, and connect. As this daughter suggested, "It's that idea of people having their funeral before they die so they can hear all the good things people say about them. [We] had that experience, and it was lovely" (FM-28). This seemed to be when family members could "just be present" (FM-20) with their loved one as a son remembered. When thinking about the days before her husband's MAID event, this wife described,

> They [their adult children] started coming around and spending their evenings here. They started pulling out photo albums and asking questions. There's something maybe you want to know. He was writing his memoir. He was writing a book and had been doing this for 10 years or perhaps more, in very short gribs and grabs. Eventually it was coming together and almost done. Some of the conversations were around finishing the book before he died, and we did, or he did, or we did. (FM-23)

Key informant participants also highlighted the impact of reminiscing, ceremony, and life review. This health care professional and MAID team member reflected their observation of a family member's grief and bereavement:

> If the person could have that life review before the actual procedure and include the family and friends in that life review, I think the after pain would be different and also probably less because there would be a real understanding of the individual's life that has chosen MAID. It's a huge piece. (KI-14)

Family member participants described many emotions on the day of the MAID event, regardless of the degree to which they supported or were ready for their loved ones' death. Sadness, emotional pain, calmness, dignity, and beautiful were some of the descriptors bereaved family members used in their interviews. Although it was difficult to know when their loved one would die, family members also spoke about the positive aspects, as well as the freedom and comfort it provided them. As this son recalled, "I just asked the doctor if it would be okay if I got into the bed with my mom.… I wanted to hear her heartbeat. I laid on her chest until I couldn't hear her heartbeat anymore" (FM-20). Intimately experiencing the death of their loved one seemed to be a way for this son to say goodbye and engage in a final ceremony with his mother:

> I was holding my mom in my arms and kissing her forehead and crying and telling her she's beautiful while she was dying. I didn't look up for the next 10 minutes while she was dying. Even after they said she had died, we were all just sitting there crying. Eventually, I asked everyone to give me a moment to be alone with her. (FM-22)

Each family member participant seemed to find their own way to say goodbye to their loved one:

> Before he died, after the group hug, there were also some individual goodbyes. I was the last one. They all left the room, and I got left alone with him. That didn't last very long but it was a goodbye. He said to me that I was the best thing that ever happened to him, and I said I knew that [laughing]. I wished him luck. It was like going away on a trip. I said, "You are going to do fine." (FM-23)

For most family members, their loved ones' MAID death was one that they were grateful and appreciative of, as this daughter expressed, "This was such a positive experience, not the loss of my mom, not that part, but the whole process, being able to say goodbye and wrap everything up" (FM-11). Some participants also shared that MAID provided an opportunity to shift some of their beliefs about assisted dying: "Since it has come into my household, I definitely have had a change of my opinion" (FM-20). One unique perspective appeared to be that sharing a MAID death did not feel "any different from any other death" (FM-32), as this loved one's sister expressed.

For most, MAID facilitated an opportunity to reminisce, celebrate, and say goodbye to their loved ones, which most family members identified as positive. However, this part of their experience was not without sadness as well. Although activities and interactions might have not appeared to be desired by their loved ones, this did not prevent many family members from engaging in ceremonies or reminiscing before their loved one's death, perhaps for themselves. It appeared that most family members felt it was beneficial to their experience that they had the opportunity to somehow say goodbye to their loved ones while they had capacity.

Keeping the Type of Death Private. When loved ones expressed interest in pursuing MAID, it appeared to spark discussions with family members about the decision. These conversations seem to have enabled a broader understanding of life, death, and dying that may not have happened otherwise. After these open conversations, many family members indicated that they did not see a need to share widely that their loved one had MAID; instead, some wanted the choice to remain private and were mindful of their word selection in communications.

Although MAID seemed to provide an opportunity for openness and sharing, not all experiences of family members reflected this. Instead, some felt it an isolating and frustrating experience, particularly when accessing information about MAID was challenging or when health care professionals were unapproachable. This feeling seemed to more likely persist for family members when they identified that others might judge or not support their loved one's choice or their engagement in the process, as this daughter recalled,

> My sister's kids were older and I remember when my sister told my niece, she was like, "Is that even legal? Can you even do that?" You walk away feeling like you have done something wrong, just because of the way it [MAID] was all set up. You don't really

> want to tell people that you aren’t sure of or comfortable with because [of the reactions]. (FM-25)

When family members confronted organizations or institutions that did not fully support MAID, this seemed to influence a family member’s decision to disclose that their loved one was requesting or having MAID and that they were supporting the request. These factors, both individually and in combination, suggest that micro-level and meso-level elements appeared influential in the experiences of family members and their decision to keep the knowledge that their loved one had MAID private. For some, their need for privacy about the type of death continued into bereavement.

When legislation was enacted (Bill C-14, 2016), it seemed that family members experienced unexpected impediments to information about MAID processes, programming, and services (FM-07; FM-12; FM-13; FM-14; KI-09). As discussed, this experience depended on when MAID was being considered in the context of legalization and implementation; however, it appeared to create tension and a feeling of apprehension for some family members (FM-10; FM-13; FM-20; FM-21; FM-25; KI-07). Family members who confronted restrictions, either from a health care provider or through policy and processes, seemed to feel unrest. For this daughter, the health care team who cared for her father told her that they,

> cannot do anything to support this [MAID], but would not interfere. That was their stand. This was just a normal day and he [her father] was going to get an expected visitor who would give him a lethal injection. They knew it, but they did not assist” (FM-28).

Some participants seemed to interpret this to mean that their loved ones’ MAID event should be kept a secret in that institution or on that unit (FM-13; FM-14; FM-19; FM-25). For example, the daughter of a MAID recipient who lived in a faith-based residential Lodge took her father to her sister's home[83] on the day his was scheduled for MAID[84] under the guise of lunch with his daughters. After her father's death through MAID, the family called the Lodge and "told them that dad didn't wake up from his sleep in the afternoon" (FM-19). What appeared to emerge through these experiences was that when policies and processes did not allow full access[85] to MAID, some family members interpreted that the choice for MAID should be kept private. One participant described that this explicit or implicit secrecy became "a major source of stress and anxiety" for some family members (KI-09).

When MAID policies and processes were not known, unclear, or misunderstood, they appeared to impact the experiences of some family members (FM-04; FM-07; FM-12; FM-13; FM-16). This wife recalled being utterly unaware of a unit-level MAID policy that restricted MAID provision until she and the rest of her husband's family arrived on the scheduled day of MAID:

> We had to arrive at the hospital a few hours before the planned time. We showed up back at the Palliative Care Unit where he had been for the last 2 weeks with all of the nurses we knew. He actually had to be moved into a different unit, which we did not know was going to be the case.
>
> He didn't seem to care so much because he was easy going, but I would say for the family, it was more bothersome because we were the ones who were going to have to be there after he was gone and now we were going to this unfamiliar unit. So, we went

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[83] The MAID recipient lived in a faith-based assisted living facility that did not permit access to MAID on site.

[84] The MAID assessments were also performed secretly at the MAID recipient's daughter's home.

[85] This includes assessment(s) and MAID provision.

> over to, I don't know where it was, still in the same building. It was a room at the very end of the hallway, and I would say there was a lot of nervous energy. (FM-16)

Other family member participants similarly mentioned that they were not informed about policies regarding access to MAID, and neither were their loved ones. These family members expressed dismay that health care professionals would not share this vital information to assist and guide them as they tried to support their loved ones' choices (FM-01; FM-04; FM-21; FM-23; KI-09).

As this former MAID team member identified, when family members had difficulty supporting their loved ones due to actual or perceived restrictions, they saw the potential impact it had on them:

> Misinformation can be really detrimental. Just making sure that people are educated. Making it not so secret. It's [the process request MAID] really hard to find on the [health service] website, according to patients and their families, they didn't have an easy time with it. (KI-15)

Some family members' need for privacy also appeared to stem from a concern that they could be a target of attack or stigma if they revealed the choice for MAID. This wife recalled, "I told them they couldn't tell anyone because I didn't want anyone to be protesting on my front lawn" (FM-13). Not revealing the type of death was similarly identified in key informant interviews:

> I feel like in [our area] there is this sense of hiding what we are doing because we don't want to offend anybody. We don't want to make anyone uncomfortable. Don't tell anybody why you are here. If you are taking a medication kit, make sure you cover it up, so no one suspects what it is. (KI-09)

Some participants also expressed concerns about sharing their loved ones' decision for MAID with people outside the immediate family group, intimating the need for privacy and needing to be more emotionally prepared to handle the reactions of others. For example, one sister and her family chose to keep the details of their sister's death private until after she died:

> A couple of them knew that she was going to do it, but they didn't know when. They live away. They were very angry. They would have phoned her up and would have been a big [deal]. The emotions of the people, your loved ones around you, would make you feel sadder.… We just phoned them after it was finished. (FM-32)

Keeping private that their loved one received MAID was difficult for some family members. This was challenging, particularly when connected to other close family members who were unaware of the details of the death. As the daughter of a MAID recipient recounted, she had a conversation with one of her brothers: "You can't be telling people. That was the only glitch of the whole thing. My son still doesn't even know" (FM-19). In their decision about whether to reveal that their loved one received MAID, some family members appeared to keep in mind the potential impact of disclosing the type of death, specifically how it might reflect on others' memory or image of their loved one, as this daughter disclosed, "I would like to tell my son sometime, but you know, first, I have to feel out how he feels about MAID because I would hate for him, he has such grand respect for my dad" (FM-19). It seemed that through privacy about the type of death, family members were protecting their loved ones and themselves.

Other family members also discussed their intentionality in selecting words to articulate their loved one's death while not fully disclosing that it was through MAID. It seemed that some participants chose to focus on the death itself rather than highlight the type of death, as this wife articulated,

> Since that time, I have confided in [a neighbour] and my other neighbour that it was MAID that he had. I didn't feel a sense of having to say that because to me, he died of MSA[86] [multiple system atrophy] with the help of MAID. I didn't feel I needed to put it in the obituary. (FM-27)

Keeping details about the death private and being selective about wording was also this participant's experience: "I do remember there was a decision made that once the date was set, that we [the family] weren't going to broadcast that and that it would just be the death announcement. The death announcement said it was by her choice" (FM-03).

Some family members also acknowledged concerns about repercussions and potential adverse reactions from people in their support systems, local organizations, or their community (e.g., church, social group) if they disclosed the type of death. As the mother of a MAID recipient described, "I didn't talk about it that much. Especially with the people at my church. I was worried that it would be frowned on" (FM-08).

The feeling of wanting to keep MAID private from support systems also appeared in the descriptions of family members who sought formal psychosocial support after the death of their loved one. Key informant participants similarly observed bereaved family members choosing not to reveal the type of death while in broad-based group bereavement counselling sessions[87] in particular. In their interview, this retired social worker spoke about what they had noted with bereaved family members of MAID recipients:

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[86] Multiple system atrophy is a rare neurodegenerative disorder that affects several areas of the brain including the cerebellum and autonomic nervous system (Multiple System Atrophy Coalition, 2020).

[87] Counselling groups not specific to those impacted by a MAID death.

> Families weren’t sharing, even with their intimate circle, that the death had been by MAID, so I began encouraging people that they could say the person died of their cancer, they didn’t need to declare that MAID was the cause of death because really, the underlying illness was the reason for the person choosing MAID. (KI-01)

This key informant discussed that family members might have been concerned about experiencing stigmatization by others because the death of their loved one was MAID. According to another key informant participant, this was not unusual: “Some [bereaved family members] got comments from other members like, ‘Well, my husband had a heart attack; he didn’t choose to die.’ There was a judgement there for some people. Alternatively, they would say, ‘In my religion…’” (KI-14). There seemed to be an impression that tension may exist, whether real or perceived, between people who lost a loved one suddenly or through natural means and those whose loved ones received MAID. This tension could create a negative experience for MAID recipients’ family members and may lead them to avoid discussing the type of death their loved one received.

When it came to the MAID death of a loved one, several family members indicated concern about the timing, method, and details of how the information might be shared. This study illuminated that many family members selected to keep the type of death private. Some individuals hesitated to share knowledge about their loved ones’ MAID death due to factors such as awareness of other people’s perspectives and the potential consequences of sharing the information. Some family members had a different experience due to factors at the meso-level, such as institutional and organizational policies and the moral and ethical values of the larger community and support groups. These factors appeared to influence the decision to disclose information about the type of death which impacted their experience when MAID was being pursued and into bereavement.

Some participants shared concerns about potentially being judged or stigmatized if they revealed their loved one's choice for MAID, even in formal support groups. In the end, family members who chose to keep the type of death private appeared to make a personal decision framed within their experience. Many of those who had concerns about the perspectives of others and how they could react to their loved ones' type of death continued to experience this into the bereavement period.

Summary of the Understanding the Experience of Bereaved Family Members

Through an iterative process, I identified three broad themes which facilitated an understanding of the experiences of bereaved family members of MAID recipients. The themes, they want MAID, now what? being prepared but maybe not ready, and an evolving understanding of this type of death primarily comprised micro-level elements; however, meso- and macro-level aspects were evident in the analysis and assisted in illuminating the subthemes.

The first theme, they want MAID, now what, primarily described the impact of meso- and macro-level elements on the individual, the bereaved family members. Navigating access to MAID appeared important in understanding the experiences of bereaved family members. This aspect of their experience seemed influenced by how health care organizations and provincial and territorial jurisdictions handled the legislation, how easy it was to access information, and how integrated MAID was in the system. Additionally, the philosophy of palliative care services and the intersection between palliative care and MAID programs were illustrated through the subtheme, appreciating palliative care.

As I discussed, most family members valued involvement when their loved one pursued MAID. This sometimes, however, caused them to experience uneasiness because of their involvement, thus describing the second theme, being prepared but maybe not ready. The subthemes to this understanding, reconciling involvement and realizing the end, described that even when family members felt prepared for their loved one to receive MAID, there seemed to be an emotional impact to confronting that their loved one was going to die and that they had supported them in achieving their choice. Family members seemed to live in a state of suspension, a third subtheme, which appeared to be important to understanding their experience. This part of a family member's experience tended to be unsettling as they waited to discover if MAID would become part of their reality. This subtheme also seemed to impact when family members started to grieve because many wanted to know that their loved one was eligible and was proceeding to MAID before psychologically preparing.

The third and final theme, an evolving understanding of this type of death, was further elucidated through the subthemes, enabling celebration, reminiscing and saying goodbye, and keeping the type of death private. Family members suggested that MAID provided a unique way to approach death. Many tended to take time to celebrate, reminisce and say goodbye to their loved ones. Though emotional, this part of their experience appeared to help them prepare for grieving. Maintaining privacy about the type of death seemed important for several family members, as sharing this information could cause anxiety and concern for repercussions. The need to maintain privacy continued even after the bereavement process had begun for some family members, further affecting their experiences.

Chapter Summary

In my exploratory interpretive description study, I aimed to understand the experiences and perspectives of bereaved family members who have had a loved one end their life through MAID. This study is a story of how families supported their loved ones regardless of their perspective on MAID. Contextual factors of knowing the perspective of their loved one, being aware of their loved ones’ suffering, and the family members’ own personal beliefs about assisted death emerged and suggest that at its foundation, family members’ experiences are complex. I also gained the perspective that each of these contextual factors seem to be essential in the overall understanding of bereaved family members’ experiences within the MAID phenomenon.

The support shown by family member participants for their loved ones who moved through the process of choosing and receiving MAID was illuminated across three overarching themes: (a) they want MAID, now what, (b) prepared but maybe not ready, and (c) evolving understanding of this type of death. Within each of the aforementioned themes, subthemes emerged that further illuminated experiences of bereaved family members. Not only were factors at the individual level seen to influence the experiences of family members, but policy, program and macro-level aspects were also appeared influential. These levels of consideration (micro-, meso- and macro-) sometimes intersected in the experiences of bereaved family members, seemingly adding to the complex and layered experiences from when MAID was chosen by their loved one and into bereavement.

Chapter 5: Interpretative Discussion

My study aimed to understand the experiences and perspectives of family members who had a loved one receive MAID. Through the discussion in this chapter, I intend to increase readers' understanding of bereaved family members' experiences and perspectives by deciphering my findings beyond the observations described in Chapter 4 to exploring what they might mean (Thorne, 2008b) and why they are important.

I have organized this chapter into four sections. In the first section, I provide an overview of the findings from my study. In the next section, I present my interpretation of the findings in relation to existing research, applying the results to the context of the practice setting, as is expected within an interpretive description study (Thorne, 2008). In this chapter's third section, I acknowledge the limitations of my study. I conclude by providing a summary of this chapter.

Overview of the Findings

In this two-setting study, I had the privilege of connecting with 31 family members of MAID recipients[88] about their perceptions and experiences as their loved ones accessed and received MAID, and I also interviewed 15 key informants[89] about their insights into family members' experiences. Compelling and emotional narratives about this time in family members' lives uncovered the contextual elements of knowing the perspective of their loved one, being aware of their loved one's suffering, and family members' personal beliefs about assisted dying as themes. The descriptive themes (a) they want MAID, now what; (b) prepared but maybe not ready; and (c) evolving understanding of this type of death, as well as the associated subthemes,

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[88] Nineteen family member participants were from Alberta and 12 were from BC. Twenty-six family member participants were female and five were male.

[89] Nine key informant participants were from Alberta and six were from BC. Thirteen key informant participants were female and two were male.

shed light on the complex and layered experience of family members whose loved one received MAID (Appendix EE).

Similar to other research findings, my study illuminated that family members generally support and care for their loved ones seeking MAID (Buchbinder et al., 2018; Gamondi et al., 2015; Ganzini et al., 2009; Holmes et al., 2018; Snijdewind et al., 2014), much like they would and did when a loved one had a life-limiting illness (Davies et al., 1995). Although most family member participants highlighted support for their loved one, this did not come without its challenges, many of which were similar to those experienced by family members of individuals with a life-limiting illness (Davies et al., 1995).

This study also revealed that the experience of family members appeared to be influenced not only by individual-level factors but also by aspects of programs, processes, policy, and macro-level elements, including the legislation (Bill C-14, 2016). The experiences of family members give the impression of being intricate and layered and influenced by micro, meso, and macro-level elements, which seem to persist as their loved one decides about MAID, while they interact with programs, and during their bereavement period.

Interpretation

My study’s findings complement the growing body of knowledge on the experiences of family members who have accompanied a loved one through to MAID (Beuthin et al., 2021; Brown et al., 2020b; Crumley et al., 2023; Frolic et al., 2020; Hales et al., 2019; Hashemi et al., 2021; Holmes et al., 2018; Laperle et al., 2022; M. Li et al., 2021; Schutt, 2020; Smolej et al., 2022; Thangarasa et al., 2021). Several international and Canadian studies have acknowledged family members’ support is crucial to a loved one obtaining an assisted death because of the complexities associated with this option (Buchbinder et al., 2018; Ganzini et al., 2009; Kimsma, 2010; Starks et al., 2007). My study aligned with this literature but also suggests that micro-, meso- and macro-level elements may influence family members' involvement in the MAID process and highlighted aspects that seem to impact their experience. I believe my study expanded grief and bereavement research as well as I uncovered micro- and meso-level factors that seem to influence and ease family members' experience after their loved one's death. Also illuminated were family members' perceptions of palliative care after pursuing MAID. I could find no other published research that provides this type of exploration into the experiences of bereaved family members, thus enhancing knowledge in this area.

My interpretation of the descriptive findings was an iterative process, critical and reflective of the words, patterns, themes, and subthemes. It was challenging to move from describing the findings to interpreting them (Thorne, 2008b), but doing so helped me gain a deeper understanding of the experiences of bereaved family members. In the following sections, I share my findings and extend these understandings, offering a more comprehensive interpretation that helps identify what they may mean regarding family members in the context of MAID and why they appear significant.

They Want MAID, Now What?

Since legalization, the manner of implementing MAID has varied throughout the country. Health Canada (2022b) identified this diversity in provincial and territorial programs, structures, and guidelines (AHS, 2016; Beuthin et al., 2018; Downie & Chandler, 2018; Government of BC, n.d.-a; Health Canada, 2017a, 2017b, 2022b, 2023; Robertson & Beuthin, 2018) beginning in 2016, with the literature suggesting the programs, processes, as well as health system factors may have an impact on family members throughout and including their bereavement (Adams & Ogbogu, 2018; Downie & Chandler, 2018; Goldberg et al., 2021; Leeder & Grant, 2018;

Patterson, 2023). As mentioned in Chapter 2 (see the “Family Members Experiences with Assisted Dying” section), I could not locate published studies investigating the impact of MAID policies on bereaved family members’ perceptions or experiences. Only a few studies highlight legislation, programs, and processes that seem to affect family members’ experiences, often from a single-centre setting (Hales et al., 2019; Hashemi et al., 2021; Oczkowski et al., 2021; Smolej et al., 2022; Thangarasa et al., 2021). Therefore, my study generates much-needed knowledge regarding the possible influence of the organization and execution of MAID programs, processes, and structures and their potential impact on the experience of bereaved family members, specifically navigating access to MAID and palliative care.

When family members became engaged in the MAID process, which typically began by navigating access to MAID programs for their loved ones, my study suggests that meso- and macro-level elements appeared to impact their experience. Key influences appear to include how health care organizations and provincial and territorial jurisdictions translated the legislation into policy, programs, and processes, the ease with which family members could access information about MAID, and family members’ interactions with health care professionals.

Family members knew only of their experience with MAID programs as their loved ones pursued this option. They did not discuss variability in MAID programs and processes that are known to exist across Canada. Operational factors (Hales et al., 2019), such as knowing whom to speak to about MAID and the MAID program, knowing where and from whom to obtain information, locating and completing documents, as well as submitting the request for MAID, including the appropriate point of contact in their jurisdiction,[90] are all points in family members’ experiences that appeared noteworthy for complexity. My study found that when meso-level

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[90] This is required for the MAID process to become activated.

operational factors required individuals to navigate access to MAID on their own, such as submitting MAID request documents to a MAID service to activate the process, this seemed to result in family members getting involved. Participants shared that becoming involved was sometimes challenging, and it impacted them. They acknowledged it caused them stress which seemed to be because of their lack of knowledge about MAID and their need to figure out how their loved one could access and initiate the process (Hales et al., 2019; Oczkowski et al., 2021). The findings of this study also illuminated that family members exhibited concern that their difficulty in accessing the MAID program and navigating the process could impact their loved one's ability to access MAID promptly. However, when a MAID program or service seemed easy to understand and connect with, including when a MAID program felt integrated into the broader health care system or existing health care services, family members typically indicated it required less coordination on their behalf. They seemed to experience fewer challenges, seemed supported and suggested being satisfied. I found this to be similar to reports in other published literature (Beuthin et al., 2021; Oczkowski et al., 2021).

Provincial and territorial health authorities and organizations developed MAID legislation into policy and created MAID programs within their cultural context (Ball et al., 2018; Dying with Dignity Canada, n.d.; Feldstain et al., 2016; M. Li et al., 2017; Taylor, 2018; A. C. Wright & Shaw, 2018). Balancing health care professionals' rights and individuals' access to MAID seemed to be a key influence in the development of policy and programs (Banner et al., 2019; Silvius et al., 2019), with some jurisdictions and organizations explicitly framing MAID programs using patient-focused, family-centred approaches (Brown et al., 2020a). As discussed in Chapter 2 (see the "Implementation" section), MAID coordination services were structured in MAID programs to address process elements in both study settings. However, in examining

MAID programs, their operationalization and the level of involvement of health care professionals and family members varied and likely evolved over the time of this study and to the present.

In Alberta, the MAID program requires the individual, and often by extension their family members or friends (Gamondi et al., 2018; Goldberg et al., 2021; Wu et al., 2018), to activate a MAID request beginning with obtaining the *Record of Request for Medical Assistance in Dying* form (AHS, 2019), located on the AHS (n.d.) *Medical Assistance in Dying* webpage. As outlined in that form, once the individual completes the form, they are encouraged to "either send or take the form" (AHS, 2019, p. 2) to their primary care provider, who can submit the document on their behalf, after which it becomes that health care professional's "responsibility to assist [them] with the next steps" (AHS, 2019, p. 2). Suppose, however, their primary care provider is unwilling to participate in the request for MAID. In that case, the instructions advise the individual to send the completed form by fax to the appropriate zone or by mail to the Provincial MAID Office (AHS, 2019). The fax numbers to the corresponding geographic zones are on the MAID request document (AHS, 2019). Once receipt of the record of request occurs at the AHS MAID CCS office in the appropriate zone, the MAID navigator "follows up with the individual or family and helps find two independent assessors if they are not already identified" (Dr. Misty Watson, Medical Lead–Medical Assistance in Dying Calgary Zone, personal communication, April 19, 2022).

In Alberta, the MAID CCS comprises physicians, nurse practitioners, nurses, operational leaders, and MAID navigators. Physicians and nurse practitioners request or are asked by navigators if they will aid in the MAID process. In Alberta, health care professionals perform MAID assessments and provisions in addition to their regular employment responsibilities.

MAID navigators[91] in Alberta coordinate with health care professionals and managers to ensure human resourcing for MAID assessments and provisions. In some jurisdictional areas, the program is “so low on [MAID practitioners but have] quite a number of people who are willing to assess, but they are not willing to provide” (KI-09). When a MAID provision occurs on an inpatient unit, key informants highlighted challenges sometimes in finding a unit nurse to insert an intravenous on the day of a MAID event, and it is not unusual for managers to state, “No, we don’t have anybody here who is willing to do that” (KI-09). Nurses’[92] availability is also not guaranteed when a provision occurs in a home-like community setting.

As the legislation (Bill C-14, 2016) requires, and consistent with the Province of Alberta (AHS, 2019), an individual who wishes to enter the MAID program and initiate the MAID process in the Province of BC must sign and date a request for a MAID form (Government of BC, Ministry of Health, 2023). Where the BC MAID program differs from Alberta’s, however, is that an individual wanting MAID “can enter the system in many ways” (KI-06). Individuals, often with assistance from family members or friends, can (a) call a MAID practitioner’s office directly,[93] (b) speak directly to their primary care provider or any specialist who could refer them to a MAID practitioner if those health care professionals do not engage in this service, or (c) be referred by their primary care providers to the CCS for MAID (KI-06). The public is made aware of the diverse ways that individuals can access the MAID program on the provincial website, including the location of CCS for MAID offices[94] (Island Health, n.d.). Once completed, the

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[91] There are five MAID navigators in the Province of Alberta.

[92] Nurses are only sometimes in attendance for MAID provisions.

[93] Clinicians who identify themselves as Island Health MAID providers can be contacted directly by individuals or their family members when they want to access the MAID process.

[94] Within VIHA, the office is located at the Victoria General Hospital.

request form is then submitted either to the individual's primary care provider or to the CCS MAID office (Government of BC, n.d.-a, "Is there a request," para. 2). In BC, physicians and nurse practitioners who are willing and able to provide information to individuals are expected to offer support related to the MAID process, including completing forms, and to engage by providing a MAID assessment (Island Health, 2019). In reflecting on their experience in another jurisdiction,[95] a MAID practitioner study participant described the BC MAID program and policy in the following way:

> The infrastructure for MAID here [VIHA/Island Health] is great.… If I have a patient who asks for MAID, I call the MAID consultant. There is someone on call all the time. It's very accessible here. Completely different from before because I had to constantly ask for favours from my colleagues. "Can you be a second assessor," and I would do all the provisions. (KI-04)

When an individual is an inpatient in a hospital in BC, the policy is that a physician can assess them for MAID during their admission and arrange for MAID provision. Individuals who are "inpatients of the Royal Jubilee or Victoria General Hospitals [for example] can access MAiD[96] through an in-house referral, assessment and provision service" (Island Health, n.d., "Requesting MAiD While in Hospital" section, para. 1) by emailing or calling the Island Health MAiD Program. This contact information is on the *Learn About Health – Medical Assistance in Dying (MAiD)* website (Island Health, n.d.), or an individual or family member can also speak with the clinical nurse leader on the unit of their loved one.

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[95] This health care professional was not previously in one of the study settings as a MAID practitioner.
[96] This is the acronym used in BC.

I understand that MAID programs have been challenging to structure and implement, partly because of funding, the many practice contexts in which individuals inquiring about this option may connect, such as primary care, surgical units, medical units, palliative care, and home care (Pesut, Thorne, Storch, et al., 2020), and that MAID is associated with a “range of moral responses” (Pesut, Thorne, Storch, et al., 2020, p. 5) from health care professionals (Bill C-14, 2016; Pesut, Thorne, Storch, et al., 2020). To focus specifically on the latter, MAID legislation (Bill C-14, 2016) established freedom of conscience for health care professionals. In reviewing MAID policies, programs, and processes from the study settings in the context of my study findings, I noted that, as Pesut, Thorne, Storch, et al. (2020) identified, influential leaders made decisions and seemed to develop policies, programs, and processes through a lens that appeared to prioritize the rights of health care providers beyond the legislation (Bill C-14, 2016) and guidelines established by health care professional associations (College of Registered Nurses of Alberta, 2022). As a key informant participant recalled, leadership did not allow her office relocation to a hospital setting, a space that was more accessible to individuals, family members, and health care professionals alike, because a senior hospital administrator was known to object to MAID.

My interpretation of the findings supports Pesut, Thorne, Schiller, et al.’s (2020) assertion that influential leaders primarily designed policies and MAID programs within jurisdictions. It is my impression based on my findings that, in certain health jurisdictions, some leaders may have framed MAID programs and processes with a foundation that health care professionals would likely morally or religiously oppose MAID, or perhaps potential problems might be reduced if MAID programs were designed to require health care providers to volunteer or notify their leadership if they did not conscientiously object and thus were willing to participate in MAID procedures. In contrast, in other jurisdictions and settings, my study findings to suggest that individuals in leadership positions seemed to frame MAID policy and programs with more visibility and a perspective that health care providers would be part of the MAID process unless they informed their leadership or manager of their objection (Pesut, Thorne, Schiller, et al., 2020; Pesut et al., 2021). Upon further examination, when a range of conscience (Pesut, Thorne, Storch, et al., 2020) or “conscientious participation” (Oliphant & Frolic, 2021, p. 51) appears to be a foundational perspective in MAID policy and programs, it seemed to facilitate smoother access to MAID, whereas other approaches may have created barriers. I interpret that, in jurisdictions where health care professionals’ objection rights seemed to frame policy or the organization and execution of MAID programs and processes, it tended not to be relational or beneficial for family members.

Another interpretation is that the development of policies and programs that appeared to yield to the rights of objecting health care professionals more so than balancing the rights of individuals wanting MAID; may have, in effect, reduced the opportunity for health care professionals to gain knowledge about MAID, MAID programs, and processes connected to this option. For example, in my study, MAID team members recalled that despite offering education sessions to nurses and doctors on MAID programs, including access and the request process, some primary care clinics and offices consistently refused any information or education. This nonacceptance of information and education has the potential to hinder the ability of nurses and physicians to increase their knowledge about the legal option for MAID and, thus, may impact their ability to provide adequate guidance to individuals and their family members as needed. This may have been why some family member participants felt they needed to become involved and support their loved ones when they wanted to inquire about MAID.

I understand that there is a broad spectrum of comfort and conscience related to assisted dying (Pesut et al., 2019); however, as a health care professional, refusing education on a legal option does not meet professional and ethical standards (Canadian Nurses Association, 2017a). This example provided during data collection led me to wonder what made these health care professionals believe they had the right to refuse information and knowledge about MAID.

If health care professionals conscientiously object to MAID, they are protected in the legislation (Bill C-14, 2016), but do they understand their responsibility concerning this legal option (Grant, 2019) and their ethical commitment to patients and families? Given that the literature noted family members benefit and have a more positive experience when they interact with health care professionals who openly and effectively communicate information about MAID (Gamondi et al., 2018; Hashemi et al., 2021), it appears health care professionals need to receive accurate information about this service. I suggest that this illuminates that MAID programs comprise a reasonable balance between the rights of health care professionals and the rights of individuals wanting access to MAID. Given my study's findings, having policies and programs that express an organizational message that is visible and respects all rights may foster more robust ethical practices toward family members who are vulnerable, along with their loved ones.

It appears from my study that family members involved with loved ones through their trajectory from diagnosis with a life-limiting condition to death wished end-of-life discussions included MAID, palliative care options, and palliative sedation. Family members, and potentially their loved ones, may see MAID and palliative care as mutually inclusive in the broader context of end-of-life care. It may be an important consideration on which leaders of programs and teams to reflect.

Similarly, the literature suggested some family members needed to initiate conversations about MAID with their loved ones because they did not experience health care professionals doing so (Smolej et al., 2022). Prior research also indicated professionals engaging in discussions about MAID tend to reduce the challenges family members face (Yan et al., 2022). As illuminated in my study, this may also include determining how to access MAID on behalf of a loved one. I interpret this finding that family members generally desired engagement and (a) may wish to be advised of end-of-life and treatment options and included in conversations if possible (Beuthin et al., 2018) and that (b) information appears vital not only for individuals making a decision but also for family members who seemed to indicate they more likely trusted that their loved one is well informed about all the options. In the process of interpretation, I wondered how health care leaders and policymakers could ensure and improve health care professionals' knowledge about MAID and potentially improve family members' knowledge and navigation of MAID and other end-of-life options. One approach might be to have MAID, including programs, be more visible in the health care system environment; this could ease some of the challenges family members experience. Findings from my study seemed to indicate that family members respected health care professionals who had knowledge about MAID and were comfortable sharing their knowledge, which tended to be in jurisdictions and areas that offered an integrated-type of MAID program.

As seen in previous studies (Hashemi et al., 2021; Milberg et al., 2003; Proot et al., 2003), I discovered the location, as well as the circumstances surrounding the death of a loved one, appeared to have an impact on family members. My interpretation from my study's findings was that those whose loved ones passed away in a hospital-type environment[97] seemed to have

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[97] The exception to this is faith-based or objecting institutions.

an easier time accessing the MAID program and finding knowledgeable health care providers and professionals willing to guide them through the process. Likewise, family members tended to experience challenges when organizational policies and processes inhibited access to MAID, including MAID provision.

The findings from this study suggest unexpected impediments to information about the MAID program or access to MAID processes appeared to create tension for family members during an already stressful time. The literature supported this finding (Hales et al., 2019). For example, family member participants shared being negatively impacted by policies in organizations and health care institutions that restricted their loved one’s access to MAID. Most of these situations occurred in institutions that chose to refrain from MAID, including objecting institutions where provisions continue to be prohibited (Downar et al., 2023). When restrictive MAID policies were in place, family members appeared to take on more responsibility to access a MAID program, during the MAID process, and often during assessments and provision. These cases sometimes required their loved one to be transferred from the location, and my study suggests that this tended to result in family members feeling burdened (Patterson, 2023).

Furthermore, study findings suggest family members whose loved ones lived in a home-like institutional setting for a significant period before pursuing MAID seemed to express fewer concerns about restrictive MAID policies. In contrast, family members in this study appeared dismayed and affected when their loved one had been admitted shortly before they pursued MAID. These family members often had little to no time to interact with the unit, institution, or health care providers. The length of time family members had to form connections with an institution seemed to impact their experiences with MAID, as those who had become familiar with the institution understood and appeared more sympathetic about the organization’s position on MAID access. I believe this may have been because family members had established relationships with the health care leaders and team members and were more aware if the organization was faith-based and would likely refrain from MAID and, thus, were less surprised by the policy positions. Alternatively, when a loved one was admitted before their MAID event or when MAID was pursued shortly after being admitted to a setting that refrained from providing all or some elements of MAID,[98] family members seemed (a) unaware of the restrictive policies impacting access to MAID and (b) more likely distressed about the policy and what it meant for their loved one (e.g., forced-transfer). This nuance offers knowledge about the possible influence of restrictive policies at institutions. The findings of my study will ideally enable health care professionals and leaders to become more cognizant of the potential wider influence of restrictive policies given their impact on individuals admitted or transferred to objecting facilities (Downar et al., 2023) as well as the possible impact on their family members (Patterson, 2023).

Having an appreciation for palliative care was another pattern identified in this study. Findings suggest this relates to both the time before the pursuit of MAID and when the MAID process was activated by a loved one. Most family member participants indicated palliative care services were in place before their loved ones requested MAID, aligning with federal monitoring data (Health Canada, 2022b, 2023) and that this service seemed to ease some of their burden. A few family members wondered if the quality of palliative care services provided was a possible consideration for their loved one pursuing MAID. Given the significant inequities regarding access to palliative care as well as adequate funding for quality hospice palliative care in Canada

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[98] For example, faith-based hospices, palliative care units, faith-based hospitals, and faith-based home-like institutions.

(CAMAP, n.d.; Reimer-Kirkham et al., 2016; Stajduhar & Mollison, 2018), this finding appears to echo similar concerns raised by some in the health care community (Miyasaki, 2021; Raycraft, 2022; Serota et al., 2023) as to "whether Canadians are considering assisted death because they lack access to quality palliative care (Canadian Institute for Health Information, 2017)" (Canadian Institute for Health Information, 2018, p. 10). My impression from the family member interviews conducted in this study is that this concern seemed fleeting for these participants and did not appear to cause much, if any, distress; however, given this finding in association with issues raised by palliative care stakeholders, it necessitates further investigation.

In addition to recalling their experience with palliative care before their loved one initiated the MAID process, family members also shared their experiences with palliative care once their loved one accessed MAID. Participants described similar concerns about the quality of palliative care but, in these situations, wondered if their loved one may have chosen to delay their MAID event if the care they had received had been more adequate. Features identified by study participants as possibly impacting the quality of palliative care services included human resource issues, irregular service, and an impression that palliative care became fractured and providers were less attentive to their loved ones after the decision to undergo MAID.

Findings from my study suggest there may be a difference in the provision of palliative care after a loved one decided to pursue MAID, based on the experiences recollected by family members. For example, the continuity of palliative care at home through community-based services felt compromised, not in synergy with MAID, according to some participants. This perceived disconnect between the palliative care and MAID environment seemed to impact family members, who suggested their loved ones' care was impaired once MAID was requested. By extension, this tended to result in family members feeling they needed to take on additional caregiving responsibilities, with some observing more suffering of their loved one. These elements caused some family members to experience increased stress and burden. Alternatively, when family members spoke of experiencing harmony and mutual respect between palliative care and MAID programs, rather than compartmentalization, disconnection or vague collaboration, not only did there seem to be less burden placed on them, but they also did not appear to question whether their loved one chose MAID earlier than needed. This is important knowledge. I offer that health care professionals providing integrated palliative care and MAID services in a collaborative environment may more likely foster trust in the care (Downar et al., 2023) and ease family members' stress during their loved ones' progress toward MAID.

I could only identify clear mandates and policies indicating a separation or disconnect between palliative care services and MAID programs concerning hospice and palliative care units in or associated with faith-based organizations and institutions (e.g., Covenant Health). Findings from my study indicate that maintaining a separation between palliative care and MAID, including providers in those programs, may be required by some organizations and in some settings, even if health care professionals are not opposed to MAID. As Downar et al. (2023) discussed, there is a history of dissension between palliative care and MAID; therefore, although my findings are important to note, they are not surprising. In Canada, influential palliative care leaders (Herx, 2015), associations (Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, 2019), and scholars (Dierickx et al., 2018) have taken this position of incompatibility of palliative care and MAID. However, over the past 7 years, we have seen some moderating of this position. In some jurisdictions, palliative care leaders were part of developing MAID programs and structures (Pesut, Thorne, Schiller, et al., 2020) at the time of implementation, which may have influenced the relationship between palliative care and MAID programs from “no integration, to an informal consulting relationship, to full clinical program integration” (Pesut et al., 2021, p. 8) at the outset. As my study suggest, having little or no integration between palliative care services and MAID programs appears to have engendered a sense of receiving less quality palliative care, with family members feeling the impact.

Another interpretation is that an integrated MAID program[99] may enable more visibility in the health care environment and may provide stronger connections to existing services, such as palliative care, and, as discussed previously, may affect health care professionals’ knowledge and confidence about MAID programs and the MAID process as well as their role in caring for someone who has chosen this option. I have also considered that moral and personal beliefs may intrude into how care is provided to individuals wanting MAID and, by extension, their family members (Hales et al., 2019; Pesut, Thorne, Schiller, et al., 2020; Pesut, Thorne, Storch, et al., 2020); however, this would require further investigation.

While there is significant research on family members and their experiences with palliative care, when a loved one is diagnosed with a life-limiting condition (Etkind et al., 2018; Midtbust et al., 2021), little is known about their experiences when that loved one chooses MAID (Hashemi et al., 2021). My study has added knowledge to this field of inquiry as well as raising further areas for study. The interpretation of my study findings may also provide supportive insight as more comprehensive information becomes available on palliative care and MAID recipients following the revised data collection requirements that began in January 2023 (Health Canada, 2022b).

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[99] Researchers noted when MAID programs are integrated with palliative care, they often “still have separate organization reporting and financial structures” (Pesut et al., 2021, p.8).

Prepared But Maybe Not Ready

The literature has shown that it is a common experience for family members to support and be involved when a loved one pursues MAID (Gamondi et al., 2015; Gamondi et al., 2018; Hales et al., 2019; Holmes et al., 2018; Oczkowski et al., 2021). My study has built on this literature by deepening and expanding people's understanding of this part of their experience. My study findings suggest, although family members may appear to be prepared for their loved one's death because they are engaged in the MAID process, this closeness to the situation does not mean they are without stress or are comfortable with the decision. As such, even when family members seem prepared and are handling their loved one's decision for MAID, they may in fact still be impacted by the choice. This interpretation is important to consider in the context of prior research.

Published research (Gamondi et al., 2015; Gamondi et al., 2018; Holmes et al., 2018) and my study acknowledge most family members valued supporting and being involved as their loved ones pursued MAID. Findings from this study suggest some family members also had reservations about their involvement in facilitating access to MAID, alluding to a sense of duty (Beuthin et al., 2021) they felt to assist their loved one in accessing the MAID program rather than it being altruistic (Feigin et al., 2019). Some study participants also speculated if they had been more involved, or had caregiving been less exhausting, that their loved ones might have chosen to live longer. This knowledge was supported by research that found family members who participate even minimally may feel uneasy about their involvement (Buchbinder et al., 2018; Oczkowski et al., 2021).

In examining my findings, when family members spoke of their involvement in the MAID process almost as a sense of duty (Beuthin et al., 2021; Kidder, 2009), it seemed often connected to jurisdictions and settings where MAID programs were less integrated into the broader system and where policy and procedural elements were challenging. I interpreted this time and these circumstances as a potentially significant point in family members' experiences. Family members' assessments of their duty to their loved one (Beuthin et al., 2021; Kidder, 2009) also seemed to occur in the context of their moral beliefs and whether they felt they could become involved (Boivin et al., 2019; Gamondi et al., 2018; Kortes-Miller, 2018; Holmes et al., 2018; Snijdewind et al., 2014; Starks et al., 2007). Family members in my study seemed to come to terms with their involvement, whether based on a sense of duty or altruism.

When MAID is requested, some family members experience guilt (Beuthin et al., 2021; Crumley et al., 2023; Frolic et al., 2020), and in my study, this seemed to occur as family members wondered if they had influenced their loved one's choice for MAID. This experience of guilt[100] is not unexpected, given the moral circumstances surrounding MAID (Bennett, 2018; Beuthin et al., 2021; Kidder, 2009). Some family members explained their guilt arose not only from a conviction of their responsibility for their loved one's well-being, but also due to the choice of their loved one. Some family members also wondered if their loved ones had possibly not received adequate care and support and, thus, requested MAID, with family members' guilt seeming to arise because they had not advocated for quality care or perhaps provided it themselves (see "They Want MAID, Now What?" section in Chapter 4). This finding is not unexpected as family members connected to MAID seem to morally question themselves when they confront a loved one's choice (Frolic et al., 2020; Gamondi et al., 2015; Ganzini et al., 2009; Harrison, 2018; Holmes et al., 2018).

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[100] Guilt is a sign of a virtuous person in a morally imperfect life (Bennett, 2018).

Nevertheless, most participants seemed to understand that they had done everything in their power to address their loved one’s needs and that it was their loved one’s decision to proceed to MAID, supporting current knowledge (Gamondi et al., 2015). I interpret this as family members recognizing that external factors had determined why and when their loved ones chose MAID.

While many family members generally reconciled their involvement, feelings, and emotions about their connection to their loved one’s MAID journey (Buchbinder et al., 2018; Ganzini et al., 2009; Kimsma, 2010; Starks et al., 2007), others appeared to struggle, even into bereavement (Adams & Ogbogu, 2018; Downie & Chandler, 2018; Goldberg et al., 2021; Leeder & Grant, 2018; Patterson, 2023). This knowledge underscores the importance of health care professionals engaging in an open dialogue with family members to determine if they are experiencing moral dilemmas (Gamondi et al., 2015; Yan et al., 2022) and if guilt is part of their experience (Beuthin et al., 2021; Crumley et al., 2023; Frolic et al., 2020). The findings from my study illuminated that, although family members may appear to embody support and involvement, they may still have had reservations. By entering into the relational space with family members (Bergum & Dossetor, 2005; Freeman et al., 2021) and engaging in respectful discussions, health care professionals may more likely be able to support family members struggling and feeling burdened as a result of their loved one’s choice (Dees et al., 2013; Gamondi et al., 2018; Goldberg et al., 2019; Snijdewind et al., 2014; Variath et al., 2020); and discover whether their emotions may be resistant to improvement as their loved one approaches their death. In doing so, the literature indicated health care professionals might be better able to intervene before family members’ grief and bereavement becomes complicated (Boivin et al., 2019; Brown et al., 2020a, 2020b; Crumley et al., 2023; Gamondi et al., 2018; Serota et al., 2023).

The literature emphasizes the importance of providing care that focuses on the individual and their family (Teno et al., 2001), particularly during the shared experience of death (Martin et al., 2022). In the context of MAID, with individual autonomy being the foundation of the legislation (Bill C-14, 2016), policies and programs are inevitably directed at the individual level. This focus, which family members in this study fully supported, may be enacted in ways that tend to overlook the role of the family according to my findings, or, as Pesut, Thorne, Schiller, et al. (2020) highlighted, the complexity of the MAID process and system capacity itself may be such that focusing on the patient may be the best that can be done currently by health care professionals.

Supporting the research by Frolic et al. (2020), the findings from my study illuminated aspects during the MAID process that appeared to have psychologically impacted family members as they accompanied their loved ones through the MAID process. In particular, family members experienced living in suspension due to critical elements in legislation, programs, and services, such as waiting for eligibility assessments, determination of eligibility, and the scheduling of the MAID event. Family members who took part in this study articulated they sometimes experienced apprehension and nervousness while waiting for information about what would come next during these intervals, impacting some family members' ability to move forward psychologically and emotionally to prepare for their loved one's death. These imposed latency periods during anticipatory grief seemed to result in aloss of their sense of agency.

Given the individual-focused nature of the MAID process, it is not unexpected for family members to potentially experience this loss of agency. However, this interpretation may also signify that more attention needs to be paid to patient-focused, family-centred MAID programs that may more effectively address the needs of family members (Frolic et al., 2022; Hales et al., 2019). Another interpretation of this finding may be that health care professionals themselves may not identify family members as a significant part of the unit of care in MAID because of the strict regulations in the legislation (Bill C-14, 2016), the potential consequences for violations (Bill C-14, 2016), and a focus on the autonomy of the individual or patient choosing MAID (Frolic et al., 2022). The complexity of the MAID process and system structure may also make it challenging for health care professionals to include family members (Pesut, Thorne, Schiller, et al., 2020). Nevertheless, I suggest living in suspension as they wait for the MAID process to unfold may result in family members being less prepared once their loved one proceeds to their death.

The imposed waiting some family members in this study experienced also connected to a lack of knowledge and not having full and open conversations with health care providers (Dees et al., 2013; Denier et al., 2010). As Hales et al. (2019) found, family members tended to lack information about the MAID process and what and when to expect changes or updates, which caused them to feel anxious and less prepared. These relational challenges, as described by Snijdewind et al. (2014), resulted in a psychological impact on family members, perhaps causing this part of their experience to feel complicated. When unexpected occurrences arise (Snijdewind et al., 2014), such as supplementary assessments for mental capacity after being found eligible, as had occurred for one family member participant in this study, family members more likely experienced time being suspended while they waited and wondered if the delay would affect their loved one’s opportunity to receive MAID. This seemed to be associated with high stress and emotional upheaval for family members.

As a loved one proceeds to MAID, my study supported other research that found it was often met with mixed emotions (Crumley et al., 2023; Frolic et al., 2020; Frolic et al., 2022; Holmes et al., 2018; Srinivasan, 2019). My study also suggested many family members found it overwhelming to know the exact date and time of their loved one’s death. Similar to other studies, these emotions were not typically about the act of an assisted death but rather the fact that their loved one’s life was ending and that they knew when it would occur (Oczkowski et al., 2021). Due to experiences in the process, such as periods of waiting and focusing their attention on their loved one’s needs (Crumley et al., 2023), another interpretation of the potential cause of this emotional upheaval was that they may not have fully addressed or reconciled their own emotions and feelings about their loved one’s death (Dees et al., 2013; Gamondi et al., 2015; Ganzini et al., 2002; Smolej et al., 2022; Thangarasa et al., 2021). The knowledge of the exact date and time meant they could no longer avoid it (Buchbinder, 2018), and my findings suggest this may have required more emotional reserve than family members anticipated.

It was not only knowing the date of their loved one’s death that family members in this study found impactful, some also found the process of determining the day and time emotional and difficult. The literature identified several elements that shape this process, including a loved one’s capacity and suffering (Shaw et al., 2019; Srinivasan, 2019). Some family members described their experience as “orchestrating the timing” (Frolic et al., 2022, p. 420) of their loved ones’ death while also considering the life context (Dees et al., 2013; Gamondi et al., 2018; Holmes et al., 2018; Srinivasan, 2018), such as the suitability of specific days and dates for the death as well as the location. These findings again suggest that, although MAID is a patient-focused undertaking, the family is consequential, illuminating that MAID programs and health care professionals should be attentive to a patient-focused, family-centred process (Brown et al., 2020a).

As indicated in a prior paragraph, findings suggest that determining the MAID event date impacted family members, particularly the mechanistic way that discussions and arrangements tended to occur with MAID team members, including conversations about options and the availability of MAID providers. Family member participants explained that how the conversations unfolded did not seem proportional to the topic of the discussion, scheduling the day of the death of their loved one. Instead, some family members found the discussions to be casual, impersonal, and unfeeling. These findings suggest the relational complexity of family members' experiences may go beyond elements Snijdewind et al. (2014) described, including the implementation of processes and how relational health care providers are when enacting them. To my knowledge, this study is the first to illuminate this connection.

An Evolving Understanding About This Type of Death

Family members seem to experience a different type of death when their loved ones choose MAID. Studies highlighted this type of death provides an opportunity to reminisce and celebrate with their loved ones while also saying goodbye (Buchbinder et al., 2018). While emotional, the literature indicated that having this time with their loved ones seems to help prepare family members as they grieve (Beuthin et al., 2021; Gamondi et al., 2019; Ganzini et al., 2009; Swarte et al., 2003; Wagner, Müller, et al., 2012). A MAID death can also be experienced differently by family members because of socio-cultural and relational influences (Gamondi et al., 2015; Wagner, Keller et al., 2012), resulting in a perceived need to keep the manner of death a secret (Crumley et al., 2023; Hashemi et al., 2021; Oczkowski et al., 2021). Findings from my study build on this knowledge, illuminating the secrecy and privacy pressures that some family members experience not only during the MAID process but also because socio-cultural and relational influences can gradually permeate into their grief and bereavement period, and in ways that scholars as well as family members may not understand.

In that they may live through periods of suspension until their loved ones' determination to receive MAID is established, findings from my study support the literature that suggests encouraging family members to reminisce, celebrate, and create memories with their loved ones (Beuthin et al., 2021; Feigin et al., 2019; Holmes et al., 2018; Martin et al., 2022; Srinivasan, 2019). An essential element in this part of their experience may not only be their loved one's expected timing of death but also the awareness of their loved one's capacity (Dees et al., 2013; Gamondi et al., 2013; Gamondi et al., 2018; Hales et al., 2019; Snijdewind et al., 2014; Srinivasan, 2019), both of which seem to provide a unique opportunity for family members and the future MAID recipient.

According to the literature, the "orchestrator role" (Martin, 2022, p. 1041) comes with personal, emotional, and financial costs, with my study suggesting the acts may be primarily personal and emotional and not without sadness, as other studies have identified (Hales et al., 2019; Holmes et al., 2018; Srinivasan, 2019). However, this aspect of their experience did not appear burdensome. Instead, findings suggest participants tended to be grateful and appreciative of MAID and reflected positively on these legacy-making events and the relational connections that evolved, many recalling them as very meaningful.

Given this finding, I believe that through ceremonies, reminiscing, and saying goodbye, MAID can provide beneficial connections to death through comfort and connection. MAID can foster relationality and open conversations that may not have otherwise occurred (Beuthin et al., 2018; Schutt, 2020) while embracing essential parts of a loved one's life while they remain physically, spiritually, and emotionally present. A surprising finding from this study was that some family members perceived the events that occurred in the days leading up to their loved one's death to be more about what family members needed rather than their loved ones, once again lending support to an understanding that health care providers make an effort to centre care on the family unit in the context of MAID.

While there seems to be a freedom in knowing when their loved one will die, providing an opportunity for openness and sharing, this research also suggests that not all family members' experiences reflect this (Frolic et al., 2020). Instead, the literature indicates that some family members' experiences are isolating (Ciesielski-Carlucci & Kimsma, 1994; Gamondi et al., 2015; Hales et al., 2019) due to the perceived need to keep the type of death chosen by their loved one private and a secret (Crumley et al., 2023). In my study, this explicit or implicit expectation to maintain privacy sometimes came from a request by a loved one, and, on occasion, it was a self-determined decision. For others in my study, it seemed to be due to external factors, including system and policy elements (Patterson, 2023), health care providers (Dees et al., 2013; Denier et al., 2010; Hales et al., 2019), and support systems. I noted that most family member participants elected to keep the choice of their loved one's death private.

When family members' experiences seemed challenging, the quality of palliative care appears to change, or when family members found health care professionals unapproachable (Hales et al., 2019) during the MAID process, my study suggests these elements shaped the experiences of family members. The literature identified when family members encountered similar elements (Snijdewind et al., 2014), it appeared to convey judgement and a lack of support for their loved one's choice by health care professionals (Gamondi et al., 2015).

Some family member participants' decisions to maintain privacy appeared internally motivated, such as an awareness of others' perspectives, including individuals in support systems, religious organizations, or community groups such as a church or social group (Frolic et al., 2022; Hales et al., 2019; Holmes et al., 2018; Srinivasan, 2019; Starks et al., 2007). Being emotionally prepared to handle the reactions of others (Buchbinder et al., 2018; Gamondi et al., 2015; Gamondi et al., 2018; Wagner et al., 2011) also seemed to be an important factor for family members.

Keeping private that their loved one received MAID was challenging, especially when the information needed to be kept from another family member. The need for privacy appeared to arise in these situations because an individual was not privy to the MAID decision and details of the death. This study illuminated that after the death, not knowing another family member's perspective on assisted dying and not wanting the memory of the loved one to be negatively affected tended to cause tension for family members. These emotions seemed to persist into bereavement as family members remained concerned that they, or someone else involved, may accidentally disclose the type of death.

There was also an acknowledgement of concerns about repercussions and potential adverse reactions from support systems and people in local organizations or communities, specifically a family member's church community, if they disclosed the type of death their loved one received. While study participants had not explicitly been informed not to avoid discussing MAID with people in these groups, it was the impression of family members that if they had chosen to do so, members of their community or church may reject the family member of a loved one who received MAID. Only one family member participant shared or sought support or counselling from individuals in religious groups, including family members who were closely affiliated with religious organizations and attended them regularly due to raised concerns. To my knowledge, this is the first Canadian study that has suggested how implied perspectives on MAID may create challenges for family members to disclose and seek counsel within their usual communities, including religious organizations, churches, and social groups. Some family members also appeared distressed by not turning to these supports or to psychosocial counselling during grief and bereavement. Outside of their usual community connections, research notes that family members also may seek out formal psychosocial support (Trouton et al., 2020), with some continuing to keep private their loved one's type of death during individual and group sessions (Andriessen et al., 2020).

Findings from my study indicate that when family members came in contact with organizations and institutions that limited access to MAID, this may have influenced their decision to not disclose that their loved one sought to or had pursued MAID and of their role. For example, some family members seemed to interpret restrictive organizational policies to mean that they should keep secret and private their loved one's choice for MAID and when the MAID event would occur.[101] This aspect of family members' experiences also seem to illuminate that they saw the privacy factor as consequential in a tight-knit community, providing the impression that keeping the type of death of their loved one a secret from those outside the immediate family was challenging for family members. This finding builds on the research by Hales et al. (2019), which identified concerns raised by family members surrounding both patient and family member privacy in the hospital setting. It is also important to note that my study suggests the length of a family member's relationship with an institution or setting that had restrictive MAID

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[101] Due to restrictive policies, their loved one was moved to a different location so the MAID event could occur.

policies (see "They Want MAID, Now What?" section in Chapter 4) did not seem to influence family members to disclose that their loved one sought to or had received MAID. It is also important to acknowledge that the socio-cultural context in jurisdictions and throughout Canada in relation MAID may have evolved since this study was undertaken.

When it comes to sharing the type of death, both the literature and my study findings suggest that family members may have concerns about revealing their loved one's decision for MAID with people outside the immediate family group (Gamondi et al., 2015, Gamondi et al., 2018; Wagner et al., 2011), noting the need to be emotionally prepared to handle the potential reaction of others (Hashemi et al., 2021; Oczkowski et al., 2021). As my study participants identified, it can be challenging to keep this type of death private from unaware yet close family members. As Snijdewind et al. (2014) found, these relational challenges can cause family members to be anxious and stressed, potentially impacting their ability to process their experiences (Gamondi et al., 2015; Hales et al., 2019) and may further complicate family members' grief.

Summary of Interpretation

The findings of my study support and deepen the knowledge of MAID and family members' experiences, illuminating influences at the micro-, meso-, and macro-levels. This study extends scholars' and health care providers' understanding of what is known about the experiences and perspectives of bereaved family members of MAID recipients in several areas, suggesting that health care professionals and health system leaders realize that even when family members seem comfortable with their loved one's decision and are involved in the process and seem prepared for the death, they may still have reservations about supporting and being involved in the MAID process.

When loved ones were in jurisdictions or settings where MAID services were not fully integrated into the broader health care system, family members seemed to assume responsibility for navigating the process and ensuring their loved one’s choice was respected. This appeared connected to policies and structures that suggested to them that it was necessary to become more involved. Family members appeared to reconcile this involvement. Some family members experienced guilt during their loved one’s MAID process, which seemed to result from wondering if they should have advocated for more or improved care for their loved one, and perhaps supported them to a greater extent, which they felt may have affected their loved one’s choice regarding MAID, or possibly have delayed their request. By the time of their loved one’s death, however, family members tended to understand and support that MAID was an autonomous choice their loved one had made, including the timing of their death.

Given that organizational policies and programs transmitted the individual-focused nature of MAID legislation, it is not unexpected that some family members experienced a loss of agency as they supported their loved ones in making their choice. This loss seemed to be experienced during latency periods as they waited with their loved one for MAID assessments and determination, wondering if or when they would know whether MAID would be their loved one’s type of death. However, given the complexity and known involvement of family members, developing programs and structures within a patient-focused, family-centred framework may allow us to be more effective at addressing the needs of these critical members in an individual’s journey toward an assisted death.

Knowing the timing of a loved one’s death seems to provide meaningful connections to death that appear beneficial. In particular, MAID provides a finite amount of time for family members to reminisce and celebrate with their loved ones while preparing to say goodbye.

However, MAID's relational complexity is intense, including confronting that they know when their loved one's life will end.

When leaders developed MAID policies and programs, some appeared to yield to the rights of objecting health care professionals, rather than balancing the rights of individuals wanting MAID. This seems to have resulted in increased stress for some family members. This decision may have also reduced the opportunity for other health care professionals to gain knowledge about MAID programs and MAID processes, adding to the possibility of challenges that family members may experience. Hospital-type environments seem to enable easier access to MAID overall, and the health care professionals in these settings appeared more knowledgeable about MAID and more willing to help guide family members through the process. However, it is important to acknowledge that the area of MAID is rapidly evolving and this finding may have shifted since this study began.

It appears that some family member participants did not identify MAID and palliative care as mutually exclusive and, therefore, seemed surprised that MAID was not introduced early in the discussion about their loved one's care, including during conversations about palliative care. Knowing all options seemed to help family members develop trust in health care professionals and the health care environment. Family members seemed to have more confidence and trust in the MAID process, their loved one's decision regarding MAID, and the health care professionals involved when they had the impression that palliative care and MAID programs were collaborative and cooperative. This integration also seemed to ease family members' stress during the MAID process.

When organizational and institutional policies were in place that restricted MAID, family members appeared to take on more responsibility for their loved one to access MAID, including obtaining assessments and on the day of provision. This tended to result in family members feeling burdened. When policies restricting access were in place, and family members had a longstanding relationship with the institution, they appeared to generally not be surprised by the policy position. These family members also seemed less impacted by what the restriction meant for their loved ones. However, family members were distressed when a loved one had been recently admitted to an institution or setting that refrained from providing full access to MAID, highlighting that they were unaware of such a policy on their loved one's admission. In these situations, family members indicated this was distressing and suggested they had been concerned about what it meant for their loved one in order to receive their choice (e.g., forced transfer).

The need that family members perceived to maintain privacy about their loved one's choice for an assisted death occurred during the MAID process and grief and bereavement. Several family members identified privacy as vital and challenging to maintain, particularly in tight-knit communities, including their town or church organizations, due to perceived socio-cultural and relational influences. In these cases, they appeared to need to keep the type of death of their loved one private, either from immediate family and friends or those outside the family, because of not wanting others to have a negative memory of the loved one, fear of retribution, further isolation or harm. The long-term impact of keeping the type of death private is unknown; however, in the immediate future, we can see that maintaining privacy may cause tension for family members.

When loved ones connected with jurisdictions and settings where MAID services were compartmentalized or less integrated into the broader system, policies and structures appeared to lead family members to experience a sense of duty to become involved navigating the process so their loved one’s choice could be realized. This seemed to result in family members having to reconcile their personal involvement in the MAID process.

Limitations of the Study

Through utilizing an interpretive description methodology, this study shed light on the experiences and perspectives of bereaved family members of recipients of MAID. The data gathered as well as the steps taken to preserve research integrity provide trustworthiness in the results. The results of this study are significant as it was one of the first to explore how MAID implementation, policy, programs, and processes in different provinces may have influenced the experiences of family members. However, as is true in all types of research, this study had limitations.

This study’s main limitation is the need for a broader sample of participants to ensure the sample best represented family members and key informants. For example, although health care and administrative decision makers involved in MAID policies were in the inclusion criteria, none were part of the study sample. Therefore, sampling policymaker and administrator perspectives would be critical in future studies. Additionally, although the final sample of family members reflected varying ages and familial connections to the MAID recipient, the sample did not seem to reflect a diversity of moral beliefs surrounding MAID; there was an urban focus, and the sample primarily identified as female.

Due to COVID-19 restrictions, most interactions with potential participants were virtual or via telephone, including recruitment, which occurred via social media and the internet. This excluded individuals who were without this access and, therefore, were unaware of the study. The exchange of study documents also required access to a computer, which suggests a level of technological privilege and comfort among the sample. Participants may have responded to the study advertisement for reasons such as an interest in research or for unknown reasons, potentially influencing the findings. It is also possible those who responded to the advertisement for research participants had a personal interest (e.g., wanted to express support for MAID) and were more likely to participate.

Since study recruitment began during the COVID-19 pandemic, as individuals and health care providers were adjusting their personal lives and work, this could have also influenced who responded to the study advertisement and recruitment information, as well as their overall perspective and emotional state given the impact and challenges that the pandemic created for those in health care and society at large. For example, one key informant participant withdrew their consent before data collection, citing workload issues.

Consistent with my inclusion criteria, I recruited only family members whose loved ones received clinician-assisted MAID, and, as such, the data collected reflects the perspectives and experiences connected with this type of MAID provision. Based on previous studies (Wagner, Müller, et al., 2012), the experience of family members who support a loved one to receive self-administered assisted dying may have aspects of their experiences that are distinct and, as such, limit the findings and interpretations of my study.

Another limitation of the study was that the sample included a range of bereavement periods of family members.[102] Therefore, the data collected did not reflect any particular subset of family members; rather, participants recalled their experiences, some of which occurred several years prior, potentially impacting the accuracy of their recollection and recounting of their experiences. It was clear that memories were still vivid, as family members easily recalled them. The diversity in bereavement periods may have been a factor connected to the

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[102] From 4 weeks to 4 years.

identification of psychosocial supports, the experience of grief, and that over the past 7 years, modifications and adjustments have occurred in MAID programs and processes, including after the death into grief and bereavement.

This study focused on family members whose loved ones received MAID based on the initial MAID legislation (Bill C-14, 2016), and as a result, their loved ones' deaths were reasonably foreseeable. MAID legislation (Bill C-7, 2021) now includes a Track 2 option, addressing procedural safeguards that apply to individuals whose natural death is not reasonably foreseeable (Government of Canada, 2023a), which may impact the experiences of family members in different ways.

Another significant limitation is that data collection occurred from 2020 to early 2021, with bereaved experiences occurring prior to this. As a result, acknowledging that data collection and study findings are from a particular point in time, early in the evolution of MAID in Canada, is essential. Since this time, not only has new legislation (Bill C-7, 2021) been implemented, but policy, programs and policies may likely have also been modified. As this study was my dissertation project, I designed it under the guidance of my doctoral supervisor and in collaboration with my doctoral committee. No family members participated in the design of my study, including developing survey and interview questions. Involving family members in the design process would be an aspect to consider when designing future studies.

Chapter Summary

MAID is experienced as complex and multifaceted by family members. In this chapter, I interpreted the findings of my study beyond the descriptive and presented them with support from existing literature, creating actionable knowledge for applied practice. I did this in an attempt to invite health care professionals, policy and health care leaders, academics, and advocates to determine the nature and scope of knowledge that may justify shifts in policy, programs, and processes (Thorne, 2016).

Chapter 6: Recommendations and Knowledge Translation

The focus of my study was to understand the experiences and perspectives of bereaved family members who had a significant other end their life through MAID and describe how MAID implementation, policy, and processes in different provinces influenced these experiences. In this chapter, I present recommendations based on the findings of my study and suggest applications with a focus on policy, practice, and education, as well as for future research. My objective through the recommendations is to foster conversation and contemplation. I propose knowledge translation activities and provide concluding remarks to complete this chapter.

Recommendations

This section outlines recommendations for policy, practice, training, and further research. Findings from my study demonstrate that, generally, family members may support their loved one's decision to receive MAID and engage in the MAID process to achieve their loved one's choice, even if it may impact them personally. My research findings suggest that family members are impacted not only by micro-level elements but also meso- and macro-level elements. Additionally, these factors do not operate in isolation but rather interconnect to influence families. With this in mind, I begin this section by putting forward six recommendations focused in the area of policy, practice, and education that address the findings in an integrative way. I then outline seven recommendations for future research. I anticipate the following recommendations will stimulate further discussion around the factors that influence the experiences of bereaved family members.

Recommendations for Policy, Practice, and Education

The following findings from my study add to these reports and health care providers' concerns in relation to these six domains:

Recommendation 1: Evolve Faith-Based Institutional Policies to Allow Full Access to the Practice of MAID. This recommendation may be controversial and will require a paradigmatic shift (T. Bryant, 2016) from one that permits faith-based institutions that receive public funds to provide health care, to develop policies in the context of their organizational values while excluding the protection of individuals and families from potential harm caused by such policies (Armstrong & Armstrong, 2016). The findings from my study illuminated that MAID policies restricting access appear to result in processes that affect family members, let alone those who seek MAID for themselves. Many family member participants also appeared to interpret these MAID policies as meaning they should keep their loved ones' choices private. Organizational policies restricting or refraining from MAID also tend to cause family members to take on additional roles and responsibilities so their loved ones can receive MAID. Family members may not be morally comfortable with the involvement they may see as necessary so their loved one can receive their choice. This may also impact family members' time for reflection and result in a need to reconcile their involvement as well as their feelings and emotions about their loved ones' MAID journey or death. This may be particularly challenging in a setting where family members may feel invisible and need to keep their loved ones' choices secret. As noted in the previous chapter, this has the potential to increase the burden on family members during an already difficult time.

To address restrictions, some health care leaders and MAID teams have attempted to bypass the impact of MAID policies that restrict access by implementing the practice of selecting admission sites and institutions that are known to permit MAID if an individual is or has alluded to the desire to pursue this option (see the “Organization and Implementation of MAID” section in Chapter 2; Pesut et al., 2021). Although this practice may address the potential impact of these policies, it also has potential implications for family members. For example, this practice is only feasible in some regions or areas because local facilities may be limited to faith-based or MAID restrictive institutions. Family members should not have to be concerned about where their loved one is admitted[103] with respect to whether an institution restricts access to MAID, which could occur after their loved one is admitted or transferred to a facility. A radical shift must occur to address the impact that seems to be occurring due to restrictive policies. This change will require strong leadership and paradigmatic policy change at organizational, institutional and possibly governmental levels.

While this shift occurs, leaders in institutions with MAID policies that restrict access must realize the potential impact of their current policies on family members. Although MAID is patient focused, given the legislation, family members are present and involved as their loved ones pursue MAID, including assuming roles and responsibilities that may make them feel morally compromised. Family members’ experiences appear to thread throughout the MAID process. The literature suggests that family members seem to feel that health care providers do not sufficiently support or openly communicate with them when MAID is part of their loved one’s journey.

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[103] For example, if taken by ambulance, they are often directed to the nearest hospital or a hospital with less wait time in their emergency department.

Recommendation 2: Call Upon Health Care Leaders, Administrators, and Managers in Institutions with MAID Policies That Restrict Access to Ensure the Provision of Family-Centred Care. Consistently providing family-centred care is a challenging endeavour, given the complexity of MAID and the environment of the health care system. However, providing nonjudgmental care with a patient focus while also centred on the family, who themselves may be struggling at points during the MAID process, appears as an essential and ethical responsibility for health care professionals in the context of care (Canadian Nurses Association, 2017a).

To facilitate the family is part of the unit of care, I suggest that health care leaders establish inclusive practice standards and guidelines, providing training and education about the experience of family members of recipients of MAID to health care professionals. Leaders can anticipate a "range in responses" (Pesut et al., 2019, p. 5) from health care professionals in their institutions, but the conscience rights of health care providers and workers objecting to MAID should not impede their ability to support and care for family members. It is essential to engage health care providers to reflect on their values and beliefs related to MAID. For example, nurses could access the *MAID Reflective Guide* (Pesut et al., n.d.). However, including ethical and legal discussions about this practice expectation may also be necessary, such as providing and encouraging access to Canadian Nurses Protective Society webinars and consultants. Moreover, organizational support is necessary for employees and providers to address potential moral tension and distress resulting from this recommendation (Beuthin et al., 2018). The support should be easily accessible during and after-work hours.

Recommendation 3: Ensure MAID Programs and Processes Utilize a Patient-Focused, Family-Centred Framework. Faith-based institutions are only one of the locations where structures of MAID programs impact family members of MAID recipients and when communication may not be experienced as open and nonjudgmental by family members (Beuthin et al., 2018). As such, I recommend that MAID programs and processes aim to provide a patient-focused, family-centred framework. While the patient must remain the focus throughout the MAID process because of the nature of the request and legislative requirements (Bill C-14, 2016), just as with other end-of-life care, family members also must be encouraged to be part of the unit of care. Family members' roles and responsibilities during this time, their relationship to the individual in focus (the future MAID recipient), and the impact of MAID on family members that seems to be present during the MAID trajectory and into bereavement, are just some factors that necessitate care being family-centred.

To begin, health care leaders, administrators, and health care professionals, including MAID team members, could evaluate MAID programs, structures, and processes currently in place with a patient-focused, family-centred lens. Given that studies, including this research, highlighted the need for "influential leaders setting the tone" (Pesut, Thorne, Schiller, et al., 2020, p. 4) for MAID programming and policy development, the design and composition of the evaluation team is an important consideration. After implementing adjustments, it may be essential to continuously evaluate MAID programs with a patient-focused and family-centred lens because of the evolving nature of MAID with legislative changes and the importance of continuing to centre on the family within the broader MAID context. Evaluations could include understanding the long-term impacts of programs and processes on the grief and bereavement of family members. Since access to information about MAID seemed to be identified as difficult to navigate, developing and ensuring information resources (e.g., pamphlets, posters) other than those online focusing on family members could demonstrate an improved focus on family and friends who take on these responsibilities.

Recommendation 4: Assess How Family-Centred Care is Actualized in Health Care Settings and Develop and Facilitate Continuing Education Opportunities for Health Care Providers on Family-Centred Care. Regardless of the findings from MAID program reviews, this recommendation is for health care leaders, administrators, and educators to assess how family-centred care is actualized in their health care settings and develop and facilitate continuing education opportunities for nurses and other health care providers on family-centred care. This would include the experience of family members when a loved one is diagnosed with a terminal illness and supporting a loved one at end-of-life, including when MAID is the choice. I suggest this continuing education be accessible across all settings because of the many points at which health care providers come in contact with family members. I also suggest the education opportunities provided be specific to MAID, since there is indication that family members may experience feelings of isolation, the need for secrecy, and a sense of burden as their loved one pursues MAID (Ciesielski-Carlucci & Kimsma, 1994; Gamondi et al., 2015; Hales et al., 2019; Holmes et al., 2018; Swarte et al., 2003; Wagner, Keller, et al., 2012), while also suggesting a need for open and respectful dialogue with health care professionals (Beuthin et al., 2021; Yan, 2022). Enhancing health care professionals' knowledge may be a way to lessen challenges experienced. Given the demands and structural challenges existing in Canada's overextended health care system, health care providers may perceive family members as difficult to include in the patient's care; however, the impact that nurses and other health care professionals can have on this population is significant if they can utilize current knowledge and effectively communicate, particularly in the context of possible broader program changes I recommend later in this section (see Recommendation 6). Therefore, I suggest the support for this recommendation be evident in structures and by actions from senior leaders, not just in the words found in program documentation and guidelines.

Recommendation 5: Modify Course and Program Objectives to Ensure Family-Centred End-of-Life Care is Included in the Foundational Knowledge and Praxis for Health Care Practitioners. This recommendation builds on Recommendation 4 to suggest that academic leaders and educators, including teaching faculty and nursing educators, ensure family-centred end-of-life care, including MAID, is foundational knowledge and incorporated into course and program-level objectives. Reviewing and updating curricula to ensure current evidence and knowledge on family and family-centred care should level across the years in pre-licensure programs and be brought forward into clinical practice (where applicable) is a beginning step. As part of this recommendation, including material on communication and course content focused on communicating with family members is essential, as well as aligning MAID and palliative care (e.g., ethical, legal, cultural safety, stigma). This could include simulation learning opportunities

Developing simulation scenarios focused on end-of-life and patient autonomy while being family-centred could facilitate a needed theory-to-practice connection. In particular, a scenario might begin at diagnosis of a life-limiting condition, including early palliative care and treatment, through discussions about the possibility of MAID, while involving family members with different perspectives[104] about the options including MAID. Simulation scenarios could also evolve to address family members' grief and bereavement, including challenges that family members experience following a natural death and an assisted one. Through simulation, students

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[104] Using actors if possible.

could also work through their beliefs and conscience relating to MAID and reflect on how to connect with family members whose significant other may choose to pursue this option.[105] These educational recommendations could prepare students for clinical experiences and competent practice following graduation or registration.

Given nurses' interactions with family members in all settings, the Canadian Association of Schools of Nursing (CASN) and program accreditation committees could also engage with this recommendation at the pre-licensure stage, possibly with entry-level competencies (where applicable). I encourage CASN to ensure the presence of patient- and family-centred entry-level competencies and invest in updating the CASN (2012) *Palliative and End-of-Life Care Teaching and Learning Resources* to reflect the evolution in this area, for example, which includes the option of MAID and a focus on family members during palliative care and MAID. Although MAID deaths account for 4.1% of all deaths in Canada as of the most recent accounting (Health Canada, 2023; see the "Current Data on MAID" section in Chapter 2), this type of death continues to increase since implementation (Health Canada, 2023).

The literature highlighted that family members appear to want nurses and other health care professionals to enter into conversations early in the end-of-life process (Schutt, 2020). Doing so may improve the quality of family members' grief. Preparing nursing students with current knowledge and practical techniques to engage in dialogue about the patient's end-of-life choices, including MAID, may not only ease the impact of any death but the skills and techniques can be transferable across settings and populations. To facilitate this recommendation, faculty members, instructors, and clinical educators would need to maintain a

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[105] Simulation may also be useful for current practicing nurses and other healthcare professionals as well (see Recommendation 4). However, it would be a human resource issue and would privilege urban locations with access to simulation suites.

currency of knowledge on family-centred care at the end of life and address curriculum changes in courses, implementing sensitive student-centred suitable teaching and learning strategies using a trauma-informed lens. It is also important through this recommendation for teaching faculty to support clinical educators in debriefing with nursing students and reflecting on clinical experiences concerning the possible legacy of a MAID event on family members.

Recommendation 6: Encourage Health Care Leaders and Professionals to Support and Integrate Palliative Care and MAID Programs. My study illuminated that[106] MAID events appeared to impact family members when MAID programs, structures, and processes were not well integrated with broader health care services, such as palliative care programs. This is the basis of this final recommendation for health care leaders and health care professionals to mutually support and find ways to integrate palliative care and MAID programs. I anticipate that this recommendation may be challenging to implement because of the range of moral responses health care professionals have about MAID (Pesut, Thorne, Storch, et al., 2020) and given that, although possibly moderating, tension appears to continue between palliative care and MAID (Antonacci et al., 2019; Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, 2019; Downar et al., 2023; Gerson et al., 2020; Pesut et al., 2021; Slade, 2020).

In some Canadian jurisdictions and settings, palliative care and MAID programs are seen to function in mutually exclusive ways and in varying degrees of integration (Pesut et al., 2021) rather than a "complementary and synergistic [manner]" (Downar et al., 2023, p. 898). As findings in my study suggest, this does not ease the burden on family members; rather, it seems to create challenges. Nevertheless, based on the literature, scholars express some optimism about

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[106] As outlined in Chapter 3, family member participants were impacted by Bill C-14 (2016).

the evolution and integration between palliative care and MAID in jurisdictions where assisted dying is legal (Hashemi et al., 2021; Vanden Berghe et al., 2017).

The literature revealed that at least one international jurisdiction[107] permits and supports an integrated understanding of assisted dying and palliative care (Vanden Berghe et al., 2017), embedding physician-assisted dying and euthanasia into palliative care. This provides optimal support to patients as well as their families and friends (Vanden Berghe et al., 2017). According to a study focused on nurses in Canada, diverse degrees of integration were noted from having no integration, informal consultative relationship to some with complete integration (Pesut et al., 2021). We know that palliative care and MAID are integrated and collaborative in at least one setting in Canada (i.e., an Ontario community palliative care program)[108] and that there are leaders in health care who making efforts to navigate between palliative care and MAID so that patients, and families, receive the care they desire. This evolution of points to the possibility of integrating palliative care and MAID in more settings, which could benefit family members and those seeking MAID.

This recommendation, however, becomes more complex in the broader understanding of MAID because of the amendments to the legislation (Bill C-7, 2021), including (a) Track 2, which permits MAID for those whose natural death is not reasonably foreseeable and (b) the anticipation that individuals with mental illness as their sole underlying condition will be permitted to receive MAID if they qualify (Government of Canada, 2023a) possibly beginning in 2024. These legislative changes, in the context of the findings from my study, suggest an integrated MAID program in the health care system may be even more essential as MAID

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[107] Flanders, Belgium.

[108] Specifically, in the home-type setting.

becomes more layered and complex as MAID eligibility expands. Although there are reports that MAID programs and processes are now “settling into an equilibrium after the implementation of Bill C-14” (Pesut, Thorne, Wright, et al., 2021, p. 11), some family members in my study experienced it differently, possibly in part because of the time this study took to complete. Moreover, if MAID programs and processes continue to be poorly understood (Pesut, Thorne, Schiller, et al., 2020), health care professionals as well as family members may continue to be impacted by program and process factors (Pesut, Thorne, Wright, et al., 2021).

Recommendations for Future Research

The findings from this study enhanced knowledge from the few prior studies published on the experiences of family members of recipients of MAID and assisted dying. My study also suggested how MAID policies, programs, and processes may impact their experience. I offer the following recommendations for further policy, practice, and interdisciplinary scholarly research into this developing area:

1. Replicate and extend the current study to focus on the experiences of family members in rural and remote regions. Research has highlighted inequity in rural health care access, including lengthy travel to urban centres for services and a need for more available primary care practitioners and resources (Canadian Institute for Health Information [CIHI], 2018; Maddison et al., 2011; Sibley & Weiner, 2011). Individuals in rural areas often prefer receiving care in their community to avoid potential travel-related issues and costs (CIHI, 2018); however, given the known concerns for confidentiality in these locations, this may cause difficulties for family members whose loved ones chose MAID. Essential elements in this future study also include understanding barriers, such as access to palliative care and providers feeling

less prepared to manage care for individuals at end of life, including MAID (Kaasalainen et al., 2012; Tedder et al., 2017). Given that this population has unique challenges and is often under-resourced, understanding family members' experiences as their loved one pursues MAID, including access to early and quality palliative care, and integrating palliative care and MAID programs will be essential.

2. While some faith-based health care organizations permit complete access to MAID, other institutions do not (De Bono, 2017), and my study provides knowledge as to the potential impact of policies in such institutions and settings on family members. My study may be the impetus to explore this area further, possibly with the inclusion of family member participants from the Province of Québec, where all hospitals are required to allow MAID (Bill 52, 2014). Further understanding of these experiences through subsequent research could enhance health care providers' knowledge to implement additional recommendations that may improve the experiences of family members, including in bereavement. Such an investigation may also uncover ways to improve programs and processes to reduce potential negative impacts and harm.
3. Although some family members spoke of having difficulty because of their loved one's choice for MAID, my study did not illuminate if there was an influence or impact due to their family and community connections, beliefs, or affiliation with religion and spirituality. Investigating the possible impact of spirituality and religion on the experience of bereaved family members is warranted at this time. Future investigations by an interdisciplinary team of researchers could explore whether and how family members who supported loved ones through MAID engaged with their usual religious and spiritual communities or advisors, whether this participation was

challenging, and by what processes. It would be vital to understand if there were negative impacts on family members and if or how difficulties may have been resolved.

4. Given that my study and previous research in this area have highlighted that privacy and secrecy seem to be a pattern in the experiences of bereaved family members, and given the relative recency of MAID legalization (Bill C-14, 2016), investigating if family members' experience with a MAID death has resulted in any long-term impacts or complications would be warranted.
5. Although research has suggested that sharing the same beliefs and values as their loved ones about end-of-life choices can facilitate involvement and collaboration in the assisted dying process (Goldberg et al., 2021; Thangarasa et al., 2021), this attitude does not reflect an absolute willingness of family members to participate (Emanuel et al., 2000; Frolic et al., 2020). It may be meaningful to understand the experiences of family members who chose to disengage or did not engage in supporting their loved ones in their pursuit of MAID in an effort to identify recommendations to assist this group.
6. Findings from my study suggest family members' impressions of and experiences with palliative care programs and services changed following the initiation of the MAID process. Building on this knowledge to investigate further if or how family members experience palliative care in the context of MAID is warranted.
7. When Bill C-7 (2021), *An Act to amend the Criminal Code (Medical Assistance in Dying)*, received Royal Assent and came into force, it amended initial MAID legislation (Bill C-14, 2016). It included provisions that excluded most individuals

with mental illness as their sole underlying medical condition from eligibility for MAID. However, Bill C-7 noted that this exclusion would be automatically repealed in March 2023.[109] Individuals with mental illness as the sole underlying condition do not currently qualify for MAID in Canada (Government of Canada, 2023a). However, with additional changes to MAID legislation (Bill C-14, 2016; Bill C-7, 2021) anticipated in 2024 to allow such individuals who meet eligibility criteria to qualify for MAID (Government of Canada, 2023a), health care providers, mental health advocates, and scholars have expressed concerns about the potential impact of these changes given the ongoing lack of access to universal, publicly funded mental health supports that address the full range of needs including substance use, resulting in inequity among those with mental illness and impacting their family and friends (Canadian Mental Health Association, 2023). In this context, it will be necessary to replicate and extend this current study to include data collected from family members of individuals who received MAID whose sole underlying condition was mental illness. These family members' perspectives and experiences will be essential to add to current knowledge.

Knowledge Translation

The findings and recommendations from my study are relevant in the Canadian context and globally. The knowledge produced from my study informs health care leaders and policymakers, health care providers including palliative care and MAID practitioners, health and social care educators, and advocacy groups. I hope that my findings not only foster conversation

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[109] This was extended by 1 year to allow preparation at the program and practice level (Government of Canada, 2023a).

but also prompt application through reflection on, enhancement of, and modifications to practice, policy, programs, and services that may positively impact family members whose loved ones pursue MAID. In this section, I propose several strategies for knowledge translation, beginning with short-term approaches.

Following this study's completion, I will email a summary of the study findings and produce a recorded video summary, which I will make available to all participants who requested an update on the outcomes of my study. For dissemination to individuals and family members who are dealing with their own loved ones' end-of-life issues and possibly contemplating MAID, or for bereaved family members who were not study participants, I will engage with non-profit organizations (e.g., Bridge C-14, MAID Family Support, Dying with Dignity Canada, the Canadian Association of MAID Assessors and Providers, and Wellspring) to determine how this knowledge can be used in the context of their groups and organizations. I anticipate this to likely involve presentations at local chapters and through webinars. I will also direct knowledge to key informant participants and, given their roles, will offer to disseminate findings and recommendations (in person or virtually) to their teams and organizations. This may include in-service training opportunities.

Knowledge dissemination at conferences and through journals focused on end-of-life, palliative care and assisted dying will be the focus for disseminating findings to health care professionals, policymakers, and health care leaders. Conferences may include the Canadian Association of Nurses in Oncology Annual Conference, MAID Conference, the Canadian Hospice Palliative Care Conference, the Canadian Gerontological Nurses Association Conference, and the International Conference on End-of-Life Law, Ethics, Policy, and Practice. Dissemination of findings through publications in academic peer-reviewed journals, including those focused on palliative and end-of-life care (e.g., *Palliative Medicine*), family (e.g., *Journal of Family Nursing*), health policy (e.g., *Health Policy and Planning* and *Policy, Political and Nursing Practice*), and, given my nursing background and the impact that nurses can have on the experience of family members, targeting knowledge dissemination toward those in the nursing profession will be vital.

Affecting change based on the findings from my study and the recommendations I put forward in this section will require not only the dissemination of knowledge but also for leadership (institutional, organizational, provincial, and federal government) to be open to acknowledge the evidence and the modifications in how to possible improve MAID programs and processes for family members. The range of this includes influential leaders in the study settings (including all publicly funded organizations and institutions) and policy consultants in Health Canada. I will also seek to connect with faith-based health care conference organizers regarding opportunities to disseminate knowledge during those conferences (e.g., the Providence Health Care Annual Ethics Conference and the Covenant Health Palliative Care Education and Research Conference) to connect to practice-based professionals in organizations that could implement or advocate for the proposed recommendations.

I will leverage my role as a nursing faculty member by engaging with nursing colleagues. This may involve connecting with colleagues in nursing faculties across Western Canada. At Mount Royal University, knowledge translation will occur at the department level, including contributing to curriculum development, and I will also undertake university-wide dissemination during scholarship opportunities (e.g., Faculty Lightning Talks at Mount Royal University's Research and Scholarship Days). Given the number of nursing programs in Western Canada, broad knowledge dissemination through the Western and Northern Regional-Canadian

Association of Schools of Nursing may be effective. I may also plan for knowledge translation at the bi-annual CASN conference.

It is essential that I monitor and evaluate the impact of the proposed knowledge translation strategies when they occur. This will require follow-up research.

Concluding Remarks

In this study, 31 bereaved family members generously shared their perceptions and experiences as their loved ones accessed and received MAID, with another 15 key informants sharing their insights into family members’ experiences and their impressions and experiences with MAID and palliative care services. The interpretive description methodology provided a framework for this two-setting study. The methodology illuminated a contextual understanding of the experiences of bereaved family members and enabled the presentation of new knowledge in a meaningful way for practice, policy, and education. The findings from this study support similar research and extend health care practitioners’ understandings of micro-, meso- and macro-level elements that seem to impact family members who have had a loved one end their life through MAID.

This study illuminated the complex and multifaceted nature of bereaved family members’ experiences in the relatively new context of assisted dying. With the evolution of MAID eligibility and access due to legislative changes (such as Bill C-7, 2021), along with attitude shifts about assisted dying and the continued impact of health inequities on individuals, it is likely that the number of people who experience bereavement after MAID will increase. Therefore, not only does my study fill a knowledge gap, but it also provides this knowledge at a critical time in the progression of MAID in Canada. Health care professionals, including palliative care providers and MAID practitioners, as well as health care leaders, policymakers, and advocates with non-profit organizations who interact with family members, must realize that MAID is much more than an autonomous decision by an individual at end of life who meets eligibility criteria; the decision for MAID, the elements that frame MAID programs and processes, and the sociocultural factors that surround patient options also all shape family members' experiences. I suggest that health care leaders ensure that health care providers can engage in family-centred care when MAID is the context, particularly given, as this study shows, family members appear to experience hidden complexities, including during bereavement, of which health practitioners may have to this point been relatively unaware.

References

Abma, T. A. (2005). Struggling with the fragility of life: A relational-narrative approach to ethics in palliative nursing. *Nursing Ethics, 12*(4), 337–348. https://doi.org/10.1191/0969733005ne799oa

Act Respecting End-Of-Life Care, CQLR, c. S-32.0001 [Québec]. https://www.canlii.org/en/qc/laws/stat/rsq-c-s-32.0001/latest/rsq-c-s-32.0001.html

Adams, E., & Ogbogu, U. (2018, November 6). How do we balance rights in cases of medically assisted dying? *The Globe and Mail*. https://www.theglobeandmail.com/opinion/article-how-do-we-balance-rights-in-cases-of-medically-assisted-dying/

Addington-Hall, J., & McPherson, C. (2001). After-death interviews with surrogates/bereaved family members: Some issues of validity. *Journal of Pain and Symptom Management*, *22*(3), 784–790. https://doi.org/10.1016/S0885-3924(01)00330-X

Alberta Health Services. (n.d.). *Medical assistance in dying.* https://www.albertahealthservices.ca/info/page13497.aspx

Alberta Health Services. (2016). *Medical assistance in dying: What are my options?*

Alberta Health Services. (2019). *Record of request for medical assistance in dying* (No. HSP11175). https://cfr.forms.gov.ab.ca/Form/HSP11175.pdf

Alberta Health Services. (2021a). *2020-21 Report to the community: AHS map and zone overview*. https://www.albertahealthservices.ca/assets/about/publications/ahs-ar-2021/zones.html

Alberta Health Services. (2021b). *Medical assistance in dying* (Policy No. HCS-165-01). https://extranet.ahsnet.ca/teams/policydocuments/1/clp-med-assist-in-death-hcs-165-01.pdf

Amies, D. (2018, April 26). *No tug of war between palliative care and assisted dying. Dying with Dignity Canada (DWDC).* https://www.dyingwithdignity.ca/no_tug_of_war

Anderson, E. W., & White, K. M. (2018). “It has changed my life”: An exploration of caregiver experiences in serious illness. *American Journal of Hospice and Palliative Medicine, 35*(2), 266–274. https://doi.org/10.1177/1049909117701895

Andriessen, K., Krysinska, K., Castelli Dransart, D. A., Dargis, L., & Mishara, B. L. (2020). Grief after euthanasia and physician-assisted suicide: A systematic review. *Crisis, 41*(4), 255–272. https://doi.org/10.1027/0227-5910/a000630

Angus Reid Institute. (2010). *Majority of Canadians support legalizing euthanasia.* https://angusreid.org/majority-of-canadians-support-legalizing-euthanasia/#:~:text=Euthanasia and Assisted Suicide,lowest in Alberta (48%25)

Antifaeff, K. (2019). Social work practice with medical assistance in dying: A case study. *Health & Social Work*, *44*(3), 185–192. https://doi.org/10.1093/hsw/hlz002

Antonacci, R., Baxter, S., Henderson, J. D., Mirza, R. M., & Klinger, C. A. (2019). Hospice palliative care (HPC) and medical Assistance in Dying (MAiD): Results from a Canada-wide survey. *Journal of Palliative Care*, *36*(3), 151–156. https://doi.org/10.1177/0825859719865548

Aoun, S. M., Kristjanson, L. J., Currow, D. C., & Hudson, P. L. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, *19*(7), 551–555. https://doi.org/10.1191/0269216305pm1053oa

Appelin, G., Brobäck, G., & Berterö, C. (2005). A comprehensive picture of palliative care at home from the people involved. *European Journal of Oncology Nursing*, *9*(4), 315–324. https://doi.org/10.1016/j.ejon.2004.11.001

Ariès, P. (1974). *Western attitudes toward death: From the middle ages to the present*. The Johns Hopkins University Press.

Armstrong, P., & Armstrong, H. (2016). *About Canada: Health care* (2nd ed.). Fernwood Publishing.

Arnup, K. (2018). *Family perspectives: Death and dying in Canada*. http://vanierinstitute.ca/deathdying2018/

Austin, W., Bergum, V., & Dossetor, J. (2003). Relational ethics: An action ethic as a foundation for health care. In V. Tschudin (Ed.), *Approaches to ethics: Nursing beyond boundaries* (pp. 45–52). Butterworth-Heinemann.

Ball, I. M., Hodge, B., Jansen, S., Nickle, S., & Sibbald, R. W. (2018). A Canadian academic hospital's initial MAID experience: A health-care systems review. *Journal of Palliative Care*, *34*(2), 78–84. https://doi.org/10.1177/0825859718812446

Band-Winterstein, T., Doron, I., & Naim, S. (2014). 'I take them with me'– reflexivity in sensitive research. *Reflective Practice*, *15*(4), 530–539. https://doi.org/10.1080/14623943.2014.900031

Banner, D., Schiller, C. J., & Freeman, S. (2019). Medical assistance in dying: A political issue for nurses and nursing in Canada. *Nursing Philosophy*, *20*(4), 1–7. https://doi.org/10.1111/nup.12281

Battams, N. (2018, February 18). *Family caregiving in Canada: A fact of life and a human right.* Vanier Institute of the Family. https://vanierinstitute.ca/family-caregiving-in-canada/

Bearskin, R. L. B. (2011). A critical lens on culture in nursing practice. *Nursing Ethics*, *18*(4), 548–559. https://doi.org/10.1177/0969733011408048

Beck, A. M., & Konnert, C. A. (2007). Ethical issues in the study of bereavement: The opinions of bereaved adults. *Death Studies*, *31*(9), 783–799. https://doi.org/10.1080/07481180701537220

Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing*, *18*(10), 1379–1393. https://doi.org/10.1111/j.1365-2702.2008.02405.x

Bennett, M. (2018). Blameless guilt: The case of carer guilt and chronic and terminal Iilness. *International Journal of Philosophical Studies*, *26*(1), 72–89. https://doi.org/10.1080/09672559.2017.1416422

Bentley, B., & O'Connor, M. (2015). Conducting research interviews with bereaved family carers: When do we ask? *Journal of Palliative Medicine, 18*(3), 241–245. https://doi.org/10.1089/jpm.2014.0320

Bergum, V. (2013). Relational ethics for health care. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 127–142). Pearson Canada.

Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. University Publishing Group.

Beuthin, R. (2018). Cultivating compassion: The practice experience of a medical assistance in dying coordinator in Canada. *Qualitative Health Research, 28*(11), 1679–1691. https://doi.org/10.1177/1049732318788850

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum, 53*(4), 511–520. https://doi.org/10.1111/nuf.12280

Beuthin, R., Bruce, A., Thompson, M., Andersen, A. E. B., & Lundy, S. (2021). Experiences of grief-bereavement after a medically assisted death in Canada: Bringing death to life. *Death Studies*, *46*(8), 1982–1991. https://doi.org/10.1080/07481187.2021.1876790

Bill 52, *An Act respecting end-of-life care*, RSQ 2014 c 2 [Québec]. https://www.legisquebec.gouv.qc.ca/en/document/cs/s-32.0001

Bill C-7, *An Act to amend the Criminal Code* (*medical assistance in dying)*. (2021). https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent

Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other acts* (*medical assistance in dying)*, RSC 2016, c 3 [Canada]. https://lop.parl.ca/staticfiles/PublicWebsite/Home/ResearchPublications/LegislativeSummaries/PDF/42-1/c14-e.pdf

Boivin, A., Gauvin, F. P., Garnon, G., Gancia, A., Rouly, G., Marcoux, I., & Lehoux, P. (2019). Information needs of francophone health care professionals and the public with regard to medical assistance in dying in Quebec: A qualitative study. *CMAJ Open*, *7*(2), E190–E196. https://doi.org/10.9778/cmajo.20180155

Braun, V., & Clarke, V. (2019). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201–216. https://doi.org/10.1080/2159676X.2019.1704846

Brémault-Phillips, S., Parmar, J., Johnson, M., Huhn, A., Mann, A., Tian, V., & Sacrey, L.-A. R. (2016). The voices of family caregivers of seniors with chronic conditions: A window into their experience using a qualitative design. *SpringerPlus*, *5,* Article 620. https://doi.org/10.1186/s40064-016-2244-z

Bridges, A. (2017, December 19). Province recording medically-assisted deaths as suicides is "unconscionable," says Sask. family. *CBC News*. https://www.cbc.ca/news/canada/saskatoon/sask-policy-records-assisted-deaths-1.4455627

British Columbia Civil Liberties Association. (2012). *Carter v. Canada case documents.* https://bccla.org/2012/12/carter-et-al-v-attorney-general-of-canada/

Brooks, E. G., & Reed, K. D. (2015). Principles and pitfalls: A guide to death certification. *Clinical Medicine and Research*, *13*(2), 74–82. https://doi.org/10.3121/cmr.2015.1276

Brown, J., Goodridge, D., Harrison, A., Kemp, J., Thorpe, L., & Weiler, R. (2020a). Care considerations in a patient- and family-centered medical assistance in dying program. *Journal of Palliative Care*, *37*(3), 341–351. https://doi.org/10.1177/0825859720951661

Brown, J., Goodridge, D., Harrison, A., Kemp, J., Thorpe, L., & Weiler, R. (2020b). Medical assistance in dying: Patients', families', and health care providers' perspectives on access and care delivery. *Journal of Palliative Medicine, 23*(11), 1468–1477. https://doi.org/10.1089/jpm.2019.0509

Brown, J., Goodridge, D., Thorpe, L., & Crizzle, A. (2021). "I am okay with it, but I am not going to do it": The exogenous factors influencing non-participation in medical assistance in dying. *Qualitative Health Research*, *31*(12), 2274–2289. https://doi.org/10.1177/10497323211027130

Brown, J., Thorpe, L., & Goodridge, D. (2018). Completion of medical certificates of death after an assisted death: An environmental scan of practices. *Healthcare Policy*, *14*(2), 59–67. https://dx.doi.org/10.12927/hcpol.2018.25685

Browne, A., & Russell, J. S. (2016). Physician-assisted death in Canada. *Cambridge Quarterly of Healthcare Ethics*, *25*(3), 377–383. https://doi.org/10.1017/S0963180116000025

Bruce, A., Beuthin, R., Sheilds, L., Molzahn, A., & Schick-Makaroff, K. (2020). Holding secrets while living with life-threatening illness: Normalizing patients' decisions to reveal or conceal. *Qualitative Health Research*, *30*(5), 655–665. https://doi.org/10.1177/1049732319887714

Bryant, A. (2014). The grounded theory method. In P. Leavy (Eds.), *The Oxford handbook of qualitative research* (pp. 116–136). Oxford University Press.

Bryant, T. (2016). *Health policy in Canada* (2nd ed.). Canadian Scholars' Press.

Buchbinder, M. (2018). Choreographing death: A social phenomenology of medical aid-in-dying in the United States. *Medical Anthropology Quarterly, 32*(4), 481–497. https://doi.org/10.1111/maq.12468

Buchbinder, M., Brassfield, E. R., & Mishra, M. (2019). Health care providers' experiences with implementing medical aid-in-dying in Vermont: A qualitative study. *Journal of General Internal Medicine*, *34*, 636–641. https://doi.org/10.1007/s11606-018-4811-1

Buchbinder, M., Ojo, E., Knio, L., & Brassfield, E. R. (2018). Caregivers' experiences with medical aid-in-dying in Vermont: A qualitative study. *Journal of Pain and Symptom Management*, *56*(6), 936–943. https://doi.org/10.1016/j.jpainsymman.2018.08.010

Burton, A. M., Sautter, J. M., Tulsky, J. A., Hoff Lindquist, J., Hays, J. C., Olsen, M. K., Zimmerman, S. I., & Steinhauser, K. E. (2012). Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers. *Journal of Pain and Symptom Management*, *44*(3), 410–420. https://doi.org/10.1016/j.jpainsymman.2011.09.018

Butler, A. E., Copnell, B., & Hall, H. (2019). Researching people who are bereaved. *Nursing Ethics*, *26*(1), 224–234. https://doi.org/10.1177/0969733017695656

Canada Health Act, RSC 1985, c C-6 [Canada]. https://www.canlii.org/en/ca/laws/stat/rsc-1985-c-c-6/latest/rsc-1985-c-c-6.html

Canadian Association of MAID Assessors and Providers. (n.d.). *Palliative care & MAiD.* https://camapcanada.ca/clinicians/clinician-resources/pallative-care-maid/

Canadian Association of MAID Assessors and Providers. (2020, February). *Key messages: End of life care and medical assistance in dying (MAiD).* https://camapcanada.ca/wp-content/uploads/2022/02/FINAL-Key-Messages-EOL-Care-and-MAiD.pdf

Canadian Association of MAID Assessors and Providers. (2022a). *Countries where assisted dying is legal.*

Canadian Association of MAID Assessors and Providers. (2022b). *MAiD resources in your province/territory.*

Canadian Association of Schools of Nursing. (2012). *Palliative and end-of-life care teaching and learning resources*. https://www.casn.ca/2014/12/palliative-end-life-care-teaching-learning-resources-2012/

Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK). (1982). https://laws-lois.justice.gc.ca/eng/const/page-12.html

Canadian Hospice Palliative Care Association. (n.d.). *Hospice palliative care*. https://www.chpca.ca/about-hpc/

Canadian Hospice Palliative Care Association. (2013). *Valuing caregiving and caregivers: Family caregivers in the integrated approach to palliative care*. http://www.hpcintegration.ca/media/37049/TWF-valuing-caregivers-report-final.pdf

Canadian Hospice Palliative Care Association. (2017). *National bereavement day in Canada 2017 FAQ's.* https://www.chpca.ca/wp-content/uploads/2019/12/faq_-national_bereavement_day_in_canada_2017_-_en_-_final.pdf

Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians. (2019, November 27). *CHPCA and CSPCP – joint call to action*. https://www.chpca.ca/news/chpca-and-cspcp-joint-call-to-action/

Canadian Institute for Health Information. (2018). *Access to palliative care in Canada*. https://www.cihi.ca/en/access-to-palliative-care-in-canada

Canadian Institute for Health Information. (2023). *Access to palliative care in Canada*. https://www.cihi.ca/sites/default/files/document/access-to-palliative-care-in-canada-2023-report-en.pdf

Canadian Mental Health Association. (2023, June 22). *Statement on upcoming changes to Canada's Medical Assistance in Dying (MAiD) law*. https://cmha.ca/brochure/statement-on-upcoming-changes-to-canadas-medical-assistance-in-dying-maid-law-2/

Canadian Nurses Association. (2017a). *Code of ethics for registered nurses*. https://www.cna-aiic.ca/en/nursing/regulated-nursing-in-canada/nursing-ethics

Canadian Nurses Association. (2017b, January). *National nursing framework on medical assistance in dying in Canada*. https://cnpea.ca/images/cna-national-nursing-framework-on-maid_jan2017.pdf

Canadian Virtual Hospice. (n.d.). *Providing care.* https://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Providing+Care.aspx

Carter v. Canada (Attorney General), 2012, BCSC 886. https://bccla.org/wp-content/uploads/2012/06/Carter-v-Canada-AG-2012-BCSC-886.pdf

Carter v. Canada, 2015, 1 SCR 331, Case No. 35591. https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do

Choi, S., & Seo, J. (2019). Analysis of caregiver burden in palliative care: An integrated review. *Nursing Forum*, *54*(2), 280–290. https://doi.org/10.1111/nuf.12328

Ciesielski-Carlucci, C., & Kimsma, G. (1994). The impact of reporting cases of euthanasia in Holland: A patient and family perspective. *Bioethics*, *8*(2), 151–158. https://doi.org/10.1111/j.1467-8519.1994.tb00251.x

Clark, L., Jarvis, K., & Karovitch, A. (2018). *MAID: A team approach (panel).* The Canadian Association of MAID Assessors and Providers.

Clarke, S. (2015). Evaluating policy structures, processes, and outcomes. In R. Patton & M. Zalon (Eds.), *Nurses making policy: From bedside to boardroom* (pp. 433–468). Springer.

College of Registered Nurses of Alberta. (2022, October). *Registered nurse role in medical assistance in dying.* https://www.nurses.ab.ca/media/wmoep2mn/registered-nurse-role-in-medical-assistance-in-dying-practice-advice-2022.pdf

Collogan, L. K., Tuma, F. K., & Fleischman, A. R. (2004). Research with victims of disaster: Institutional review board considerations. *The Hastings Centre*, *26*(4), 9–11.

Courtney, K. L., Beuthin, R., & Bliss, G. (2022). Exploring population age as a utilization variable in medical assistance in dying in British Columbia, Canada. *International Journal of Nursing and Health Science*, *8*(3), 14–18. https://doi.org/10.14445/24547484/ijnhs-v8i3p103

Covenant Care. (2016). *Responding to requests for medical assistance in dying.* https://covenantcare.ca/wp-content/uploads/2016/05/responding-to-requests-for-medical-assistance-in-dying-may-24-2016.pdf

Covenant Health. (2018). *Responding to requests for medical assistance in dying* (Policy No. VII-B-440). https://www.covenanthealth.ca/media/124082/medical-assistance-in-dying-vii-b-440-december-3-2018-final.pdf

Covenant Health. (2019). *Called to serve strong partner: Adding value to Alberta's integrated health system*. https://www.covenanthealth.ca/media/124349/20190603-called_to_serve_.pdf

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). SAGE.

Creswell, J. W., & Poth, C. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). SAGE.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. SAGE.

Crumley, E. T., Kelly, S., Young, J., Phinney, N., McCarthy, J., & Gubitz, G. (2021). How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. *BMJ Open*, *11*(7). https://doi.org/10.1136/bmjopen-2021-048698

Crumley, E. T., LeBlanc, J., Henderson, B., Jackson-Tarlton, C. S., & Leck, E. (2023). Canadian family members' experiences with guilt, judgment and secrecy during medical assistance in dying: a qualitative descriptive study. *CMAJ Open*, *11*(4), E782–E789. https://doi.org/10.9778/cmajo.20220140

Davies, B., Chekryn Reimer, J., Brown, P., & Martens, N. (1995). *Fading away: The experience of transition in families with terminal illness*. Baywood.

Davis, A. J., Phillips, L., Drought, T. S., Sellin, S., Ronsman, K., & Hershberger, A. K. (1995). Nurses' attitudes toward active euthanasia. *Nursing Outlook*, *43*(4), 174–179. https://doi.org/10.1016/S0029-6554(05)80026-0

de Boer, M. E., Dröes, R., Jonker, C., Eefsting, J. A., & Hertogh, C. (2011). Advance directives for euthanasia in dementia: How do they affect resident care in Dutch nursing homes? Experiences of physicians and relatives. *Journal of the American Geriatrics Society*, *59*(6), 989–996. https://dx.doi.org/10.1111/j.1532-5415.2011.03414.x

De Bono, C. (2017, December). Faith-based care and medical assistance in dying. *Policy Options*. http://policyoptions.irpp.org/magazines/december-2017/faith-based-care-and-medical-assistance-in-dying/

Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Elwyn, G., Vissers, K. C., & Van Weel, C. (2013). Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliative Medicine*, *27*(1), 27–37. https://doi.org/10.1177/0269216312463259

Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., & van Weel, C. (2011). “Unbearable suffering”: A qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics*, *37*(12), 727–734. https://doi.org/10.1136/jme.2011.045492

Denier, Y., Gastmans, C., De Bal, N., & Dierckx De Casterlé, B. (2010). Communication in nursing care for patients requesting euthanasia: A qualitative study. *Journal of Clinical Nursing*, *19*(23–24), 3372–3380. https://doi.org/10.1111/j.1365-2702.2010.03367.x

DePasquale, N., Davis, K. D., Moen, P., Hammer, L. B., Polenick, C. A., & Almeida, D. M. (2015). The psychosocial implications of managing work and family caregiving roles: Gender differences among information technology professionals. *Journal of Family Issues*, *38*(11), 1495–1519. https://doi.org/10.1177/0192513x15584680

DeRosa, K. (2023, June 23). Woman with terminal cancer forced to transfer from St. Paul’s Hospital for assisted dying. *Vancouver Sun*. https://vancouversun.com/news/local-news/woman-with-terminal-cancer-forced-to-family-upset-by-st-pauls-hospital-maid-policy

Dierickx, S., Deliens, L., Cohen, J., & Chambaere, K. (2018). Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study. *Palliative Medicine*, *32*(1), 114–122. https://doi.org/10.1177/0269216317727158

Dionne-Odom, J. N., Willis, D. G., Bakitas, M., Crandall, B., & Grace, P. J. (2014). Conceptualizing surrogate decision making at end of life in the intensive care unit using cognitive task analysis. *Nursing Outlook*, *63*(3), 331–340. https://doi.org/10.1016/j.outlook.2014.10.004

Doane, G., & Varcoe, C. (2015). *How to nurse: Relational inquiry with individuals and families in changing health and health care contexts*. Lippincott Williams & Wilkins.

Dobscha, S. K., Heintz, R. T., Press, N., & Ganzini, L. (2004). Oregon physicians’ responses to requests for assisted suicide: A qualitative study. *Journal of Palliative Medicine*, *7*(3), 451–461. https://doi.org/10.1089/1096621041349374

Donnelly, S. [Sarah], Prizeman, G., Coimín, D. Ó., Korn, B., & Hynes, G. (2018). Voices that matter: End-of-life care in two acute hospitals from the perspective of bereaved relatives. *BMC Palliative Care*, *17*(117), 1–13. https://doi.org/10.1186/s12904-018-0365-6

Donnelly, S. [Sinead], & Battley, J. (2010). Relatives’ experience of the moment of death in a tertiary referral hospital. *Mortality*, *15*(1), 81–100. https://doi.org/10.1080/13576270903537641

Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher*, *13*(3), 7–21. https://dx.doi.org/10.7748/nr2006.04.13.3.7.c5975

Downar, J., & Francescutti, L. H. (2017). Medical assistance in dying: Time for physicians to step up to protect themselves and patients. *Canadian Medical Association Journal, 189*(25), E849–E850. https://doi.org/10.1503/cmaj.170462

Downar, J., MacDonald, S., & Buchman, S. (2023). Medical assistance in dying and palliative care: Shared trajectories. *Journal of Palliative Medicine*, *26*(7), 896–899. https://doi.org/10.1089/jpm.2023.0209

Downie, J. (2018, December 17). Opinion: Alarming gap in assisted dying in Antigonish. *The Chronicle Herald*. https://www.saltwire.com/nova-scotia/opinion/opinion-alarming-gap-in-assisted-dying-in-antigonish-268714/

Downie, J., & Chandler, J. A. (2018, March). *Interpreting Canada's medical assistance in dying legislation*. Institute for Research on Public Policy. https://irpp.org/wp-content/uploads/2018/03/Interpreting-Canadas-Medical-Assistance-in-Dying-Legislation-MAiD.pdf

Dunsford, J., & Wiebe, K. (2018). *MAID in Manitoba: Describing a team approach to the implementation of a new clinical service.* Canadian Association of MAID Assessors and Providers.

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2018). What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Medicine, 36*(5), 436–446. https://doi.org/10.1177/1049909118814240

Dying with Dignity Canada. (n.d.). *Navigating a request for medical assistance in dying*. https://www.dyingwithdignity.ca/end-of-life-support/navigating-a-request-for-medical-assistance-in-dying/

Elmir, R., Schmied, V., Jackson, D., & Wilkes, L. (2011). Interviewing people about potentially sensitive topics. *Nurse Researcher, 19*(1), 12–16. https://doi.org/10.7748/nr2011.10.19.1.12.c8766

Emanuel, E. J. (1994). Euthanasia: Historical, ethical and empiric perspectives. *Arch Intern Med.*, *154*(17), 1890–1901. https://doi.org/10.1001/archinte.1994.00420170022003

Emanuel, E. J., Fairclough, D., & Emanuel, L. (2000). Attitudes and desires related to euthanasia and physician- assisted suicide among terminally ill patients and their caregivers. *Journal of the American Medical Association*, *284,* 2460–2468.

Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *Journal of the American Medical Association, 316*(1), 79–90. https://doi.org/10.1001/jama.2016.8499

Engel, J. (2024). Practical nursing in Canada. In B. J. Astle, W. Duggleby, P. A. Potter, A. G. Perry, P. A. Stockert, & A. M. Hall (Eds.), *Canadian fundamentals of nursing* (7th ed., pp. 60–72). Elsevier.

Etkind, S. N., Bone, A. E., Lovell, N., Higginson, I. J., & Murtagh, F. E. M. (2018). Influences on care preferences of older people with advanced illness: A systematic review and thematic synthesis. *Journal of the American Geriatrics Society*, *66*(5), 1031–1039. https://doi.org/10.1111/jgs.15272

Etkind, S. N., Bone, A. E., Lovell, N., Higginson, I. J., & Murtagh, F. E. M. (2018). Influences on care preferences of older people with advanced illness: A systematic review and thematic synthesis. *Journal of the American Geriatrics Society*, *66*(5), 1031–1039. https://doi.org/10.1111/jgs.15272

Evans, W. G., Cutson, T. M., Steinhauser, K. E., & Tulsky, J. A. (2006). Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *Journal of Palliative Medicine, 9*(1), 100–110. https://doi.org/10.1089/jpm.2006.9.100

Feigin, S., Owens, R. G., & Goodyear-Smith, F. (2019). Helping a loved one die: The act of assisted dying in New Zealand. *Mortality, 24*(1), 95–110. https://doi.org/10.1080/13576275.2017.1382461

Feldstain, A., Bultz, B. D., Cooke, L., Wasylenko, E., & Wu, J. S. (2016). Medical assistance in dying. What to do? What to say? *Oncology Exchange*, *15*(4), 10–11.

Ferrell, B., Hanson, J., & Grant, M. (2013). An overview and evaluation of the oncology family caregiver project: Improving quality of life and quality of care for oncology family caregivers. *Psycho-Oncology*, *22*(7), 1645–1652. https://doi.org/10.1002/pon.3198

Flick, U. (2014). *An Introduction to Qualitative Research* (5th ed.). SAGE.

Forstmeier, S., & Maercker, A. (2007). Comparison of two diagnostic systems for complicated grief. *Journal of Affective Disorders*, *99*(1–3), 203–211. https://doi.org/10.1016/j.jad.2006.09.013

Forum Research. (2015, August 28). *Support for assisted suicide increases across four years.* http://poll.forumresearch.com/post/1365/opposition-down-sharply

Freeman, S., Banner, D., & Ward, V. (2021). Hospice care providers experiences of grappling with medical assistance in dying in a hospice setting: A qualitative descriptive study. *BMC Palliative Care*, *20*(1), 1–12. https://doi.org/10.1186/s12904-021-00740-3

Frolic, A. N., Miller, P., Harper, W., & Oliphant, A. (2022). MAiD to last: Creating a care ecology for sustainable medical assistance in dying services. *HEC Forum*, *34*(4), 409–428. https://doi.org/10.1007/s10730-022-09487-7

Frolic, A. N., Swinton, M., Murray, L., & Oliphant, A. (2020). Double-edged MAiD death family legacy: A qualitative descriptive study. *BMJ Supportive and Palliative Care*. Advance online publication. https://doi.org/10.1136/bmjspcare-2020-002648

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of medical assistance in dying: A scoping review of health care providers' perspectives. *Journal of Pain and Symptom Management, 55*(6), 1564–1576.e9. https://doi.org/10.1016/j.jpainsymman.2018.02.011

Funk, L. M., Mackenzie, C. S., Cherba, M., Del Rosario, N., Krawczyk, M., Rounce, A., Stajduhar, K., & Cohen, S. R. (2022). Where would Canadians prefer to die? Variation by situational severity, support for family obligations, and age in a national study. *BMC Palliative Care*, *21*(1), 1–12. https://doi.org/10.1186/s12904-022-01023-1

Funk, L. M., & Obedzinski, K. (2019, March 26). Caregiver Recognition Act falls through cracks. *The Winnipeg Free Press*. https://www.winnipegfreepress.com/opinion/analysis/caregiver-recognition-act-falls-through-cracks-507657372.html

Funk, L. M., Stajduhar, K., & Outcalt, L. (2015). What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets. *Palliative and Supportive Care*, *13*(03), 425–433. https://doi.org/10.1017/S1478951513001168

Gallagher, A., Gould, O., LeBlanc, M., Manuel, L., & Brideau-Laughlin, D. (2019). Knowledge and attitudes of hospital pharmacy staff in Canada regarding medical assistance in dying (MAiD). *The Canadian Journal of Hospital Pharmacy*, *72*(1), 16–26.

Gamondi, C., Fusi-Schmidhauser, T., Oriani, A., Payne, S., & Preston, N. (2019). Family members' experiences of assisted dying: A systematic literature review with thematic synthesis. *Palliative Medicine*, *33*(8), 1091–1105. https://doi.org/10.1177/0269216319857630

Gamondi, C., Pott, M., Forbes, K., & Payne, S. (2015). Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: A qualitative study. *BMJ Supportive and Palliative Care*, *5*(2), 146–152. https://doi.org/10.1136/bmjspcare-2013-000483

Gamondi, C., Pott, M., & Payne, S. (2013). Families' experiences with patients who died after assisted suicide: A retrospective interview study in Southern Switzerland. *Annals of Oncology*, *24*(6), 1639–1644. https://doi.org/10.1093/annonc/mdt033

Gamondi, C., Pott, M., Preston, N., & Payne, S. (2018). Family caregivers' reflections on experiences of assisted suicide in Switzerland: A qualitative interview study. *Journal of Pain and Symptom Management*, *55*(4), 1085–1094. https://doi.org/10.1016/j.jpainsymman.2017.12.482

Ganzini, L., Beer, T. M., & Brouns, M. C. (2006). Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management*, *32*(3), 230–236. https://doi.org/10.1016/j.jpainsymman.2006.04.004

Ganzini, L., Goy, E. R., & Dobscha, S. K. (2008). Why Oregon patients request assisted death: Family members' views. *Journal of General Internal Medicine*, *23*(2), 154–157. https://doi.org/10.1007/s11606-007-0476-x

Ganzini, L., Goy, E. R., Dobscha, S. K., & Prigerson, H. (2009). Mental health outcomes of family members of Oregonians who request physician aid in dying. *Journal of Pain and Symptom Management*, *38*(6), 807–815. https://doi.org/10.1016/j.jpainsymman.2009.04.026

Ganzini, L., Harvath, T. A., Jackson, A., Goy, E. R., Miller, L. L., & Delorit, M. A. (2002). Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. *The New England Journal of Medicine*, *347*(8), 582–588. https://doi.org/doi:10.1056/NEJMsa020562

Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W., & Lee, M. A. (1998). Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *New England Journal of Medicine*, *339*(14), 967–973. https://doi.org/10.1056/nejm199810013391406

Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2016). Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review. *Health and Social Care in the Community*, *24*(5), 519–531. https://doi.org/10.1111/hsc.12253

Genworth Financial. (2018). *How caregiving impacts families, communities and society*. https://mma.prnewswire.com/media/784202/Genworth_Beyond_Dollars_Study_2018_Executive_Summary.pdf

Gerson, S. M., Koksvik, G., Richards, N., Materstvedt, L. J., & Clark, D. (2020). The relationship of palliative care with assisted dying where assisted dying is lawful: A systematic scoping review of the literature. *Journal of Pain and Symptom Management*, *59*(6), 1287–1303. https://doi.org/https://doi.10.1016/j.jpainsymman.2019.12.361

Giesbrecht, M., Wolse, F., Crooks, V. A., & Stajduhar, K. (2013). Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study. *Palliative and Supportive Care, 13*(3), 555–565. https://doi.org/10.1017/S1478951513001028

Giesbrecht, M., Wolse, F., Crooks, V. A., & Stajduhar, K. (2015). Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study. *Palliative and Supportive Care, 13*(3), 555–565. https://doi.org/10.1017/S1478951513001028

Gilbert, D. (2020). Faith and/in medicine: Religious and conscientious objections to MAiD. *Dalhousie Law Journal, 43*(2), 657–695. https://digitalcommons.schulichlaw.dal.ca/cgi/viewcontent.cgi?article=2142&context=dlj

Given, B. A., & Reinhard, S. (2017). Caregiving at the end of life: The challenges for family caregivers. *Journal of the American Society on Aging, 41*(1), 50–57.

Goldberg, R., Nissim, R., An, E., & Hales, S. (2021). Impact of medical assistance in dying (MAiD) on family caregivers. *BMJ Supportive and Palliative Care, 11*, 107–114. https://doi.org/10.1136/bmjspcare-2018-001686

Government of British Columbia. (n.d.-a). *Medical assistance in dying*. https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying

Government of British Columbia. (n.d.-b). *Provincial Health Services Authority*. https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/provincial-health-services-authority

Government of British Columbia, Ministry of Health. (2023, September). *Medical assistance in dying: Request for medical assistance in dying* (No. 1632). https://www2.gov.bc.ca/assets/gov/health/forms/1632fil.pdf

Government of Canada. (2022, December 28). *Monitoring system for medical assistance in dying in Canada*. https://www.canada.ca/en/health-canada/services/publications/health-system-services/monitoring-system-medical-assistance-dying.html

Government of Canada. (2023a). *Canada's medical assistance in dying (MAID) law.* https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada. (2023b, June 30). *Medical assistance in dying*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Grant, K. (2018, January 5). Assisted dying in religious facilities means tough choices for families. *The Globe and Mail*. https://www.theglobeandmail.com/news/national/assisted-dying-in-religious-facilities-means-tough-choices-forfamilies/article37516504/

Grant, K. (2019, May 15). Ontario's top court rules religious doctors must offer patients an 'effective referral' for assisted dying, abortion. *The Globe and Mail.* https://www.theglobeandmail.com/canada/article-religious-doctors-must-make-referrals-for-assisted-dying-abortion/

Group opposes forced transfer of B.C. patients seeking medically-assisted deaths. (2022, March 7). *Global News*. https://globalnews.ca/news/8664275/group-opposes-forced-health-transfers-bc/

Hales, B. M., Ford, B., Bean, S., Isenberg-Grzeda, E., & Selby, D. (2019). Improving the medical assistance in dying (MAID) process: A qualitative study of family caregiver perspectives. *Palliative & Supportive Care*, *17*(5), 590–595. https://doi.org/10.1017/S147895151900004X

Hall, C. (2014). Bereavement theory: Recent developments in our understanding of grief and bereavement. *Bereavement Care*, *33*(1), 7–12. https://doi.org/10.1080/02682621.2014.902610

Hall, P. A. (1993). Policy paradigms, social learning, and the state: The case of economic policymaking in Britain. *Comparative Politics*, *25*(3), 275–296. https://doi.org/10.2307/422246

Harrison, R. (2018). An old story about this new place [Blog post]. *Dying with Dignity Canada.* http://www.dyingwithdignity.ca/richard_old_story

Harvath, T. A., Miller, L. L., Smith, K. A., Clark, L., Jackson, A., & Ganzini, L. (2006). Dilemmas encountered by hospice workers when patients wish to hasten death. *Journal of Hospice & Palliative Nursing*, *8*(4), 200–209. https://dx.doi.org/10.1097/00129191-200607000-00011

Hashemi, N., Amos, E., & Lokuge, B. (2021). The quality of bereavement for caregivers of patients who died by medical assistance in dying at home and the factors impacting their experience: A qualitative study. *Journal of Palliative Medicine*, *24*(9), 1351–1357. https://doi.org/10.1089/jpm.2020.0654

Health Canada. (2017a, October 6). *2nd interim report on medical assistance in dying in Canada*. https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-sep-2017.html

Health Canada. (2017b, April 26). *Guidelines for death certificates*. https://www.canada.ca/en/health-canada/services/publications/health-system-services/guidelines-death-certificates.html

Health Canada. (2018). *Third interim report on medical assistance in dying in Canada*. https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-june-2018/medical-assistance-dying-interim-report-june-2018-eng.pdf

Health Canada. (2019). *Fourth interim report on medical assistance in dying*. https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf

Health Canada. (2021, June). *Second annual report on medical assistance in dying*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2020/annual-report-2020-eng.pdf

Health Canada. (2022a, December 28). *Monitoring system for medical assistance in dying in Canada*. https://www.canada.ca/en/health-canada/services/publications/health-system-services/monitoring-system-medical-assistance-dying.html

Health Canada. (2022b, July). *Third annual report on medical assistance in dying in Canada, 2021*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2021/annual-report-2021.pdf

Health Canada. (2023, October). *Fourth annual report on medical assistance in dying in Canada, 2022*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2022/annual-report-2022.pdf

Heggerud, J., & Faulder, D. (2018). Medical assistance in dying in Alberta: Implementation of a provincial care coordination service for an unprecedented clinical activity. *Journal of the American Medical Directors Association, 19*(3), B19–B20. https://doi.org/10.1016/j.jamda.2017.12.062

Hentelef, Y. M., Shariff, M. J., & MacPherson, D. L. (2011). Palliative care: An enforceable Canadian human right? *McGill Journal of Law and Health*, *5*(1), 107–160.

Herx, L. (2015). Physician-assisted death is not palliative care. *Current Oncology*, *22*(2), 82–83. https://doi.org/10.3747/co.22.2631

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The seismic shift in end-of-life care: Palliative care challenges in the era of medical assistance in dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Holland, J. M., & Neimeyer, R. A. (2005). Reducing the risk of burnout in end-of-life care settings: The role of daily spiritual experiences and training. *Palliative & Supportive Care, 3*(3), 173–181. https://doi.org/10.1017/S1478951505050297

Holm, M., Henriksson, A., Carlander, I., Wengström, Y., & Öhlen, J. (2013). Preparing for family caregiving in specialized palliative home care: An ongoing process. *Palliative and Supportive Care*, *13*(3), 767–775. https://doi.org/10.1017/S1478951514000558

Holmes, S., Wiebe, E. R., Shaw, J., Nuhn, A., Just, A., & Kelly, M. (2018). Exploring the experience of supporting a loved one through a medically assisted death in Canada. *Canadian Family Physician*, *64*(9), e387–e393.

Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, *10*(2), 58–65. https://doi.org/10.12968/ijpn.2004.10.2.12454

Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine*, *14*(7), 864–869. https://doi.org/10.1089/jpm.2010.0413

Huizinga, G. A., Visser, A., Van Der Graaf, W. T. A., Hoekstra, H. J., Stewart, R. E., & Hoekstra-Weebers, J. E. H. M. (2011). Family-oriented multilevel study on the psychological functioning of adolescent children having a mother with cancer. *Psycho-Oncology*, *20*(7), 730–737. https://doi.org/10.1002/pon.1779

Hull, M. M. (1990). Sources of stress for hospice caregiving families. *Journal of Psychosocial Oncology*, *6*(2), 29–54. https://dx.doi.org/10.1080/0742-969x.1990.11882670

Hunstad, I., & Svindseth, M. F. (2014). Challenges in home-based palliative care in Norway: A qualitative study of spouses' experiences. *International Journal of Palliative Nursing*, *17*(7), 398–404. https://doi.org/10.12968/ijpn.2011.17.7.398

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, *19*(9), 1284–1292. https://doi.org/10.1177/1049732309344612

Hurst, S. A., & Mauron, A. (2003). Assisted suicide and euthanasia in Switzerland: Allowing a role for non-physicians. *BMJ*, *326*(7383), 271–273. https://doi.org/10.1136/bmj.326.7383.271

Implementation. (n.d.). In *Merriam-Webster.com dictionary*. https://www.merriam-webster.com/dictionary/implementation?utm_campaign=sd&utm_medium=serp&utm_source=jsonld

Ipsos. (2022, May 9). *2022 poll: Support for medically assisted dying in Canada*. https://www.dyingwithdignity.ca/wp-content/uploads/2022/05/DWDC_Ipsos_2022-Final-Report.pdf

Island Health. (n.d.). *Medical assistance in dying (MAiD)*. https://www.islandhealth.ca/learn-about-health/medical-assistance-dying/medical-assistance-dying

Island Health. (2019, April 23). *Medical assistance in death (MAiD): A guide to support patients & families*. https://www.islandhealth.ca/sites/default/files/MAiD/documents/maid-bereavement-guide-patients-families.pdf

Johnson, J. M., & Rowlands, T. (2012). The interpersonal dynamics of in-depth interviewing. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (2nd ed., pp. 99–113). SAGE.

Jones, A. M., & Cousins, B. (2020, January 20). Standoff between B.C. and hospice refusing to offer assisted dying. *CTV News*. https://www.ctvnews.ca/health/standoff-between-b-c-and-hospice-refusing-to-offer-assisted-dying-1.4773755

Kaasalainen, S., Brazil, K., Williams, A., Wilson, D., Willison, K., Marshall, D., & Taniguchi, A. (2012). Barriers and enablers to providing palliative care in rural communities: A nursing perspective. *Journal of Rural and Community Development*, *7*(4), 4–19.

Keyko, K. (2014). Work engagement in nursing practice. *Nursing Ethics*, *21*(8), 879–889. https://doi.org/10.1177/0969733014523167

Kidder, R. M. (2009). *How good people make touch choices: Resolving the dilemmas of ethical living*. Harper Collins Publishing.

Kimsma, G. K. (2010). Death by request in the Netherlands: Facts, the legal context and effects on physicians, patients and families. *Medicine, Health Care and Philosophy*, *13*(4), 355–361. https://doi.org/10.1007/s11019-010-9265-0

Kimsma, G. K., & van Leeuwen, E. (2007). The role of family in euthanasia decision making. *HEC Forum*, *19*(4), 365–373. https://dx.doi.org/10.1007/s10730-007-9048-z

Koenig Kellas, J., Castle, K. M., Johnson, A. Z., & Cohen, M. Z. (2021). Cancer as communal: Understanding communication and relationships from the perspectives of survivors, family caregivers, and health care providers. *Health Communication*, *36*(3), 280–292. https://doi.org/10.1080/10410236.2019.1683952

Kortes-Miller, K. (2018). *Talking about death won't kill you: The essential guide to end-of-life conversations*. ECW Press.

Kouwenhoven, P. S. C., van Thiel, G. J. M. W., van der Heide, A., Rietjens, J. A. C., & van Delden, J. J. M. (2018). Developments in euthanasia practice in the Netherlands: Balancing professional responsibility and the patient's autonomy. *European Journal of General Practice*, *25*(1), 44–48. https://doi.org/10.1080/13814788.2018.1517154

Krawczyk, M., Sawatzky, R., Schick-Makaroff, K., Stajduhar, K., Öhlen, J., Reimer-Kirkham, S., Mercedes Laforest, E., & Cohen, R. (2019). Micro-meso-macro practice tensions in using patient-reported outcome and experience measures in hospital palliative care. *Qualitative Health Research*, *29*(4), 510–521. https://doi.org/10.1177/1049732318761366

Kristjanson, L. J., & White, K. (2002). Clinical support for families in the palliative care phase of hematologic or oncologic illness. *Hematology/Oncology Clinics of North America*, *16*(3), 745–762. https://dx.doi.org/10.1016/S0889-8588(02)00023-0

Laperle, P., Achille, M., & Ummel, D. (2022). To lose a loved one by medical assistance in dying or by natural death with palliative care: A mixed methods comparison of grief experiences. *Omega – Journal of Death and Dying*. Advance online publication. https://doi.org/10.1177/00302228221085191

Leeder, J., & Grant, K. (2018). Assisted death, but not on her terms: Audrey Parker is bent on changing Canada's late-stage consent rule – if only posthumously. *The Globe and Mail*. https://www.theglobeandmail.com/canada/article-assisted-death-but-not-on-her-terms-audrey-parker-is-bent-on/

Lemiengre, J., Dierckx de Casterle, B., Schotsmans, P., & Gastmans, C. (2014). Written institutional ethics policies on euthanasia: An empirical-based organizational-ethical framework. *Medicine, Health Care and Philosophy*, *17*(2), 215–228. https://doi.org/10.1007/s11019-013-9524-y

Li, M., Shapiro, G. K., Klein, R., Barbeau, A., Rydall, A., Bell, J. A. H., Nissim, R., Hales, S., Zimmermann, C., Wong, R. K. S., & Rodin, G. (2021). Medical assistance in dying in patients with advanced cancer and their caregivers: A mixed methods longitudinal study protocol. *BMC Palliative Care*, *20*(117), 1–13. https://doi.org/10.1186/s12904-021-00793-4

Li, M., Watt, S., Escaf, M., Gardam, M., Heesters, A., O'Leary, G., & Rodin, G. (2017). Medical assistance in dying — implementing a hospital-based program in Canada. *New England Journal of Medicine*, *367*(21), 2082–2088. https://doi.org/10.1056/NEJMms1700606

Li, Q., & Loke, A. Y. (2014). A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: ‘Communication’, ‘reciprocal influence’, and ‘caregiver-patient congruence’. *European Journal of Oncology Nursing*, *18*(1), 58–65. https://doi.org/10.1016/j.ejon.2013.09.003

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4th ed., pp. 97–128). SAGE.

Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers’ experiences of their caring role in palliative home care. *Cancer Nursing*, *33*(1), 28–36. https://doi.org/10.1097/NCC.0b013e3181af4f61

Lofland, J., Snow, D., Anderson, L., & Lofland, L. (2006). *Analyzing social settings: A guide to qualitative observation and analysis* (4th ed.). Thomson, Wadsworth.

Lowers, J., Scardaville, M., Hughes, S., & Preston, N. J. (2020). Comparison of the experience of caregiving at end of life or in hastened death: A narrative synthesis review. *BMC Palliative Care*, *19,* Article 154. https://doi.org/10.1186/s12904-020-00660-8

Lundberg, T., Olsson, M., & Fürst, C. J. (2013). The perspectives of bereaved family members on their experiences of support in palliative care. *International Journal of Palliative Nursing*, *19*(6), 282–288. https://doi.org/10.12968/ijpn.2013.19.6.282

Machlin, L. (2009). *Working with loss and grief: A new model for practitioners*. SAGE.

Maddison, A. R., Asada, Y., & Urquhart, R. (2011). Inequity in access to cancer care: A review of the Canadian literature. *Cancer Causes and Control*, *22*(3), 359–366. https://doi.org/10.1007/s10552-010-9722-3

Maessen, M., Veldink, J. H., Onwuteaka-Philipsen, B. D., Hendricks, H. T., Schelhaas, H. J., Grupstra, H. F., van der Wal, G., & van den Berg, L. H. (2014). Euthanasia and physician-assisted suicide in amyotrophic lateral sclerosis: A prospective study. *Journal of Neurology, 261*(10), 1894–1901. https://doi.org/10.1007/s00415-014-7424-6

Markusa, M. (2017, October 30). Medically assisted dying: What happens when religious and individual rights conflict? *CBC News*. https://www.cbc.ca/news/canada/manitoba/medically-assisted-dying-allison-fenske-rights-1.4378241

Martin, T., Freeman, S., Lalani, N., & Banner, D. (2022). Qualities of the dying experience of persons who access medical assistance in dying: A scoping review. *Death Studies, 47*(9), 1033–1043. https://doi.org/10.1080/07481187.2022.2160033

Mauthner, N. S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology, 37*(3), 413–431. https://doi.org/10.1177/00380385030373002

Maxwell, J. A. (1992). Understanding and validity in qualitative research. *Harvard Educational Review, 62*(3), 279–300. https://doi.org/10.17763/haer.62.3.8323320856251826

McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science and Medicine, 70*(7), 1035–1041. https://doi.org/10.1016/j.socscimed.2009.11.029

McPhee, J. (2018, January 8). Antigonish’s Catholic hospital allowed to opt out of assisted dying policies. *Herald News*. http://thechronicleherald.ca/novascotia/1534933-antigonish’s-catholic-hospital-allowed-to-opt-out-of-assisted-dying-policies

Meiers, S. J., & Brauer, D. J. (2008). Existential caring in the family health experience: A proposed conceptualization. *Scandinavian Journal of Caring Sciences*, *22*(1), 110–117. https://doi.org/10.1111/j.1471-6712.2007.00586.x

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.

Mertz, E. (2018, November 5). Alberta needs legislation to ensure medically assisted death is accessed equally: Advocates. *Global News*. https://globalnews.ca/news/4632810/alberta-medical-assistance-dying-legislation-faith-covenant-health/

Midtbust, M. H., Alnes, R. E., Gjengedal, E., & Lykkeslet, E. (2021). Separation characterized by responsibility and guilt: Family caregivers’ experiences with palliative care for a close family member with severe dementia in long-term care facilities. *Dementia*, *20*(2), 518–533. https://doi.org/10.1177/1471301219898341

Milberg, A., & Strang, P. (2003). Meaningfulness in palliative home care: An interview study of dying cancer patients’ next of kin. *Palliative & Supportive Care*, *1*(2), 171–180. https://doi.org/10.1017/s1478951503030311

Milberg, A., & Strang, P. (2007). What to do when ‘there is nothing more to do’? A study within a salutogenic framework of family members’ experience of palliative home care staff. *Psycho-Oncology*, *16*(8), 741–751. https://doi.org/10.1002/pon.1124

Milberg, A., Strang, P., Carlsson, M., & Börjesson, S. (2003). Advanced palliative home care: Next-of-kin’s perspective. *Journal of Palliative Medicine*, *6*(5), 749–756. https://doi.org/10.1089/109662103322515257

Miller, F. A., & Alvarado, K. (2005). Incorporating documents into qualitative nursing research. *Journal of Nursing Scholarship*, *37*(4), 348–353. https://doi.org/10.1111/j.1547-5069.2005.00060.x

Miyasaki, J. (2021, June 14). Why is access to medically assisted death a legislated right, but access to palliative care isn't? *The Conversation.* https://theconversation.com/why-is-access-to-medically-assisted-death-a-legislated-right-but-access-to-palliative-care-isnt-161994

Morris, S. M., King, C., Turner, M., & Payne, S. (2015). Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative Medicine*, *29*(6), 487–495. https://doi.org/10.1177/0269216314565706

Morse, J. M. (1991). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 127–145). SAGE. https://doi.org/10.4135/9781483349015

Morse, J. M. (1994). "Emerging from the data": The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 23–45). SAGE.

Morse, J. M., & Field, A. (1995). *Qualitative research methods for health professionals*. SAGE.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, *1*(2), 13–22. https://doi.org/10.1177/160940690200100202

Multiple System Atrophy Coalition. (2020). *What is multiple system atrophy?* https://www.multiplesystematrophy.org/about-msa/

National Alliance for Caregiving. (2009). *The economic downturn and its impact on family caregiving*. https://www.caregiving.org/wp-content/uploads/2020/05/EVC_Caregivers_Economy_Report-FINAL_4-28-09.pdf

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review, 44*, 75–93. https://doi.org/10.1016/j.cpr.2016.01.002

Oczkowski, S. J. W., Ball, I., Saleh, C., Kalles, G., Chkaroubo, A., Kekewich, M., Miller, P, Dees, M., & Frolic, A. (2017). The provision of medical assistance in dying: Protocol for a scoping review. *BMJ Open*, *7*(8), 1–5. https://doi.org/10.1136/bmjopen-2017-017888

Oczkowski, S. J. W., Crawshaw, D., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P. Q., Kelly, M., Wiebe, E., Dees, M., & Frolic, A. (2020). How we can improve the quality of care for patients requesting medical assistance in dying: A qualitative study of health care providers. *Journal of Pain and Symptom Management, 61*(3), 513–521. https://doi.org/10.1016/j.jpainsymman.2020.08.018

Oczkowski, S. J. W., Crawshaw, D. E., Austin, P., Versluis, D., Kalles-Chan, G., Kekewich, M., Curran, D., Miller, P., Kelly, M., Weibe, E., & Frolic, A. (2021). How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliative Care, 20*, Article 185. https://doi.org/10.1186/s12904-021-00882-4

Ogilvie, K. K., & Oliphant, R. (2016). *Medical assistance in dying: A patient-centred approach*: *Report of the Special Joint Committee on Physician-Assisted Dying.* https://www.parl.ca/content/committee/421/pdam/reports/rp8120006/pdamrp01/pdamrp01-e.pdf

Oliphant, A., & Frolic, A. N. (2021). Becoming a medical assistance in dying (MAiD) provider: An exploration of the conditions that produce conscientious participation. *Journal of Medical Ethics*, *47*(1), 51–58. https://doi.org/10.1136/medethics-2019-105758

Patterson, S. (2023, June 26). Parents of Vancouver woman denied medically-assisted death at St. Paul's Hospital speak out. *CTV News*. https://bc.ctvnews.ca/parents-of-vancouver-woman-denied-medically-assisted-death-at-st-paul-s-hospital-speak-out-1.6457075

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). SAGE.

Pesut, B., & Johnson, J. (2008). Reinstating the 'Queen': Understanding philosophical inquiry in nursing. *Journal of Advanced Nursing*, *61*(1), 115–121. https://doi.org/10.1111/j.1365-2648.2007.04493.x

Pesut, B., Thorne, S., Barnwell, M., Burgess, M., Chambaere, K., Greig, M., Hall, M., Roussel, J., Schiller, C. J., Storch, J. Tishelman, C., & Wright, D. K. (n.d.). *MAID reflective guide*. https://www.maidreflectiveguide.ca/

Pesut, B., Thorne, S., & Greig, M. (2019). Shades of gray: Conscientious objection in medical assistance in dying. *Nursing Inquiry, 27*(1), e12308. https://doi.org/10.1111/nin.12308

Pesut, B., Thorne, S., Schiller, C. J., Greig, M., & Roussel, J. (2020). The rocks and hard places of MAiD: A qualitative study of nursing practice in the context of legislated assisted death. *BMC Nursing*, *19*(12), 1–14. https://doi.org/https://doi.org/10.1186/s12912-020-0404-5

Pesut, B., Thorne, S., Storch, J., Chambaere, K., Greig, M., & Burgess, M. (2020). Riding an elephant: A qualitative study of nurses' moral journeys in the context of Medical Assistance in Dying (MAiD). *Journal of Clinical Nursing*, *29*(19–20), 3870–3881. https://doi.org/10.1111/jocn.15427

Pesut, B., Thorne, S., Wright, D. K., Schiller, C., Huggins, M., Puurveen, G., & Chamberee, K. (2021). Navigating medical assistance in dying from Bill C-14 to Bill C-7: A qualitative study. *BMC Health Services Research*, *21*(1195), 1–16. https://dx.doi.org/10.1186/s12913-021-07222-5

Picard, A. (2015, August 25). Less than a third of doctors willing to aid in assisted dying: CMA poll. *The Globe and Mail*. https://www.theglobeandmail.com/news/national/less-than-a-third-of-doctors-willing-to-participate-in-assisted-dying-poll/article26100505/

Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, *52*(2), 137–145. https://doi.org/10.1037/0022-0167.52.2.137

Pronk, R., Willems, D. L., & van de Vathorst, S. (2021). What about us? Experiences of relatives regarding physician-assisted death for patients suffering from mental illness: A qualitative study. *Culture, Medicine, and Psychiatry, 47*, 237–251. https://doi.org/10.1007/s11013-021-09762-1

Proot, I. M., Abu-Saad, H. H., Crebolder, H. F. J. M., Goldsteen, M., Luker, K. A., & Widdershoven, G. A. M. (2003). Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian Journal of Caring Sciences*, *17*(2), 113–121. https://doi.org/10.1046/j.1471-6712.2003.00220.x

Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting family caregivers at the end of life: “They don’t know what they don’t know.” *Journal of the American Medical Association, 291*(4), 483–491. https://dx.doi.org/10.1001/jama.291.4.483

Rainsford, S., MacLeod, R. D., Glasgow, N. J., Phillips, C. B., Wiles, R. B., & Wilson, D. M. (2017). Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review. *Palliative Medicine*, *31*(10), 895–912. https://doi.org/10.1177/0269216316685234

Rainsford, S., MacLeod, R. D., Glasgow, N. J., Wilson, D. M., Phillips, C. B., & Wiles, R. B. (2018). Rural residents’ perspectives on the rural ‘good death’: A scoping review. *Health and Social Care in the Community*, *26*(3), 273–294. https://doi.org/10.1111/hsc.12385

Raisio, H., Vartiainen, P., & Jekunen, A. (2015). Defining a good death: A deliberative democratic view. *Journal of Palliative Care*, *31*(3), 158–165. https://doi.org/10.1177/082585971503100305

Raycraft, R. (2022, January 2). Years after medical assistance in dying became legal, the debate rages on. *CBC News*. https://www.cbc.ca/news/politics/maid-access-debate-contentious-1.6300345

Reid, R. C., Stajduhar, K. I., & Chappell, N. L. (2010). The impact of work interferences on family caregiver outcomes. *Journal of Applied Gerontology*, *29*(3), 267–289. https://doi.org/10.1177/0733464809339591

Reimer-Kirkham, S., Stajduhar, K., Pauly, B., Giesbrecht, M., Mollison, A., McNeil, R., & Wallace, B. (2016). Death is a social justice issue: Perspectives on equity-informed palliative care. *Advances in Nursing Science*, *39*(4), 293–307. https://doi.org/10.1097/ANS.0000000000000146

Rieger, S. (2018, June 2). Stigma, access still barriers to medically assisted death in Alberta 2 years after law passed, advocates say. *CBC News*. https://www.cbc.ca/news/canada/calgary/medically-assisted-death-alberta-1.4689599

Rivard, C., Wiebe, K., Trouton, K., de Wet, F., & Ashe, G. (2018). *X-country check-up: Issues and challenges* [Panel]. Presented at the 2nd Annual Medical Assistance in Dying Conference, Ottawa, Canada.

Robertson, W. D., & Beuthin, R. (2018). *A review of medical assistance in dying on Vancouver Island: The first two years, July 2016-July 2018*. https://www.islandhealth.ca/sites/default/files/2018-11/maid-report-2016-2018.pdf

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25–41. https://doi.org/10.1080/14780887.2013.801543

Rodney, P., Burgess, M., Phillips, J. C., McPherson, G., & Brown, H. (2013). Our theoretical landscape: A brief history of health care ethics. In Janet Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 59–83). Pearson-Prentice Hall.

Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: A systematic mixed studies review. *BMC Medical Ethics*, *20*(23), 1–21. https://doi.org/10.1186/s12910-019-0361-2

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist*, *55*(2), 309–319. https://doi.org/10.1093/geront/gnu177

Roulston, K. (2012). The pedagogy of interviewing. In J. F. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), *The SAGE Handbook of interview research: The complexity of the craft* (2nd ed., pp. 61–74). SAGE.

Rousseau, S., Turner, S., Chochinov, H. M., Enns, M. W., & Sareen, J. (2017). A national survey of Canadian psychiatrists' attitudes toward medical assistance in death. *Canadian Journal of Psychiatry*, *62*(11), 787–794. https://doi.org/10.1177/0706743717711174

Rurup, M. L., Smets, T., Cohen, J., Bilsen, J., Onwuteaka-Philipsen, B. D., & Deliens, L. (2012). The first five years of euthanasia legislation in Belgium and the Netherlands: Description and comparison of cases. *Palliative Medicine*, *26*(1), 43–49. https://doi.org/10.1177/0269216311413836

Russell, J. (2018a, October 25). Alberta doesn't track how many patients transferred for assisted-dying assessments. *CBC News*. https://www.cbc.ca/news/canada/edmonton/alberta-doesn-t-track-how-many-patients-transferred-for-assisted-dying-assessments-1.4877025

Russell, J. (2018b, October 24). Alberta government must quash Covenant Health assisted-dying policy, professor says. *CBC News*. *https*://www.cbc.ca/news/canada/edmonton/edmonton-alberta-covenant-health-medically-assisted-death-1.4875394

Russell, J. (2018c, November 5). Alberta legislation needed to address Covenant Health assisted-dying policy, says advocacy group Social Sharing. *CBC News*. https://www.cbc.ca/news/canada/edmonton/alberta-legislation-needed-to-address-covenant-health-assisted-dying-policy-says-advocacy-group-1.4892846

Russell, J. (2018d, November 2). Paralyzed, terminally ill man had to sign assisted-dying papers in bus shelter. *CBC News*. https://www.cbc.ca/news/canada/edmonton/convenant-health-assisted-dying-edmonton-1.4888114

Russell, J. (2018e, December 4). Camrose man died in pain after Covenant Health hindered access to assisted-dying services, son says. *CBC News*. https://www.cbc.ca/news/canada/edmonton/camrose-man-died-in-pain-after-covenant-health-hindered-access-to-assisted-dying-services-son-says-1.4927739

Salem, T. (1999). Physician-assisted suicide: Promoting autonomy or medicalizing suicide? *The Hastings Centre Report*, *29*(3), 30–36. https://doi.org/10.2307/3528193

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, *18*(2), 179–183. https://doi.org/10.1002/nur.4770180211

Schulman-Green, D., & Feder, S. (2018). Integrating family caregivers into palliative oncology care using the self- and family management approach. *Seminars in Oncology Nursing*, *34*(3), 252–263. https://doi.org/10.1016/j.soncn.2018.06.006

Schutt, K. C. H. (2020). *Exploring how family members experience medical assistance in dying* (*MAiD)* [Master's thesis, Trinity Western University]. https://core.ac.uk/download/pdf/322800357.pdf

Serota, K., Atkinson, M., & Buchman, D. Z. (2023). Unacknowledged pain and Ddsenfranchised grief: A narrative analysis of physical and emotional pain in complex MAiD Bereavement stories. *Canadian Journal of Pain*, *7*(2), 1–8. https://doi.org/10.1080/24740527.2023.2231046

Shapiro, C., & Dunsford, J. (2024). Legal implications in nursing practice. In B. J. Astle, W. Duggleby, P. A. Potter, A. G. Perry, P. A. Stockert, & A. M. Hall (Eds.), *Canadian fundamentals of nursing* (7th ed., pp. 121–133). Elsevier.

Shaw, J., Harper, L., Preston, E., Wright, A., Kelly, M., & Wiebe, E. (2019). Perceptions and experiences of medical assistance in dying among illicit substance users and people living in poverty. *Omega- Journal of Death and Dying*, *84*(1), 1–22. https://doi.org/10.1177/0030222819889827

Shaw, J., Wiebe, E. R., Nuhn, A., Holmes, S., Kelly, M., & Just, A. (2018). Providing medical assistance in dying: Practice perspectives. *Canadian Family Physician*, *64*(9), e394–e399.

Sibley, L. M., & Weiner, J. P. (2011). An evaluation of access to health care services along the rural-urban continuum in Canada. *BMC Health Services Research*, *11*(20), 1–11. https://doi.org/10.1186/1472-6963-11-20

Silva, N., Carona, C., Crespo, C., & Canavarro, M. C. (2015). Caregiving burden and uplifts: A contradiction or a protective partnership for the quality of life of parents and their children with asthma? *Journal of Family Psychology*, *29*(2), 151–161. https://doi.org/10.1037/fam0000071

Silvius, J. L., Memon, A., & Arain, M. (2019). Medical assistance in dying: Alberta approach and policy analysis. *Canadian Journal on Aging*, *38*(3), 397–406. https://doi.org/10.1017/S0714980819000175

Slade, G. (2020, October 10). Assisted dying hurdles unfair, doctor says. *The Medicine Hat News*. https://medicinehatnews.com/news/local-news/2020/10/10/assisted-dying-hurdles-unfair-doctor-says/?fbclid=IwAR2dWnrT5242LquYdsULFynutzUy6qxVR3hJtJr2xiaAeUHpxhkTE2ErT_U

Smolej, E., Malozewski, M., McKendry, S., Diab, K., Daubert, C., Farnum, A., Orianna, S., & Cameron, J. I. (2022). A qualitative study exploring family caregivers' support needs in the context of medical assistance in dying. *Palliative and Supportive Care, 21*(2), 254–260. https://doi.org/10.1017/s1478951522000116

Snijdewind, M. C., Van Tol, D. G., Onwuteaka-Philipsen, B. D., & Willems, D. L. (2014). Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives. *Journal of Pain and Symptom Management*, *48*(6), 1125–1134. https://doi.org/10.1016/j.jpainsymman.2014.04.016

Snijdewind, M. C., Willems, D. L., Deliens, L., Onwuteaka-Philipsen, B. D., & Chambaere, K. (2015). A study of the first year of the end-of-life clinic for physician-assisted dying in the Netherlands. *JAMA Internal Medicine*, *175*(10), 1633–1640. https://doi.org/10.1001/jamainternmed.2015.3978

Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, A., & Baker, F. (2008). Family caregivers and guilt in the context of cancer care. *Psychosomatics*, *49*(6), 511–519. https://doi.org/10.1176/appi.psy.49.6.511

Sque, M. (2000). Researching the bereaved: An investigator's experience. *Nursing Ethics*, *7*(1), 23–34. https://doi.org/10.1177/096973300000700105

Srinivasan, E. G. (2018). Grief and medical assistance in dying: Lessons learned from Oregon. *Journal of Pain and Symptom Management*, *56*(6), e30–e31. https://doi.org/10.1016/j.jpainsymman.2018.10.028

Srinivasan, E. G. (2019). Bereavement and the Oregon Death with Dignity Act: How does assisted death impact grief? *Death Studies*, *43*(10), 647–655. https://doi.org/10.1080/07481187.2018.1511636

Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*(1), 27–35. https://doi.org/10.1177/082585970301900105

Stajduhar, K. I. (2011). Chronic illness, palliative care, and the problematic nature of dying. *Canadian Journal of Nursing Research*, *43*(3), 7–15.

Stajduhar, K. I., & Davies B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine*, *19*(1), 21–32. https://dx.doi.org/10.1191/0269216305pm963oa

Stajduhar, K. I., & Dionne-Odom, J. N. (2019). Supporting families and family caregivers in palliative care. In Betty Ferrell & J. Paice (Eds.), *The Oxford textbook of palliative nursing* (5th ed., pp. 405–419). Oxford University Press.

Stajduhar, K. I., & Mollison, A. (2018). *Too little, too late: How we fail vulnerable Canadians as they die and what to do about it*. https://www.virtualhospice.ca/Assets/report-too-little-too-late_20210618100943.pdf

Stajduhar, K. I., Funk, L., & Outcalt, L. (2013). Family caregiver learning—how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets. *Palliative Medicine, 27*(7), 657–664. https://doi.org/10.1177/0269216313487765

Stajduhar, K. I., Funk, L., Toye, C., Grande, G., Aoun, S., & Todd, C. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998–2008). *Palliative Medicine*, *24*(6), 573–593. https://doi.org/10.1177/0269216310371412

Stajduhar, K. I., Nickel, D. D., Martin, W. L., & Funk, L. (2008). Situated/being situated: Client and co-worker roles of family caregivers in hospice palliative care. *Social Science and Medicine*, *67*(11), 1789–1797. https://doi.org/10.1016/j.socscimed.2008.09.012

Starks, H., Back, A. L., Pearlman, R. A., Koenig, B. A., Hsu, C., Gordon, J. R., & Bharucha, A. J. (2007). Family member involvement in hastened death. *Death Studies*, *31*(2), 105–130. https://doi.org/10.1080/07481180601100483

Starks, H., Pearlman, R. A., Hsu, C., Back, A. L., Gordon, J. R., & Bharucha, A. J. (2005). Why now? Timing and circumstances of hastened deaths. *Journal of Pain and Symptom Management*, *30*(3), 215–226. https://doi.org/10.1016/j.jpainsymman.2005.03.012

Statistics Canada. (2016). *Ethnic origin: Single or multiple response indicator*. https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TVD=257505&CVD=257505&CLV=0&MLV=1&D=1

Statistics Canada. (2018, March 29). *General social survey - Caregiving and care receiving (GSS)*. http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4502

Steele, R., & Davies, B. (2015). Supportive families in palliative care. In B. R. Ferrell, N. Coyle, & J. Paice (Eds.), *The Oxford textbook of palliative nursing* (4th ed., pp. 500–514). Oxford University Press. https://doi.org/10.1093/med/9780199332342.001.0001

Steinhauser, K. E., Christakis, N., Clipp, E. C., McIntyre, L., & Tulsky, J. (2000). End of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, *284*(19), 2476–2482. https://doi.org/10.1001/jama.284.19.2476

Stenberg, U., Ruland, C. M., Olsson, M., & Ekstedt, M. (2012). To live close to a person with cancer-Experiences of family caregivers. *Social Work in Health Care*, *51*(10), 909–926. https://doi.org/10.1080/00981389.2012.714847

Storch, J, Starzomski, R., & Rodney, P. (2013). Ethics and end-of-life decisions. In J. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 333–357). Pearson Canada.

Sumner, L. W. (2017). *Physician-assisted death: What everyone needs to know*. Oxford University Press.

Swain, G., Ward, G. K., & Hartlaub, P. P. (2005). Death certificates: Let's get it right. *American Family Physician*, *71*(4), 652–656.

Swarte, N. B., van der Lee, M. L., van der Bom, J. G., van den Bout, J., & Heintz, A. P. M. (2003). Effects of euthanasia on the bereaved family and friends: A cross sectional study. *BMJ*, *327*(7408), 189–193. https://doi.org/10.1136/bmj.327.7408.189

Taylor, S. (2018, November 15). People seeking medically assisted death can now call Sask.'s health line. *CBC News*. https://www.cbc.ca/news/canada/saskatchewan/saskatchewan-health-1.4905981

Taylor, S., & Bridges, A. (2018, October 5). Sask. ends practice of recording medically assisted deaths as suicides. *CBC News*. https://www.cbc.ca/news/canada/saskatchewan/maid-medically-assisted-deaths-suicide-saskatchewan-1.4851451

Tedder, T., Elliott, L., & Lewis, K. (2017). Analysis of common barriers to rural patients utilizing hospice and palliative care services: An integrated literature review. *Journal of the American Association of Nurse Practitioners*, *29*(6), 356–362. https://doi.org/10.1002/2327-6924.12475

Teno, J. M., Casey, V. A., Welch, L. C., & Edgman-Levitan, S. (2001). Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *Journal of Pain and Symptom Management*, *22*(3), 738–751. https://doi.org/10.1016/S0885-3924(01)00335-9

Teodoro, I. P. P., Rebouças, V. de C. F., Thorne, S. E., de Souza, N. K. M., & Alencar, A. M. P. G. (2018). Interpretive description: A viable methodological approach for nursing research. *Escola Anna Nery*, *22*(3), Article e20170287. https://doi.org/10.1590/2177-9465-ean-2017-0287

Thangarasa, T., Hales, S., Tong, E., An, E., Selby, D., Isenberg-Grzeda, E., Li, M., Rodin G., Bean, S., Bell, J. A. H., & Nissim, R. (2021). A race to the end: Family caregivers' experience of medical assistance in dying (MAiD)—a qualitative study. *Journal of General Internal Medicine, 37*, 809–815. https://doi.org/10.1007/s11606-021-07012-z

Thiele, T., & Dunsford, J. (2017). Nurse leaders' role in medical assistance in dying: A relational ethics approach. *Nursing Ethics*, *26*(4), 993–999. https://doi.org/10.1177/0969733017730684

Thorne, S. (2008a). Chronic disease management: What is the concept? *Canadian Journal of Nursing Research*, *40*(3), 7–14.

Thorne, S. (2008b). *Interpretive description*. Left Coast Press.

Thorne, S. (2009). The role of qualitative research within an evidence-based context: Can metasynthesis be the answer? *International Journal of Nursing Studies*, *46*(4), 569–575. https://doi.org/10.1016/j.ijnurstu.2008.05.001

Thorne, S. (2014). Applied interpretive approaches. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 99–114). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780199811755.013.002

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.

Thorne, S., & Sawatzky, R. (2014). Particularizing the general: Sustaining theoretical integrity in the context of an evidence-based practice agenda. *Advances in Nursing Science*, *37*(1), 5–18. https://doi.org/10.1097/ANS.0000000000000011

Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, *20*(2), 169–177. https://doi.org/10.1002/(sici)1098-240x(199704)20:2<169::aid-nur9>3.0.co;2-i

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, *3*(1), 1–11. https://doi.org/10.1177/160940690400300101

Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing's disciplinary epistemology. *Journal of Advanced Nursing*, *72*(2), 451–460. https://doi.org/10.1111/jan.12822

Torke, A. M., Sachs, G. A., Helft, P. R., Montz, K., Hui, S. L., Slaven, J. E., & Callahan, C. M. (2014). Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Internal Medicine, 174*(3), 370–377. https://dx.doi.org/10.1001/jamainternmed.2013.13315

Trouton, K., Beuthin, R., Thompson, M., Bruce, A., Lemire-Elmore, C., Zhang, A., & Daudt, H. (2020). Attitudes and expectations regarding bereavement support for patients, family members, and friends: Findings from a survey of MAID providers. *British Columbia Medical Journal*, *62*(1), 18–23.

Ullrich, A., Theochari, M., Bergelt, C., Marx, G., Woellert, K., Bokemeyer, C., & Oechsle, K. (2020). Ethical challenges in family caregivers of patients with advanced cancer — a qualitative study. *BMC Palliative Care*, *19*(1), 1–13. https://doi.org/10.1186/s12904-020-00573-6

Valentich, M. (2021). *Fighting for Hanne*. Austin Macauley.

Van Den Noortgate, N., & Van Humbeeck, L. (2020). Medical assistance in dying and older persons in Belgium: Trends, emerging issues and challenges. *Age and Ageing*, *50*(1), 68–71. https://doi.org/10.1093/ageing/afaa116

Vanden Berghe, P., Mullie, A., Desmet, M., & Huysmans, G. (2017). Assisted dying: The current situation in Flanders: Euthanasia embedded in palliative care. *Euthanasia and Assisted Suicide: Lessons from Belgium*, *20*(6), 67–85. https://doi.org/10.1017/9781108182799.005

Vanier Institute of the Family. (n.d.). *Definition of family*. https://vanierinstitute.ca/definition-family/

Variath, C., Peter, E., Cranley, L., Godkin, D., & Just, D. (2020). Relational influences on experiences with assisted dying: A scoping review. *Nursing Ethics*, *27*(7), 1501–1516. https://doi.org/10.1177/0969733020921493

Vikander, T. (2021). Patients to begin transferring from Delta hospice that refused to offer medical assistance in dying. *CTV News*. https://bc.ctvnews.ca/patients-to-begin-transferring-from-delta-hospice-that-refused-to-offer-medical-assistance-in-dying-1.5299303

Villeneuve, M. J. (2017). *Public policy and Canadian nursing: Lessons from the field*. Canadian Scholars' Press.

Villeneuve, M. J., Skelton-Green, J., & Shamian, J. (2019). Influencing policy and leading change: Essential steps in successful transformations. In C. McDonald & M. McIntyre (Eds.), *Realities of Canadian nursing: Professional, practice, and power issues* (5th ed.). Wolters Kluwer.

Wagner, B., Boucsein, V., & Maercker, A. (2011). The impact of forensic investigations following assisted suicide on posttraumatic stress disorder. *Swiss Medical Weekly, 141*(w13284), 1–6. https://doi.org/10.4414/smw.2011.13284

Wagner, B., Keller, V., Knaevelsrud, C., & Maercker, A. (2012). Social acknowledgement as a predictor of post-traumatic stress and complicated grief after witnessing assisted suicide. *International Journal of Social Psychiatry*, *58*(4), 381–385. https://doi.org/10.1177/0020764011400791

Wagner, B., Müller, J., & Maercker, A. (2012). Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide. *European Psychiatry*, *27*(7), 542–546. https://doi.org/10.1016/j.eurpsy.2010.12.003

Wellspring Cancer Support Alberta. (n.d.). *About us*. https://wellspringalberta.ca/about/

Whitfield, V., Havyatt, J., Buckley, T., Bartrop, R., McKinley, S., Roche, D., Spinaze, M., Bramwell, M., & Tofler, G. (2015). The complexities of recruiting bereaved family members into a research study in the critical care environment: A discussion paper. *Australian Critical Care*, *28*(2), 77–81. https://doi.org/10.1016/j.aucc.2014.11.002

Willick, F. (2018, December 28). Ban on assisted dying at St. Martha's hospital should end, says law prof. *CBC News*. https://www.cbc.ca/news/canada/nova-scotia/st-martha-s-hospital-assisted-dying-ban-1.4955584

Wilson, E., Caswell, G., Turner, N., & Pollock, K. (2018). Managing medicines for patients dying at home: A review of family caregivers' experiences. *Journal of Pain and Symptom Management*, *56*(6), 962–974. https://doi.org/10.1016/j.jpainsymman.2018.08.019

Wong, W. K. T., & Ussher, J. (2009). Bereaved informal cancer carers making sense of their palliative care experiences at home. *Health and Social Care in the Community*, *17*(3), 274–282. https://doi.org/10.1111/j.1365-2524.2008.00828.x

Woods, S. (2005). Respect for persons, autonomy and palliative care. *Medicine, Health Care and Philosophy*, *8*(2), 243–253. https://doi.org/10.1007/s11019-005-2506-y

World Health Organization. (2020, March 11). *WHO Director-General's opening remarks at the media briefing on COVID-19*. https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020

Wright, A. C., & Shaw, J. C. (2018). The spectrum of end of life care: An argument for access to medical assistance in dying for vulnerable populations. *Medicine, Health Care and Philosophy*, *Advanced, 22*, 211–219. https://doi.org/10.1007/s11019-018-9860-z

Wright, D., Brajtman, S., & Bitzas, V. (2009). Human relationships at the end of life: An ethical ontology for practice. *Journal of Hospice & Palliative Nursing*, *11*(4), 219–227. https://doi.org/0.1097/NJH.0b013e3181aada4c

Wright, D., Brajtman, S., & Macdonald, M. E. (2018). Relational ethics of delirium care: Findings from a hospice ethnography. *Nursing Inquiry*, *25*(3), 1–10. https://doi.org/10.1111/nin.12234

Wright, K., Chirchikova, M., Daniel, V., Bitzas, V., Elmore, J., & Fortin, M. (2017). Engaging with patients who desire death: Interpretation, presence, and constraint. *Canadian Oncology Nursing Journal*, *27*(1), 56–64. https://doi.org/10:5737/236880762715664

Wu, J. S., Pinilla, J., Watson, M., Verma, S., & Olivotto, I. A. (2018). Medical assistance in dying for cancer patients one year after legalization: A collaborative approach at a comprehensive cancer centre. *Current Oncology*, *25*(5), e486–e489. https://doi.org/10.3747/co.25.4118

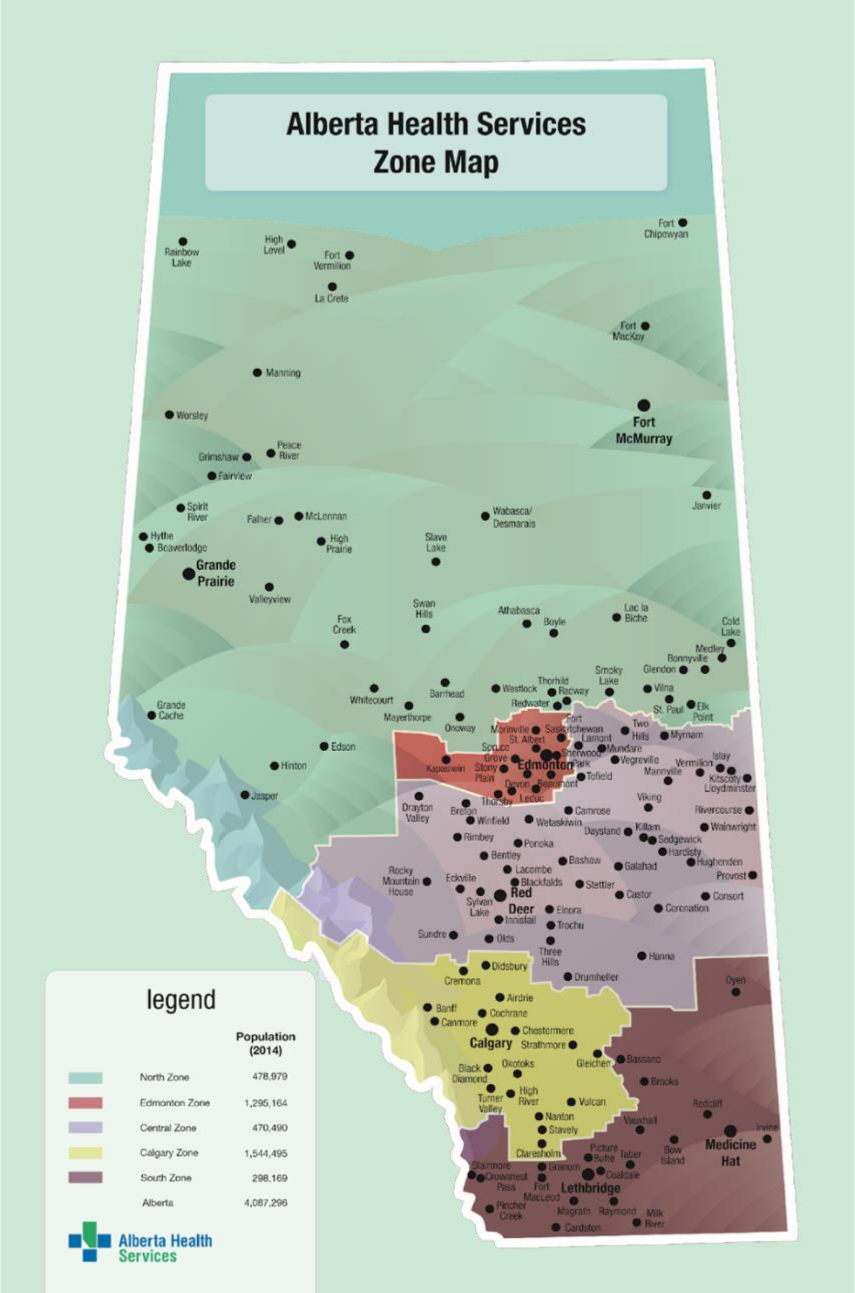
Yan, H., Bytautas, J., Isenberg, S. R., Kaplan, A., Hashemi, N., Kornberg, M., & Hendrickson, T. (2022). Grief and bereavement of family and friends around medical assistance in dying: Scoping review. *BMJ Supportive and Palliative Care*. Advance online publication. https://doi.org/10.1136/spcare-2022-003715

Yin, R. K. (2018). *Case study research and applications: Design and methods* (6th ed.). SAGE.

Yoon, K. H., Moon, Y. S., Lee, Y., Choi, S. H., Moon, S. Y., Seo, S. W., Park, K. W., Ku, B. D., Han, H. J., Park, K. H., Han, S.-H., Kim, E.-J., Lee, J.-H., Park, S. A., Shim, Y. S., Kim, J. H., Hong, C. H., Na, D. L., Ye, B. S., … CARE (Caregivers of Alzheimer’s Disease Research) Investigators. (2018). The moderating effect of religiosity on caregiving burden and depressive symptoms in caregivers of patients with dementia. *Aging and Mental Health*, *22*(1), 141–147. https://doi.org/10.1080/13607863.2016.1232366

Zamawe, F. C. (2015). The implication of using NVivo software in qualitative data analysis: Evidence-based reflections. *Malawi Medical Journal*, *27*(1), 13–15. https://doi.org/10.4314/mmj.v27i1.4

Appendix A: Alberta Health Services: Zone Map 2020–2021



Note. From AHS Map and Zone Overview, by Alberta Health Services, 2021 (https://www.albertahealthservices.ca/assets/about/publications/ahs-ar-2021/zones.html).

Appendix B: Alberta Health Services: MAID Policy

Alberta Health Services

TITLE: MEDICAL Assistance in Dying

SCOPE
Provincial

DOCUMENT # HCS-165-01

APPROVAL AUTHORITY
Clinical Operations Executive Committee

INITIAL EFFECTIVE DATE
February 6, 2016

SPONSOR
Seniors Health

REVISION EFFECTIVE DATE
March 26, 2021

PARENT DOCUMENT TITLE, TYPE, AND NUMBER Not applicable

SCHEDULED REVIEW DATE
March 26, 2024

NOTE: The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

If you have any questions or comments regarding the information in this document, please contact Policy Services at [email address]. The Policy Services website is the official source of current approved policies, procedures, directives, standards, protocols, and guidelines. Only the electronic version of this document, as hosted on the Policy Services website or www.ahs.ca, is valid.

OBJECTIVES

- To facilitate a consistent, compassionate, **patient**-centred approach when responding to an **adult** patient's request for **medical assistance in dying**.

PRINCIPLES

Patient autonomy: Patients with **capacity** will be able to make their own decisions about their own lives and bodies based on their own preferences, values, and beliefs.

Equitable access: Patients who make a request for medical assistance in dying, who meet the mandatory requirements and when all the safeguards have been addressed, should have timely and reasonable access to this service. Consistent with other Alberta Health Services (AHS) services and program areas, reasonable access means that medical assistance in dying services may not be available at all **AHS settings**.

Respect for moral conscience: **Health care providers** may follow their beliefs and values when deciding whether or not to participate in medical assistance in dying.

Respect and dignity: Patients and their **families** shall be cared for by health care providers with open-mindedness, respect, compassion, and a thoughtful regard for their dignity and unique lived experience, including cultural elements that are important to the patient.

Health care provider qualifications: Health care providers participating in medical assistance in dying must have the requisite knowledge, care and skill, and be acting within their scope of practice, supported by all applicable laws, practice standards, bylaws, AHS policies, and other applicable requirements.

Duty to provide care: Patients shall not be abandoned or denied appropriate health care because of their request for or participation in medical assistance in dying.

Criminal law application and protections: Changes to the *Criminal Code* (Canada) mean that Physicians or Nurse Practitioners may provide medical assistance in dying and allow other health care providers to assist Physicians or Nurse Practitioners in their provision of this service for patients. Physicians, Nurse Practitioners, and other health care providers may provide patients with information about the lawful delivery of medical assistance in dying. The law also extends to protect those who are acting on a reasonable but mistaken belief about a fact that is an element of the mandatory requirements or the required safeguards in this Policy.

Protection of vulnerable patients: Attention to the conditions and context generating vulnerability which might have an influence on a patient's request for medical assistance in dying must be part of AHS' comprehensive and ongoing multi-disciplinary patient care. AHS' multi-disciplinary patient care teams must be committed to protecting vulnerable patients from discrimination, coercion, exploitation, and undue influence.

APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, students, volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

ELEMENTS

1. Points of Emphasis

1.1 This Policy addresses the following activities associated with medical assistance in dying:

. responding to inquiries;

a. assessing whether a patient meets the mandatory requirements while ensuring that safeguards are observed, and the provision of medical assistance in dying by the administering by the **most responsible health practitioner** (for the purpose of this Policy, the most responsible health practitioner is a Physician or Nurse Practitioner) of a substance to a patient, at that patient's request, that causes that patient's death;

b. reporting requirements after the patient's death.

0. AHS respects a patient’s right to make informed health care decisions, including the right to consent to or decline specific health care interventions. <u>Only adult</u> <u>patients</u> who have the capacity to provide **informed consent** may be eligible for medical assistance in dying.

0. AHS shall support patients and families by providing clear and accurate information about medical assistance in dying.

0. AHS shall respect individual health care providers’ rights to decline participation in medical assistance in dying, while ensuring that patients’ care needs are met.

2. Patient Eligibility of Medical Assistance in Dying: Mandatory Requirements

2.1 Only adult patients that meet the following mandatory requirements, as determined by two (2) independent Physicians or Nurse Practitioners (refer to Section 3 below), are eligible for medical assistance in dying.

. The patient is eligible for health services funded by a federal, provincial, or territorial government in Canada (existing waiting periods or minimum residency requirements do not apply).

a. The patient has a grievous and irremediable medical condition. This means all of the following criteria are met:

.the patient has a serious and incurable illness, disease, or disability;

i.the patient is in an advanced state of irreversible decline in capability;

ii.that illness, disease, disability, or state of decline causes the patient enduring physical or psychological suffering that:

- is intolerable to the patient; and
- cannot be relieved under conditions or with treatment that the patient considers acceptable;

Note: For the purposes of Section 2.1(b) above, a mental illness is not considered to be an illness, disease, or disability.

iv. except as outlined by Section 6 below, their natural death has become reasonably foreseeable, taking into account all of their medical circumstances. A specific prognosis as to the specific length of time remaining is not required.

c. The patient has made a request for medical assistance in dying on the prescribed *Record of Request for Medical Assistance in Dying* Form (Alberta). This request must be voluntary.

.If the patient requesting medical assistance in dying is unable to physically sign and date the request for medical assistance in dying on the prescribed *Record of Request for Medical Assistance in Dying* Form (Alberta), another person – who is at least 18 years of age, who understands the nature of the request for medical assistance in dying, and who does not know or believe that they are a beneficiary under the will of the patient making the request or a recipient, in any way, of a financial or other material benefit

resulting from that patient's death – may do so in the person's presence, on the person's behalf, and under the person's express direction.

d. The patient has the capacity to provide informed consent for medical assistance in dying, in accordance with the AHS *Consent to Treatment/Procedure*(*s)* Policy Suite.

> **Note:** An **alternate decision-maker** cannot make a request for, or consent to, medical assistance in dying on behalf of a patient who lacks capacity.

e. The patient has given **express informed consent** for the delivery of medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care. The patient's express informed consent shall be obtained in writing on the AHS *Consent to Treatment Plan or Procedure* Form unless use of this form is impracticable or unreasonable.

.If the patient is physically unable to provide express informed consent in writing:

- a blind or disabled patient's mark is recognized as a valid signature on the consent form; or
- verbal or other express (e.g., blinking, grunting) informed consent is acceptable with a minimum, one (1) witness, and this consent shall be documented on the AHS *Consent to Treatment Plan or Procedure* Form along with why the patient was physically unable to sign.

i.This informed consent is separate and in advance of the informed consent required immediately prior to the provision of medical assistance in dying as per Section 5.1(h) below and subject to Sections 5.2 or 6.1(k) below.

3. Determining Independence of a Physician or Nurse Practitioner

3.1 The Physician or Nurse Practitioner who provides the medical assistance in dying, and the Physician or Nurse Practitioner who provides the opinion referred to in Sections 5.1I or 6.1I below, are independent if they:

. are not in a mentorship or supervisory relationship with each other;

a. do not know or believe that they are a beneficiary under the will of the patient making the request or a recipient, in any other way, of a financial or other material benefit resulting from that patient's death, other than standard compensation for their services relating to the request; and

b. do not know or believe that they are connected to the other Physician or Nurse Practitioner or to the patient making the request in any other way that would affect their objectivity.

4. Determining Independence of a Witness

4.1 An independent witness must be an adult who understands the nature of the request for medical assistance in dying. The witness must not act as a witness if they:

. know or believe that they are a beneficiary under the will of the patient making the request or a recipient, in any other way, of a financial or other material benefit resulting from that patient's death;

a. are an owner or operator of any health care facility at which the patient making the request is being treated or any facility in which that patient resides;

b. are directly involved in providing health care services to the patient making the request; or

c. directly provide personal care to the patient making the request.

4.2 Despite Sections 4.1I and 4.1(d) above, a person who provides health care services or personal care as their primary occupation and who is paid to provide that care to the person requesting medical assistance in dying, is permitted to act as an independent witness, except for:

. the Physician or Nurse Practitioner who will provide medical assistance in dying to the person; and

a. the Physician or Nurse Practitioner who provides an opinion in Sections 5.1I or 6.1I below, as the case may be, in respect of the patient.

5. Safeguards for Natural Death that is <u>Reasonably Foreseeable</u>

5.1 Before a Physician or Nurse Practitioner provides medical assistance in dying to a patient whose natural death is <u>reasonably foreseeable</u>, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining, the Physician or Nurse Practitioner must:

. be of the opinion that the patient meets all of the mandatory requirements as per Section 2 above;

a. ensure the request for medical assistance in dying is in writing, dated, and signed by the patient after the patient was informed by a Physician or Nurse Practitioner that the patient has a grievous and irremediable medical condition;

b. be satisfied the request in Section 5.1(b) above is signed (subject to Sections 2.1(c) and 2.1(c)(i) above) before an independent witness (refer to Section 4 above) who then also signs and dates the request;

c. ensure the patient was advised that they may withdraw their request at any time and in any manner;

d. ensure that a second assessing Physician or Nurse Practitioner has provided a written opinion confirming that the patient meets all of the mandatory requirements (see Section 2 above);

e. be satisfied that they and the second assessing Physician or Nurse Practitioner referred to in Section 5.1I above are independent (see Section 3 above);

g. if the patient has difficulty communicating, take all necessary measures to provide a reliable means by which the patient may understand the information that is provided to them and communicate their decision; and

. subject to Section 5.2 below, immediately before medical assistance in dying is provided, give the patient an opportunity to withdraw their request and ensure that the patient gives express informed consent to receive medical assistance in dying. The Physician or Nurse Practitioner shall obtain the patient's express informed consent for medical assistance in dying. The Physician or Nurse Practitioner shall document express informed consent by:

.having the patient re-sign the original AHS *Consent to Treatment Plan or Procedure* Form (dated again, with one [1] witness), understanding that a blind or disabled patient's mark is recognized as a valid signature;

i.having the patient sign a new AHS *Consent to Treatment Plan or Procedure* Form (dated, with one [1] witness), understanding that a blind or disabled patient's mark is recognized as a valid signature; or

ii.documenting the patient's express verbal or other express (e.g., blinking, grunting) informed consent in front of at minimum, one (1) witness (refer to Section 4 above), with documentation that specifies the witness name(s) and date on the patient's **health record**.

5.2 The Physician or Nurse Practitioner may administer a substance to a patient whose death is reasonably foreseeable to cause their death without meeting the requirement set out in Section 5.1(h) above if:

. before the person loses the capacity to consent to receiving medical assistance in dying:

.the patient meets all of the mandatory requirements set out in Section 2 above and all other safeguards set out in Section 5.1 above are met;

i.the patient enters into an agreement in writing with the Physician or Nurse Practitioner that the Physician or Nurse Practitioner would administer a substance to cause their death on a specified day;

ii.the patient is informed by the Physician or Nurse Practitioner of the risk of losing the capacity to consent to receiving medical assistance in dying prior to the day specified in the agreement; and

iii.in the written agreement, the patient consented to the administration by the Physician or Nurse Practitioner of a substance to cause their death on or before the day specified in the agreement if they lost their capacity to consent to receiving medical assistance in dying prior to that day;

a. the patient has lost the capacity to consent to receiving medical assistance in dying;

b. the substance is administered to the patient in accordance with the terms of the agreement; and

c. the patient does not demonstrate, by words, sounds, or gestures, refusal to have the substance administered or resistance to its administration.

.For greater certainty, involuntary words, sounds, or gestures made <u>in response to contact</u> do not constitute a demonstration of refusal or resistance for the purposes of Section 5.1(d) above.

i.Once a patient demonstrates, by words, sounds, or gestures, refusal to have the substance administered or resistance to its administration, medical assistance in dying can no longer be provided to the patient on the basis of the consent given by them under Section 5.2(a)(iv) above.

6. Safeguards for Natural Death that is <u>Not Reasonably Foreseeable</u>

6.1 Before a Physician or Nurse Practitioner provides medical assistance in dying to a patient whose natural death is <u>not reasonably foreseeable</u>, taking into account all of their medical circumstances, the Physician or Nurse Practitioner must:

. be of the opinion that the patient meets all of the mandatory requirements set out in Section 2 above;

a. ensure that the patient's request for medical assistance in dying was:

.made in writing on the *Record of Request for Medical Assistance in Dying* Form (Alberta) and signed and dated by the patient (or in accordance with Sections 2.1I and 2.1I(i) above); and

i.signed and dated after the patient was informed by a Physician or Nurse Practitioner that the patient has a grievous and irremediable medical condition;

c. be satisfied that the request was signed and dated by the patient (or in accordance with Sections 2.1I and 2.1I(i) above) before an independent witness (see Section 4 above) who then also signed and dated the request;

. ensure that the patient has been informed that the person may, at any time and in any manner, withdraw their request;

. ensure that a written opinion from another independent Physician or Nurse Practitioner (as per Section 3 above) confirming that the patient meets all of the mandatory requirements set out in Section 2 above has been provided;

> **Note:** If neither Physician or Nurse Practitioner has expertise in the condition that is causing the patient's suffering, then one of the two (2) assessing Physicians or Nurse Practitioners shall consult with another Physician or Nurse Practitioner with that expertise and share the results of that consultation.

f. be satisfied that they and the Physician or Nurse Practitioner in Section 6.1I above are independent (refer to Section 3 above);

. ensure that the patient has been informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services, and palliative care, and has been offered consultations with relevant professionals who provide those services or that care;

. ensure that they and the Physician or Nurse Practitioner referred to in Section 6.1I above have discussed with the patient the reasonable and available means to relieve the patient's suffering and they and the Physician or Nurse Practitioner referred to in Section 6.1I above agree with the patient that the patient has given serious consideration to those means;

. ensure that there are at least 90 clear days between the day on which the first assessment of whether the patient meets the mandatory requirements set out in Section 2 above begins and the day on which medical assistance in dying is provided to them or — if the assessments have been completed and they and the Physician or Nurse Practitioner referred to in Section 6.1I above are both of the opinion that the loss of

the patient's capacity to provide consent to receive medical assistance in dying is imminent — any shorter period that the first assessing Physician or Nurse Practitioner considers appropriate in the circumstances;

j. if the patient has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision; and

. immediately before providing the medical assistance in dying, give the patient an opportunity to withdraw their request and ensure that the patient gives express informed consent to receive medical assistance in dying.

7. Alberta Health Services' Responsibilities in Medical Assistance in Dying

7.1 AHS has a responsibility to assist Albertans with reasonable access to medical assistance in dying, in safe and clinically appropriate AHS settings, which means environments where health services are delivered by, on behalf of, or in conjunction with AHS, including the patient's home.

7.2 AHS shall:

. provide comprehensive multi-disciplinary care including non-Physician health care providers working within their scope of practice, to patients and families when the patient is exploring end-of-life decisions;

a. provide non-judgmental, comprehensive care without bias;

b. provide timely and reasonable access to information about palliative and all end-of-life care options, including bereavement care;

c. honour health care providers' decisions regarding their participation in the provision of medical assistance in dying;

d. take reasonable steps to facilitate self-referrals, referrals of patients from Physicians or Nurse Practitioners who decline to participate in medical assistance in dying, and referrals from AHS-contracted service providers for those patients intending to access medical assistance in dying;

e. ensure patients may access medical assistance in dying in a timely and coordinated fashion;

f. accommodate requests for timely patient transfers from health care settings opting not to deliver medical assistance in dying to an appropriate AHS setting or other non-objecting setting;

g. ensure access to consultation services, including but not limited to, Clinical Ethics, legal services for staff, Spiritual Care, Social Work, and Addiction and Mental Health services, as needed;

i. ensure that if **concerns** about a patient's health care experience arise, the patient concerns resolution process shall be available in accordance with the AHS *Patient Concerns Resolution Process* Policy Suite; and

. enable the reporting of information related to medical assistance in dying as required by the Office of the Chief Medical Examiner and/or the Medical Assistance in Dying Regulatory Review Committee.

7.3 AHS' Medical Assistance in Dying Care Coordination Service shall offer:

. support to patients and families by providing information and access to education and supports, and linkages to all end-of-life care options including medical assistance in dying, and grief and bereavement services; and

a. support to both AHS and non-AHS Physicians, Nurse Practitioners, and interdisciplinary health care team members in the coordination of care and services related to medical assistance in dying and all end-of-life care options, and provide linkages to education, resource materials, specialty consultation services, and grief and bereavement services.

7.4 AHS' procedures and processes shall support the Physicians' and Nurse Practitioners' ability to:

. support patients;

a. assess mandatory requirements and ensure safeguards are met;

b. prescribe and/or administer the drugs recommended for use that intentionally bring about a patient's death by established drug lists and protocols developed and maintained in consultation with the Alberta College of Pharmacy;

c. comply with documentation requirements; and

d. comply with any legal and AHS reporting requirements.

7.5 AHS shall ensure that the care provided to the patient and family after death is provided in accordance with established organizational policies and processes.

8. Health Care Providers' Responsibilities in Medical Assistance in Dying

8.1 Prior to participation in any aspect of care related to medical assistance in dying, health care providers should inform themselves of the direction being provided by their respective regulatory bodies and must comply with that direction.

8.2 Health care providers should also inform themselves with information, support, and guidance provided by the Medical Assistance in Dying Care Coordination Service, referral services, and the patient self-referral process.

8.3 Health care providers who are not Physicians or Nurse Practitioners shall respond to medical assistance in dying inquiries in a timely and non-judgmental, comprehensive manner without bias and shall notify a patient's most responsible health practitioner.

. If the patient does not have a most responsible health care practitioner or if the patient does not wish for their most responsible health practitioner to learn of the request, then the health care provider shall notify the relevant Manager and the Medical Assistance in Dying Care Coordination Service in a timely manner.

a. Health care providers may share information about medical assistance in dying with patients.

8.4 Health care providers electing not to participate in medical assistance in dying for appropriate reasons, including reasons of conscience, are not required to participate.

. The health care provider shall inform their Manager if they are unwilling or unable to support the provision of either the patient’s usual care or care specific to medical assistance in dying.

a. The Manager shall ensure another appropriate health care provider who is willing and able, assumes the objecting health care provider’s role.

0. An AHS Pharmacist may only dispense drugs for medical assistance in dying consistent with the list of drugs developed and maintained with the assistance of the Alberta College of Pharmacy and supported by any applicable practice standards or other governing documents, and must comply with any legal, regulatory body, and mandatory reporting obligations.

0. Health care providers shall ensure documentation in the patient’s health record is in accordance with AHS policies and legislative requirements.

9. Physicians’ and Nurse Practitioners’ Responsibilities in Medical Assistance in Dying

9.1 Only appropriately qualified Physicians and Nurse Practitioners may determine requirements for and provide medical assistance in dying. Physicians providing assessments or provisions within AHS settings require privileges to do so. Nurse Practitioners are required to maintain their own competency as set out by regulatory bodies and AHS.

9.2 Prior to assessing a patient for medical assistance in dying, the Physicians and Nurse Practitioners involved should review and follow advice documents and Standards of Practice set out by their respective regulatory bodies regarding their participation in aspects of care related to medical assistance in dying and may consult with their insurers / protective associations.

9.3 Upon receiving the formal request for medical assistance in dying, the Physician and/or Nurse Practitioner involved shall advise the Medical Assistance in Dying Care Coordination Service of the request.

9.4 Physicians or Nurse Practitioners who elect not to participate in medical assistance in dying for appropriate reasons, including reasons of conscience, are not required to participate.

. Physicians or Nurse Practitioners who elect not to participate in medical assistance in dying, and have a patient who has requested medical assistance in dying, shall provide the patient’s information to the Medical Assistance in Dying Care Coordination Service. The Medical Assistance in Dying Care Coordination Service shall provide the patient with information and resources to facilitate access to a Physician or Nurse Practitioner who is willing to provide medical assistance in dying services.

b. Physicians or Nurse Practitioners shall continue to provide required health care to the patient until that Physician's or Nurse Practitioner's services are no longer required or wanted by the patient or until another Physician or Nurse Practitioner has assumed responsibility for the patient.

9.5 Under no circumstances shall the responsibility for providing medical assistance in dying be delegated or transferred from one Physician or Nurse Practitioner to another Physician or Nurse Practitioner who:

. has not independently verified the patient's mandatory requirements and express informed consent for medical assistance in dying; or

a. is receiving supervision or mentorship (e.g., trainee) from any Physician or Nurse Practitioner.

0. With the patient's express informed consent, the provision of medical assistance in dying may be observed for learning purposes.

0. Only Physicians and Nurse Practitioners shall prescribe the drugs for medical assistance in dying. The most responsible health practitioner shall inform the Pharmacist involved when a prescription is being prescribed or obtained for the purpose of delivering medical assistance in dying.

0. The most responsible health practitioner shall obtain express informed written (signed) consent for a treatment plan developed together with a patient.

a) The treatment plan shall include administration of the drugs by the most responsible health practitioner.

9.9 The most responsible health practitioner shall review, affirm, and/or determine that the patient's **advance care planning** and **goals of care designation** have occurred as per the AHS *Advance Care Planning and Goals of Care Designation* Policy Suite.

9.10 Physicians and Nurse Practitioners shall ensure documentation in the patient's health record is in accordance with AHS policies and legislative requirements. This documentation shall include, but is not limited to, capacity assessment, mandatory requirements, goals of care designation, completed consent forms, and record of medication administration.

9.11 Physicians and Nurse Practitioners shall comply with any legal, federal or provincial government, regulatory body, and mandatory medical assistance in dying reporting requirements.

DEFINITIONS

Adult, for the purposes of this Policy, means a person aged 18 years and older and excludes mature minors.

Advance care planning, for the purposes of this Policy, means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their agent/alternate decision-maker and their health care team; and record those choices.

Alberta Health Services (AHS) setting means any environment where treatment/procedures and other health services are delivered by, on behalf of or in conjunction with, Alberta Health Services.

Alternate decision-maker means a person who is authorized to make decisions with or on behalf of the patient. These may include, specific decision-maker, a minor's legal representative, a guardian, a 'nearest relative' in accordance with the *Mental Health Act* (Alberta), an agent in accordance with a Personal Directive, or a person designated in accordance with the *Human Tissue and Organ Donation Act* (Alberta). This also includes what was previously known as the substitute decision-maker.

Capacity means the ability for the patient to (1) understand the nature, risks, and benefits of the procedure and the consequences of consenting or refusing and (2) understand that this explanation applies to them.

Concern means a written or verbal expression of dissatisfaction that may be related to:
- the provision of goods and services to a patient;
- a failure or refusal to provide goods and services to a patient; or
- terms and conditions under which goods and services are provided to a patient, by Alberta Health Services or by a service provider under the direction, control, or authority of Alberta Health Services.

It may also include dissatisfaction with professional practice and/or an allegation of unprofessional conduct. The concern may be clinical or non-clinical and may be directed at any member of the organization or the organization as a whole. The concern may also include the dissatisfaction with an Alberta Health Services owned or operated facility.

Express informed consent, for the purposes of this Policy, means direct, explicit agreement to undergo a treatment/procedure(s), given either verbally or non-verbally (e.g., blinking, grunting), or in writing (information on Consent can be found on the AHS external website by searching 'Consent to Treatment/Procedure').

Family(-ies) means one or more individuals identified by the patient as an important support, and who the patient wishes to be included in any encounters with the health care system, including, but not limited to, family members, legal guardians, friends and informal caregivers.

Goals of care designation means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decisionmaker.

Health care provider means a person who provides goods or services to a patient, inclusive of health care professionals, staff, students, volunteers and other persons acting on behalf of or in conjunction with Alberta Health Services.

Health record means the collection of all records documenting individually identifying health information in relation to a single person.

Informed consent, for the purposes of the Policy, means the patient's agreement to undergo a treatment/procedure after being provided, in a manner the patient can understand, with the relevant information about the treatment/procedure(s), its risks and alternatives, and the consequences.

Medical assistance in dying means the administering by a Physician or Nurse Practitioner of a substance to a patient, at their request, that causes their death.

Most responsible health practitioner means the health practitioner who has the responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s) within the scope of their practice. For the purpose of this Policy, this may only be either a Physician or Nurse Practitioner.

Patient means, for the purposes of this Policy, an adult who receives or has requested health care or services from Alberta Health Services and its health care providers or individuals authorized to act on behalf of Alberta Health Services. This term is inclusive of residents, clients, and outpatients.

REFERENCES

- Alberta Health Services Governance Documents: o *Advance Care Planning and Goals of Care Designation* Policy Suite (#HCS-38) o *Consent to Treatment/Procedure*(*s)* Policy Suite (#PRR-01) o *Patient Concerns Resolution Process* Policy Suite (#PRR-02)
- Alberta Health Services Forms: o *Combined Assessment/Providing Practitioner Record for Medical Assistance in Dying*

  Form (#21566) o *Consent to Treatment Plan or Procedure* Form (#09741)
- *Providing Practitioner Record for Medical Assistance in Dying* Form (#21565) o *Specialist Assessment for Medical Assistance in Dying* (#21567)
- Non-Alberta Health Services Documents:
- *Advice to the Profession – Medical Assistance in Dying*, June 2016, (College of

  Physicians and Surgeons of Alberta) o *Alberta Monitoring of MAID Physician/Nurse Practitioner* Form (#HSP12101) o *An Act to amend the Criminal Code and to make related amendments to other Acts* (Medical Assistance in Dying), June 17, 2016 (Government of Canada) Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331 (Supreme Court of Canada) o *Criminal Code* (Canada)
- *Medical Assistance in Dying Care Coordination Service Ministerial Order* D2-2016, June

  2016 (Government of Alberta) o *Medical Assistance in Dying: Guidelines for Nurse Practitioners*, March 2017, CARNA o *Medical Assistance in Dying: Guidelines for Nurses in Alberta*, March 2017, CARNA o *Medical Assistance in Dying Standard of Practice*, June 2016 (College of Physicians and

  Surgeons of Alberta) o *Pharmacist Record for Medical Assistance in Dying* Form (#HSP11662) (Alberta) o *Record of Request for Medical Assistance in Dying* Form (#HSP11175) (Alberta)

Note. From *Medical Assistance in Dying*, by Alberta Health Services, 2021 (https://extranet.ahsnet.ca/teams/policydocuments/1/clp-med-assist-in-death-hcs-165-01.pdf).

Appendix C: Alberta Health Services: MAID Care Coordination Service

Alberta Health Services

Medical Assistance in Dying Care Coordination Service

Alberta Health Services has developed a Medical Assistance in Dying Care Coordination Service to act as a single point of contact for patients, families and health care providers. Three teams have been set up; one based in Edmonton (to support the Edmonton and North Zones), one based in Calgary (for Calgary and Central Zones) and one in Lethbridge (for the South Zone).

These teams are available to generally discuss all end-of-life options available, including Medical Assistance in Dying. These teams will also connect a patient to the health care provider or team who can best meet their unique needs so that further, in depth, discussions can be had to understand those needs. The teams recognize that choices may vary from patient to patient and acknowledge that there is no right or wrong choice.

Care Coordination Service Responsibilities

- Support patients and families by providing information and access to education and supports, and linkages to all end-of-life care options including Medical Assistance in Dying care and services.
- Support AHS physicians, non-AHS physicians and members of interdisciplinary health care teams across the province in the coordination of care and services related to Medical Assistance in Dying and all end-of-life care options, and provide linkages to education, resource materials, and specialty consultation services.

Composition of Care Coordination Service teams

The "core" Care Coordination Service will be made up of nurse navigators, physicians and operational leaders.

Local and provincial multidisciplinary providers (including AHS Legal, Ethics, Addictions and Mental Health, spiritual care, social work, cultural care, and palliative care) may be accessed by the core Care Coordination Service to connect the patient with the most appropriate services or facilitate the request for medical assistance in dying.

Specialty health care providers from relevant programs and services (e.g. Cancer Control, Neurology, etc.) may be accessed by the core Care Coordination Service to connect the patient with the most

appropriate services or facilitate the request for medical assistance in dying.

Contact Information

To find out more about medical assistance in dying visit www.ahs.ca/MAID.

To request information about the Medical Assistance in Dying Care Coordination Service, email [email address].

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Note. From *Medical Assistance in Dying Care Coordination Service*, by Alberta Health Services, 2021. (https://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-coordination-service.pdf).

Appendix D: Covenant Health Policy: Responding to Requests for Medical Assistance in Dying

Covenant Health	**Responding to Requests for Medical Assistance in Dying**	**Corporate Policy & Procedures Manual**
		Policy No. VII-B-440
		Date December 3, 2018
Approved by: Chief Medical Officer Chief Mission and Ethics Officer		**Date Effective** December 3, 2018
		Next Review (3 years from Effective Date) December 2021

Purpose

The purpose of this policy is to provide a consistent ethical and compassionate approach, reflective of the *Health Ethics Guide* and Catholic teaching when responding to a person in care within Covenant Health who voluntarily requests

assistance to intentionally end their own life, or who voluntarily requests administration of a lethal medication resulting in their own death. The fulfilment of these acts, when complying with Canadian law are collectively referred to as medical assistance in dying (MAID).

Policy Statement

As a Catholic health care organization, Covenant Health is committed to uphold the inherent dignity of every human being throughout the entire continuum of life from conception to natural death. Therefore, Covenant Health will not provide nor explicitly refer for MAID given the incompatibility of MAID with the organization's mission and ethical tradition. At the same time, Covenant Health is committed to the principles of justice and non-abandonment, and thus must ensure persons in our care seeking further information, assessment, and potentially, provision of MAID are able to access navigation resources within the health system which can facilitate these processes independently of Covenant Health.

This balancing of rights that respects the interests of all without compromising personal or institutional integrity equally expresses Covenant Health's mission and tradition of service.

Applicability This policy applies to all Covenant Health facilities, staff, physicians, volunteers, students and to any other persons acting on behalf of Covenant Health ("personnel") when acting on behalf of Covenant Health or at one of our facilities. It does not apply to a health practitioner whose practice is conducted external to Covenant Health, such as physicians who hold multiple site privileges, or to other Covenant Health staff in any role they may have concurrently working at non-Covenant Health sites or facilities. Questions of actual or perceived conflict of interests raised while acting simultaneously on behalf of Covenant and an external provider must be declared and managed appropriately among the clinical care team.

Responsibility While Covenant Health personnel shall neither unnecessarily prolong nor hasten death, the organization nevertheless reaffirms its commitment to provide quality palliative/hospice and end-of-life care, promoting compassionate support for persons in our care and their families, including:

1. Honouring patient/resident self-determination through the use of advance care planning, goals of care designation, and/or personal directives, including clear recognition of the role of substitute decision-makers/agents chosen by and acting on behalf of the patient/resident;
2. Offering quality palliative/hospice and end-of-life care, at the patient/resident's or families' request and agreement, that addresses physical, psychological, social, and spiritual needs of persons who are dying and their families;
3. Delivering effective and timely pain and symptom management as outlined in the *Health Ethics Guide*, the foundational ethics resource used by Covenant Health; and
4. Providing ethics services and support through the Covenant Health Ethics Centre.

Principles An expressed request from a person in our care for MAID must be respectfully acknowledged in a non-coercive and non-discriminatory manner. The response should focus on providing information and access to appropriate physical, psychological and spiritual supports, as requested, to help address the person's needs that may underlie their expressed request.

This policy recognizes that suffering is part of the human experience which occurs throughout life and is not related only to dying. A person who may be experiencing deep existential anguish needs to be appropriately supported to acknowledge, address, and ameliorate their suffering. The goal of care is to reduce such suffering.

Covenant Health and its personnel are prohibited from participating in any actions of commission or omission that are directly intended to cause death through the deliberate prescribing or administration of a lethal agent. The values of Covenant Health nevertheless ethically oblige appropriate personnel to explore and seek to understand the nature of the person's expressed request, and to provide unconditional support.

As affirmed in *Our Commitment to Ethical Integrity* and in the *Health Ethics Guide,* including the standards of practice of regulated members, Covenant Health will support those in good conscience who cannot participate in an activity to which they morally object, or that is contrary to their professional codes of conduct. It is our responsibility to do so without abandoning those who may be impacted by such conscientious or professional decisions by reviewing circumstances on a case-by-case basis and exercising prudential judgment. At minimum, provision of information on MAID to the patient/resident, and ensuring reasonable access to the Alberta Health Service Care Coordination Service for further exploratory discussion is required.

Covenant Health is morally and legally bound to work together with patients/residents, families and personnel to resolve potential conflict around the goals of care and find proactive solutions that seek to respect the wishes and integrity of all. In response to both a patient/resident's consented request and an external provider arrangement to assume care of the patient/resident, this may require safe and timely transfer of the patient/resident and their records to their home or to a nonobjecting institution which can support the provision of MAID. Consistent with Covenant Health's mission and values, our interaction in such patient/resident and external provider requested assessments or transfers should be conducted in a compassionate and respectful manner.

While Covenant Health will not participate in the formal eligibility determination or provision of MAID, it is recognized that various components of the determination phase undertaken by the Alberta Health Services Care Coordination Service of such medically fragile patients/residents will take place on Covenant sites (e.g., witnessing and signing of legal documents, assessments of eligibility, or transfer of care arrangements). That is a matter solely organized and arranged between the patient/resident and AHS personnel within the privileged relationship they share, for whom this aspect of care has been assumed by AHS within the mandate of the Care Coordination Service.

Similarly, in those instances when the patient/resident chooses to coordinate their own arrangements for determining eligibility and provision of MAID, this too is conducted within the privileged relationship the person has with the community assessor and/or provider. Timely and respectful access of community practitioners to Covenant Health sites would be expected to conduct assessments for eligibility, and potentially, to assume responsibility in transferring the patient/resident to another facility or home for provision of MAID. Covenant Health personnel would be required to ensure a written release of care is signed, and to support the patient/resident initiated transfer, as per standard of practice.

Covenant Health, however, will not allow the provision of MAID on Covenant property at any time given the incompatibility of MAID with Covenant's mission and ethical tradition.

Procedure **A. Responsible Parties**

This policy recognizes the long standing Catholic moral tradition of neither prolonging death by subjecting persons to disproportionately burdensome, medically inappropriate or futile treatments, nor intentionally hastening death through assisted suicide and/or voluntary euthanasia. Our response to persons requesting MAID therefore must be timely, compassionate and appropriate, while respecting our institutional identity and tradition.

1. Covenant Health will inform all individuals receiving care of the person's right to make decisions concerning their medical care including the right to accept or withdraw medical or surgical treatment and the right to formulate advance directives.

0. Covenant Health will transparently provide information on its policy related to MAID, adhering with the principle of non-abandonment and the duty to inform.

0. Patients/residents, families, caregivers, physicians and other members of the care team will be encouraged to fully explore and discuss care and treatment options for patients/residents.

0. Covenant Health respects the rights of patients/residents/caregivers and clinicians to explore all available options, but fully expects that patients/residents/caregivers and clinicians will respect Covenant Health's position as set forth in this policy while providing care within Covenant Health facilities, programs and services.

B. Specific Inpatient Physician/Nurse Practitioner, Administrative and Other Personnel Responsibilities

Physician and Nurse Practitioner Responsibilities:

See also the professional obligations of regulated members under each respective *body's Standard of Practice*.

1. When a person verbalizes a request for MAID, the attending physician, and/or nurse practitioner will be promptly notified. The information and support provided will be guided by the patient/resident's or families' needs or explicit requests. In some settings, this may also require concurrent notification of other allied staff, including Social Work.

0. The attending physician and/or nurse practitioner must review the person's medical status and seek to understand the person's reasons for the request. Additionally:

. The attending physician and/or nurse practitioner will discuss the full range of available options with the person, including all factually relevant information as would be expected with any end of life discussion. This may require responding to questions about MAID, as well as Covenant Health's relevant policy. It may also require other information sources being left with the person such as those available from AHS.

b. This response may require consultation with other health care personnel to assess the person's decision-making capacity, to be cognizant of particular circumstances of vulnerability that might motivate choices, and to provide emotional and spiritual support, as indicated.

0. Covenant Health encourages physicians, nurse practitioners and patients/residents and/or their substitute decision-makers to engage in conversations regarding the person's treatment/care options at the end of life, and discuss the provision of quality palliative/hospice care.

0. The patient/resident is informed of the options for meeting the person's care needs within the Covenant Health environment including palliative and hospice services for comfort and support as appropriate.

0. When, after discussion with the attending physician or nurse practitioner, the patient/resident still expresses a desire to further explore MAID, alternatives will be explored with clear communication that the actual provision of MAID is not done in Covenant Health facilities. The patient/resident may choose to involve the AHS Care Coordination Service either through Health Link (811), or by asking Covenant Health to contact AHS at their request (see www.ahs.ca/MAID for a link to resources).

0. Once a discussion with the AHS Care Coordination Service has taken place, the patient/resident may subsequently request that this team help them navigate access to external providers. The Care Coordination Service would be responsible to arrange for further assessment of eligibility.

These arrangements will be made directly between such medically fragile individuals and the AHS Care Coordination Service and Navigator without Covenant Health participation, other than ensuring AHS access to the site and an appropriate location or means (e.g., telehealth) for conversations to take place and/or education materials to be left.

Personnel with joint privileges acting simultaneously on behalf of Covenant as well as an external provider which raises questions of perceived or actual conflicts of interest must be declared and managed appropriately among the clinical care team.

0. The AHS Care Coordination Service will assume responsibility for those aspects of the MAID process within their mandate and which are not otherwise able to be coordinated directly by the requesting individual and/or their family/supports. This includes witnessing and signing of the “Record of Request,” and arrangements for conducting formal assessments of eligibility and potential transfers. It is understood that such activities may occur on Covenant Health sites but will not be arranged by Covenant staff.

It is expected that assessments conducted by the AHS Care Coordination Service on a Covenant Health site would be held in an appropriate setting, including, but not limited to the patient or resident’s room, or a private meeting room at a Covenant Health facility if that is more appropriate for the assessment.

0. Throughout the process, Covenant Health will continue to provide ongoing treatment and care to a person while they are in our facilities. This would be to the point of time when an external provider has explicitly requested they are assuming total care of the person, and either:

. A transfer of the patient/resident and records has been completed to a non-objecting institution; or

a. The person is transferred home.

0. Responding to a person’s clearly consented written request to be released of their care by Covenant Health and its personnel must always be timely, safe, compassionate, and respectful, through non-coercive and non-discriminatory dialogue.

0. Physicians and nurse practitioners are expected to comply with all federal and provincial regulatory reporting requirements that have been established when in receipt of a written request for MAID. For more information on these legal obligations, see the AHS website, MAID Reporting for Alberta Practitioners at: https://www.albertahealthservices.ca/info/Page16124.aspx as well

as:https://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-faq.pdf

Administrative Responsibilities:

1. Senior Director, Operations (or appropriate clinical designate) will serve as the main point of contact with the AHS Care Coordination Service and address questions arising, in keeping with the principles outlined in this policy. Escalation to the Chief Medical Officer or to the Chief Mission and Ethics Officer is available, as required.

0. Senior Director, Operations (or appropriate clinical designate) must notify the Ethics Centre staff at [telephone number], [telephone number] or by email at [email address] for monitoring and statistical purposes, as well to provide additional ethics consultation support, as required. Current internal reporting on date of known requests, location of and reason for transfers, and other supports provided to patient/residents will be reconciled quarterly with Alberta Health Services to ensure data integrity.

Nursing, Pharmacy, Allied Staff and other involved personnel:

1. Personnel will respond to inquiries about MAID with compassion and respect. This includes listening to the person to ensure they feel heard and bringing inquiries forward to the appropriate member of the health care team.

0. Nursing, Pharmacy, Allied Staff and other involved personnel, including those in Spiritual Care and Social Work will continue to provide effective pain and symptom management along with emotional and spiritual support for the patient/resident.

0. Emotional and spiritual support will be offered to family members/significant others, as required, including for the care team.

0. Pharmacy staff will not be involved in providing medications intended for MAID, either directly or indirectly.

0. Regarding transfers, Covenant Health Integrated Access will hold the patient/resident’s bed until confirmation has been received from the AHS Care Coordination Service that the person will not be returning to Covenant Health.

0. The exercise of conscientious objection as a fundamental right of all personnel, insofar as the person in care is not put at risk of harm or abandonment, shall apply.

C. Documentation

The attending physician or nurse practitioner, and other involved members of the care team will document in the medical record a summary of discussion(s) with a person regarding their request for MAID when such discussions occur. This should include all relevant information that would normally be documented as a statement of fact in compliance with regulatory and legal requirements to ensure safe management of the person’s care (e.g., the CPSA Standards of Practice). Documenting the scheduling of eligibility assessments, or potential transfer arranged by the AHS Care Coordination Service Team would therefore be expected, including any other required contact information to ensure timely communication.

When MAID assessments are completed by AHS at a Covenant Health site, the AHS assessor is encouraged to make notes in the patient/resident chart to ensure continuity of care and good team communication. They may wish to indicate in the progress notes that the assessment was done, or to make suggestions to the most responsible practitioner about enhancements to the existing care that would improve the patient or resident’s care.

The AHS Care Coordination Service will store all forms and assessments electronically within AHS systems on a secure drive, accessible only to the navigation teams and the AHS clinical lead for MAID.

D. Consultation Services

If situations arise that present further ethical and/or legal issues, the Chief Medical Officer or Chief Mission and Ethics Officer shall be contacted about questions around the application of this policy. After consulting Covenant Health, AHS and other relevant stakeholders, the Chief Medical Officer or Chief Mission and Ethics Officer may provide advice or direction concerning the interpretation or application of this policy.

Clinical Ethics, Legal Services, the Critical Incident Stress Management Team (CISM), Social Work, or the Employee Family Assistance Program (EFAP) can be contacted for additional individual or group support as needed.

Definitions Advance care planning: is a process whereby individuals indicate their treatment goals and preferences with respect to care at the end of life. This can result in a written directive, or advance care plan, also known as a living will.

Continuous palliative sedation therapy (CPST): intentional lowering of a patient's level of consciousness in the last one to two weeks of life. It involves the proportional (titrated) and monitored use of specific sedative medications to relieve refractory symptoms and intolerable suffering. Sedation as a consequence of medications used to relieve a specific symptom is not regarded as CPST.

Euthanasia: means knowingly and intentionally performing an act, with or without consent, that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition; commits the act with the primary intention of ending the life of that person; and the act is undertaken with empathy and compassion and without personal gain.

Medical aid in dying: refers to a situation whereby a physician intentionally participates in the death of a patient by directly administering the substance themselves, or by providing the means whereby a patient can self-administer a substance leading to their death.

Palliative care: is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other symptoms, physical, psychosocial and spiritual.

Palliative sedation: refers to the use of sedative medications for patients who are terminally ill with the intent of alleviating suffering and the management of [intolerable and refractory] symptoms. The intent is not to hasten death although this may be a foreseeable but unintended consequence of the use of such medications. This is NOT euthanasia or physician-assisted death.

Physician-assisted death: means that a physician knowingly and intentionally provides a person with the knowledge or means or both required to end their own life, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs. This is sometimes referred to as physician-assisted suicide. Euthanasia and physician-assisted death are often regarded as morally equivalent, although there is a clear practical distinction, as well as a legal distinction, between them.

Withdrawing or withholding life sustaining interventions: such as artificial ventilation or nutrition, that are keeping the patient alive but are no longer wanted or indicated, is NOT euthanasia or physician assisted death.

Source*: Canadian Medical Association, 2014*

Related Documents

“Comprehensive Clinical Guide for Medical Assistance in Dying for Physicians and Nurse Practitioners,” *Alberta Health Services,* February, 2017.

“Conscientious Objection” (formally issued as “Moral or Religious Beliefs Affecting Medical Care),”Standards of Practice, *College of Physicians and Surgeons of Alberta,* June 2016. See: http://www.cpsa.ca/standardspractice/conscientious-objection/ (Accessed November 27, 2018).

“Discussion Paper on Euthanasia and Physician-Assisted Dying,” *Covenant Health Palliative Institute,* 2013.

Early Induction of Labour, Policy VII-B-10, Covenant Health.

“Evidence-Based Management Tools, Protocols and Guidelines,” *Edmonton Zone Palliative Care Program.* See: http://www.palliative.org/guidelines.html (Accessed November 27, 2018).

Health Ethics Guide, Ottawa: Catholic Health Alliance of Canada, 2012.

“Medical Assistance in Dying: Guidelines for Nurses in Alberta” *CARNA Provincial Council* (College & Association of Registered Nurses of Alberta, College of Licensed Practical Nurses of Alberta, College of Registered Psychiatric Nurses of Alberta), March, 2017. See: http://www.nurses.ab.ca/content/dam/carna/pdfs/DocumentList/Guidelines/MAIDGuid elinesForNurses_March2017.pdf (Accessed November 27, 2018).

“Medical Assistance in Dying – Information for Social Workers,” *Alberta College of Social Workers,* December 20, 2016. See: http://acsw.in1touch.org/company/roster/companyRosterDetails.html?companyId=24 355&companyRosterId=53 (Accessed November 27, 2018).

"Medical Assistance in Dying (MAID) – Advice to the Profession," *Alberta College of Pharmacists.* June 6, 2016. See: https://pharmacists.ab.ca/medical-assistancehttps://pharmacists.ab.ca/medical-assistance-dying-maiddying-maid (Accessed November 27, 2018).

"Medical Assistance in Dying – MAID," Covenant Health CEO video interview series, November 2018. See: http://www.compassionnet.ca/Page4921.aspx (Accessed November 27, 2018).

"Medical Assistance in Dying Policy," *Alberta Health Services,* May 5, 2016. See: https://extranet.ahsnet.ca/teams/policydocuments/1/clp-med-assist-in-death-hcs-165https://extranet.ahsnet.ca/teams/policydocuments/1/clp-med-assist-in-death-hcs-165-01.pdf01.pdf (Accessed November 27, 2018).

"Ministerial Order #38/2016 Medical Assistance in Dying Review Committee," *Minister of Health,* Alberta, June 7, 2016. See: http://www.health.alberta.ca/documents/MO-38-2016-MAID-Reg-Reviewhttp://www.health.alberta.ca/documents/MO-38-2016-MAID-Reg-Review-Committee.pdfCommittee.pdf (Accessed November 27, 2018).

"Nurse Practitioner Standards of Practice for Medical Assistance in Dying," *College & Association of Registered Nurses of Alberta,* December 13, 2016). See: *http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-nurse*http://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-nurse-practitioners.pdf*practitioners.pdf* (Accessed November 27, 2018).

"Order in Council O.C. 142/2016 June 10, 2016" Order respecting Medical Assistance in Dying Standard of Practice for Physicians. See: http://www.qp.alberta.ca/documents/orders/Orders_in_Council/2016/616/2016_142.ht ml (Accessed November 27, 2018)

"Order in Council O.C. 320/2016 December 6, 2016" Order respecting Medical Assistance in Dying Standards of Practice for Nurse Practitioners. See:http://www.qp.alberta.ca/documents/orders/Orders_in_Council/2016/1216/2016_320. html (Accessed November 27, 2018).

Our Commitment to Ethical Integrity (Code of Conduct), Covenant Health.
"Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report," November 30, 2015. See: http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf (Accessed November 27, 2018).

"Transfer of Care," Standards of Practice, *College of Physicians and Surgeons of Alberta,* no. 41, April 2014. See: http://www.cpsa.ca/standardspractice/transfer-ofhttp://www.cpsa.ca/standardspractice/transfer-of-care/care/ (Accessed November 27, 2018).

References

"A Catholic Perspective on Health Decisions and Care at the End of Life," Ottawa: *Catholic Health Alliance of Canada*, 2014.

"A Moral Analysis of Cooperating in the Wrongdoing of Physician Assisted Suicide," *Cataldo, Peter J.,* Commissioned by the *Catholic Health Alliance of Canada,* March 2016.

"Advice to the Profession – Medical Assistance in Dying (MAID)," *College of Physicians and Surgeons of Alberta,* July, 2016. See: http://www.cpsa.ca/wphttp://www.cpsa.ca/wp-content/uploads/2016/06/AP_Medical-Assistance-in-Dying.pdfcontent/uploads/2016/06/AP_Medical-Assistance-in-Dying.pdf (Accessed November 27, 2018).

Bill C-14, "An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), *Statutes of Canada,* Assented to June 16, 2016. See: http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royalhttp://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assentassent (Accessed November 27, 2018).

"CHPCA Issues Paper on Euthanasia, Assisted Suicide and Quality End-of-Life Care," April, 2010. See: http://www.chpca.net/media/7835/PAD_Issues_Paper_-_April_24_2010_http://www.chpca.net/media/7835/PAD_Issues_Paper_-_April_24_2010_-_Final.pdf_Final.pdf (Accessed November 27, 2018).

"Conscience, Cooperation, and Full Disclosure: Can Catholic health care providers disclose 'prohibited options' to patients following genetic testing?" *Panicola, Michael, and Ron Hamel*, *Health Progress*. 87, no.1 (January-February, 2006): 52-59.

Cooperation and Service Agreement between Alberta Health Services and Covenant Health, 2010.

"CMA Policy Statement: Euthanasia and Assisted Suicide," Ottawa: *Canadian Medical Association, Update 2014*. See: https://www.cma.ca/Assets/assetshttps://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/CMA_Policy_Euthanasia_Assisted Death_PD15-02-e.pdflibrary/document/en/advocacy/EOL/CMA_Policy_Euthanasia_Assisted%20Dea th_PD15-02-e.pdf (Accessed November 27, 2018).

"End-of-Life Care: A National Dialogue," *Ottawa: Canadian Medical Association, 2014*. See: https://www.cma.ca/Assets/assetshttps://www.cma.ca/Assets/assets-library/document/en/advocacy/end-of-life-care-report-e.pdflibrary/document/en/advocacy/end-of-life-care-report-e.pdf (Accessed November 27, 2018).

"MAID Reporting for Alberta Practitioners," *Alberta Health Services.* See: https://www.albertahealthservices.ca/info/Page16124.aspx (Accessed November 27, 2018).

"Medical Assistance in Dying Reporting Regulation Questions, MAID Webinar FAQs", *Alberta Health Services,* October 25, 2018. See: https://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-faq.pdf (Accessed November 27, 2018)

"Medical Assistance in Dying," Standard of Practice, *College of Physicians and Surgeons of Alberta,* June 2016. See: http://www.cpsa.ca/standardspractice/medical-assistance-dying/ (Accessed November 27, 2018).

"Medical Assistance in Dying Standards of Practice for Nurse Practitioners, *College and Association of Registered Nurses of Alberta,* December 6, 2016. See: http://www.nurses.ab.ca/content/dam/carna/pdfs/DocumentList/Standards/MAI D-standards-for-NPs.pdf (Accessed November 27, 2018)

"Physician-Assisted Suicide and Euthanasia," Furton, Edward J. *Catholic Health Care Ethics: A Manual for Ethics Committees*, Peter J. Cataldo and Albert S. Moraczewski, OP, eds. Chapter 13 (Boston: National Catholic Bioethics Center, 2002).

"Physician-Hastened Death, Category Archives," *Canadian Society of Palliative Care Physicians*. See: https://www.cspcp.ca/category/medical-aid-in-dying-maid/ (Assessed November 27, 2018).

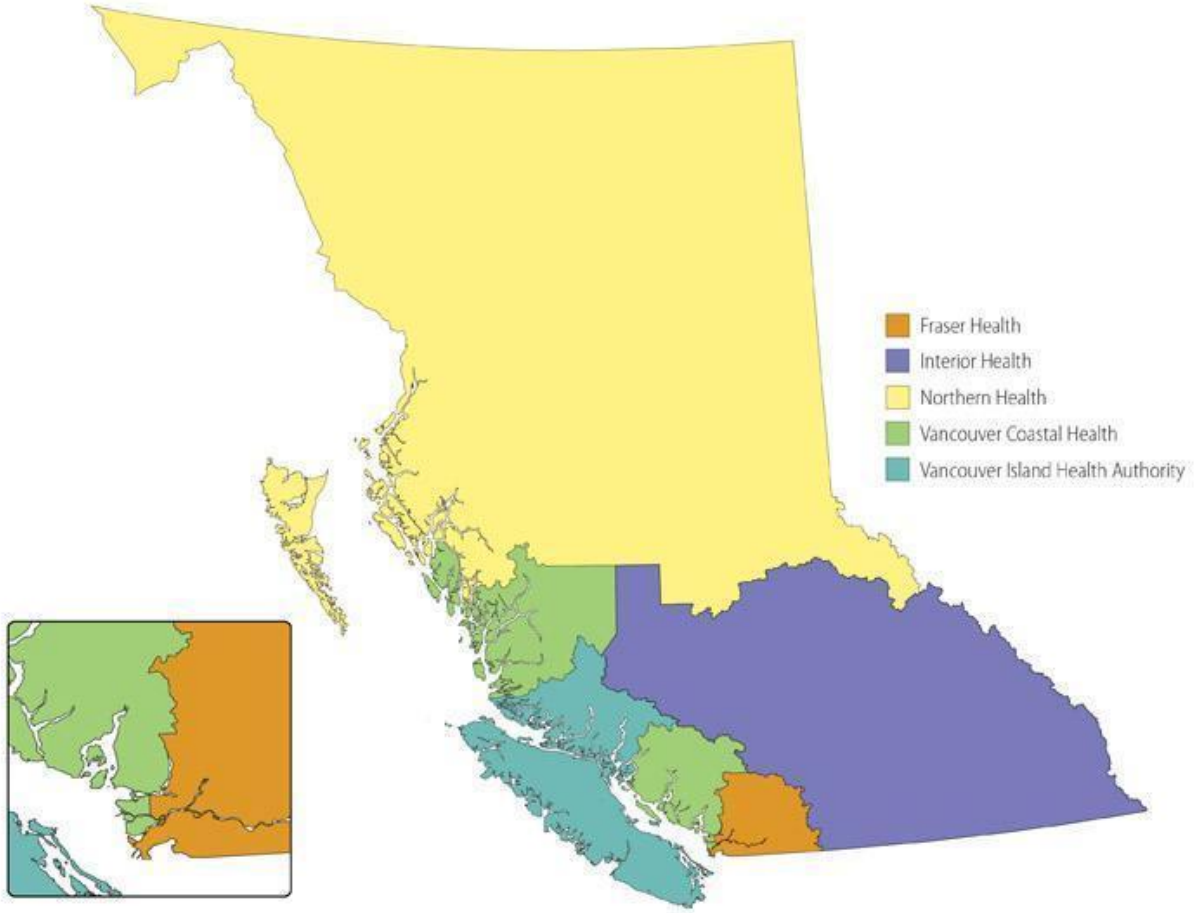
Revisions July 13, 2018

September 15, 2017 May 24, 2016

Note: From *Responding to Requests for Medical Assistance in Dying*, by Covenant Health, 2018 (https://www.covenanthealth.ca/media/124082/medical-assistance-in-dying-vii-b-440-december-3-2018-final.pdf).

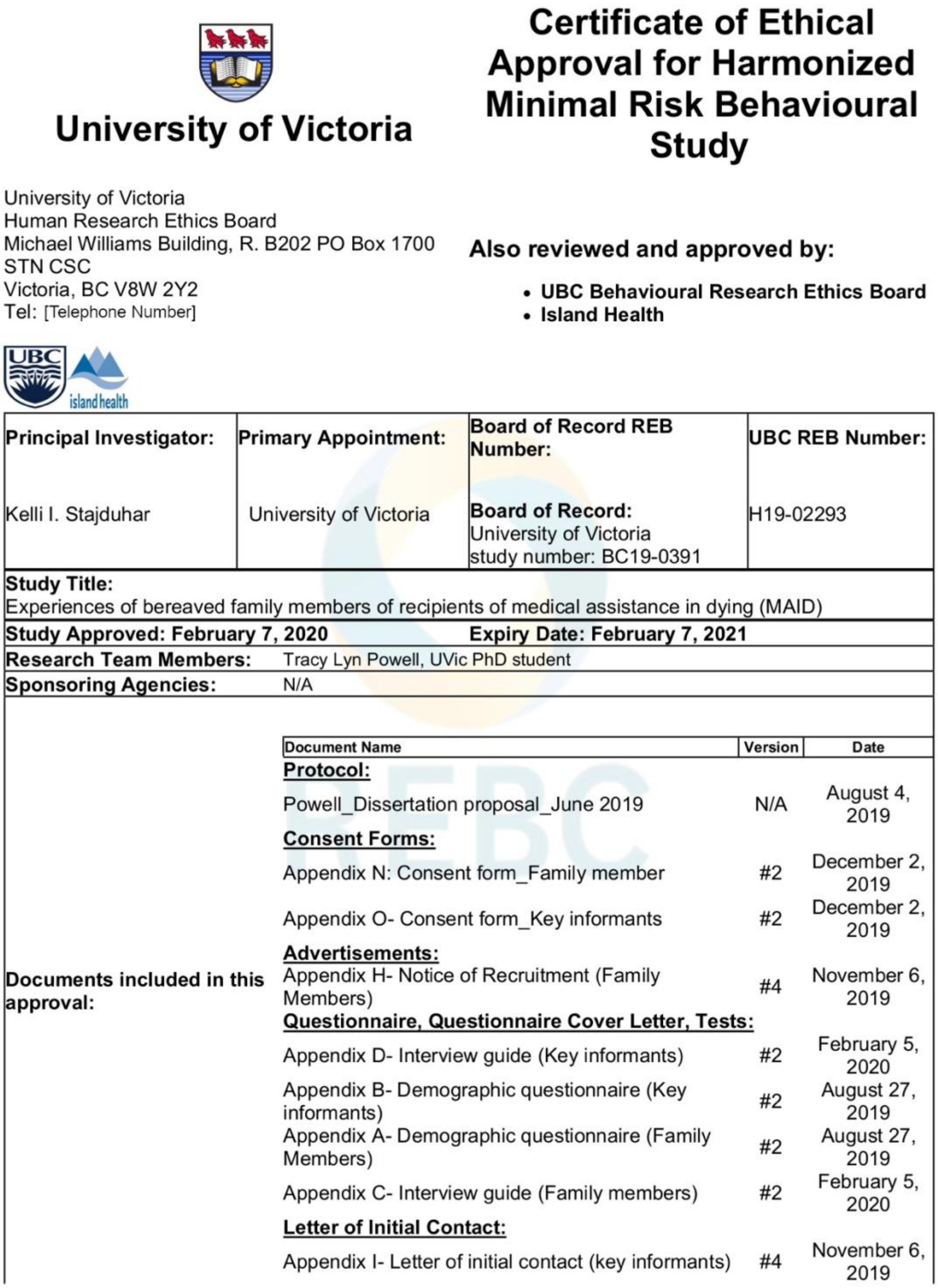
Appendix E: Geographic Regions of British Columbia Health Authorities

BC Health authority area boundaries



Note. From *Regional Health Authorities,* by Government of British Columbia, 2021 (https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/regional-health-authorities).

Appendix F: University of Victoria Certificate of Ethical Approval for Harmonized Minimal Risk Behavioural Study



University of Victoria

Certificate of Ethical Approval for Harmonized Minimal Risk Behavioural Study

University of Victoria
Human Research Ethics Board
Michael Williams Building, R. B202 PO Box 1700
STN CSC
Victoria, BC V8W 2Y2
Tel: [Telephone Number]

Also reviewed and approved by:

- **UBC Behavioural Research Ethics Board**
- **Island Health**

Principal Investigator:	**Primary Appointment:**	**Board of Record REB Number:**	**UBC REB Number:**
Kelli I. Stajduhar	University of Victoria	**Board of Record:** University of Victoria study number: BC19-0391	H19-02293

Study Title:
Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Study Approved: February 7, 2020 **Expiry Date: February 7, 2021**

Research Team Members:	Tracy Lyn Powell, UVic PhD student
Sponsoring Agencies:	N/A

Documents included in this approval:

Document Name	Version	Date
Protocol:		
Powell_Dissertation proposal_June 2019	N/A	August 4, 2019
Consent Forms:		
Appendix N: Consent form_Family member	#2	December 2, 2019
Appendix O- Consent form_Key informants	#2	December 2, 2019
Advertisements:		
Appendix H- Notice of Recruitment (Family Members)	#4	November 6, 2019
Questionnaire, Questionnaire Cover Letter, Tests:		
Appendix D- Interview guide (Key informants)	#2	February 5, 2020
Appendix B- Demographic questionnaire (Key informants)	#2	August 27, 2019
Appendix A- Demographic questionnaire (Family Members)	#2	August 27, 2019
Appendix C- Interview guide (Family members)	#2	February 5, 2020
Letter of Initial Contact:		
Appendix I- Letter of initial contact (key informants)	#4	November 6, 2019

Other Documents:

Appendix L- Resources and supports_Calgary zone Alberta	#1	August 9, 2019
Appendix F- Plan for analysis	#1	June 25, 2019
Response to Provisos	#1	February 5, 2020
Appendix M- Resources and supports_ South zone Alberta	#1	August 14, 2019
UVic Ink Sign Off/Signatures	#1	October 28, 2019
Appendix P- Recruitment Poster_FMs	#1	November 6, 2019
Appendix K- Resources and supports_Central Alberta	#1	August 9, 2019
Appendix E- Process for field notes/memos	#1	June 25, 2019
Appendix J- Resources and supports_Vancouver Island	#1	August 9, 2019
Appendix G- Study timeline	#1	June 25, 2019

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

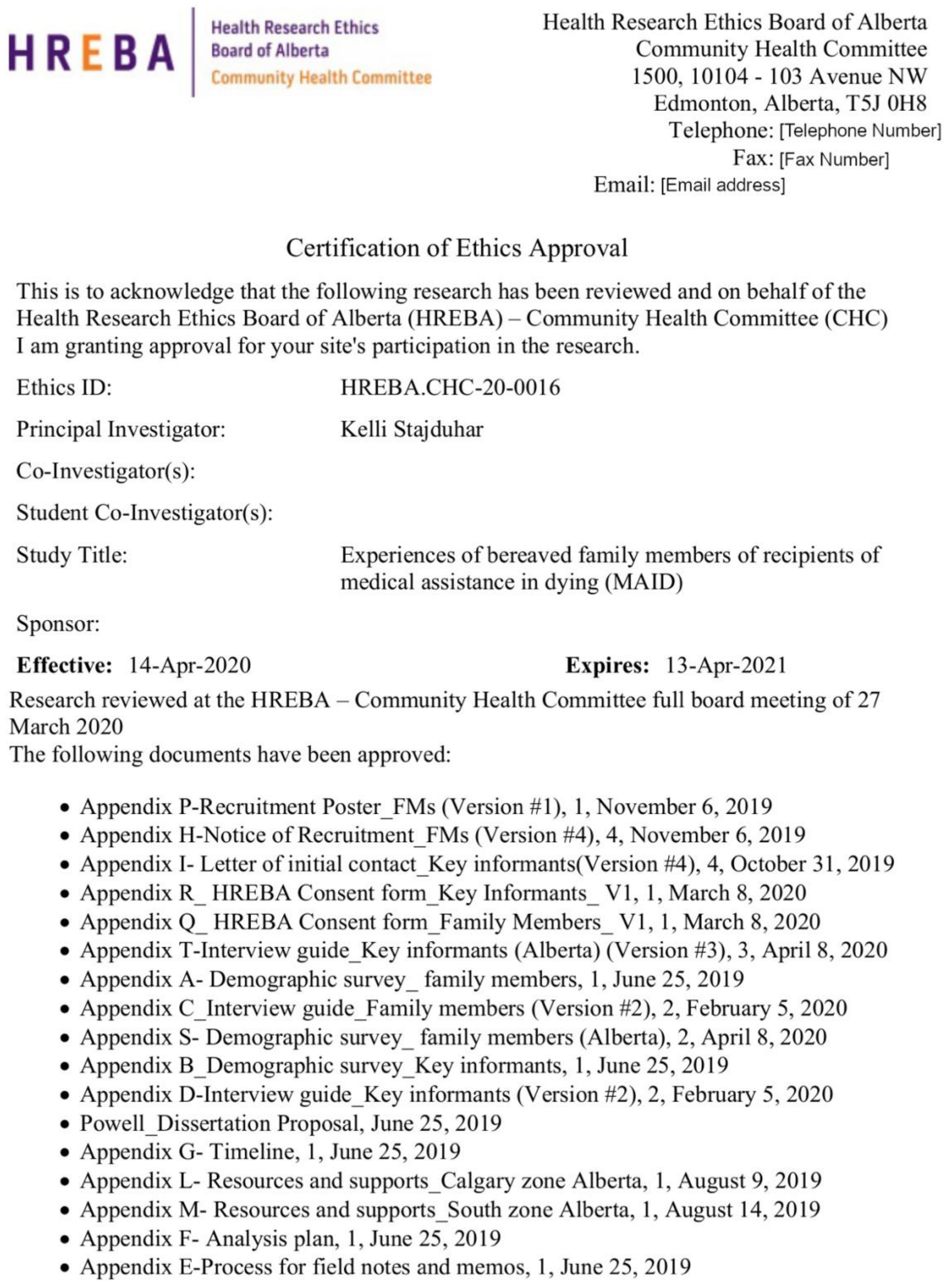
The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2014).

The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

This study has been approved either by the Board of Record’s full REB or by an authorized delegated reviewer.

Appendix G: Health Research Ethics Board of Alberta Certification of Ethical Approval



HREBA
Health Research Ethics
Board of Alberta
Community Health Committee

Health Research Ethics Board of Alberta
Community Health Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: [Telephone Number]
Fax: [Fax Number]
Email: [Email address]

Certification of Ethics Approval

This is to acknowledge that the following research has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Community Health Committee (CHC) I am granting approval for your site's participation in the research.

Ethics ID:	HREBA.CHC-20-0016
Principal Investigator:	Kelli Stajduhar
Co-Investigator(s):	
Student Co-Investigator(s):	
Study Title:	Experiences of bereaved family members of recipients of medical assistance in dying (MAID)
Sponsor:	

Effective: 14-Apr-2020 **Expires:** 13-Apr-2021

Research reviewed at the HREBA – Community Health Committee full board meeting of 27 March 2020

The following documents have been approved:

- Appendix P-Recruitment Poster_FMs (Version #1), 1, November 6, 2019
- Appendix H-Notice of Recruitment_FMs (Version #4), 4, November 6, 2019
- Appendix I- Letter of initial contact_Key informants(Version #4), 4, October 31, 2019
- Appendix R_ HREBA Consent form_Key Informants_ V1, 1, March 8, 2020
- Appendix Q_ HREBA Consent form_Family Members_ V1, 1, March 8, 2020
- Appendix T-Interview guide_Key informants (Alberta) (Version #3), 3, April 8, 2020
- Appendix A- Demographic survey_ family members, 1, June 25, 2019
- Appendix C_Interview guide_Family members (Version #2), 2, February 5, 2020
- Appendix S- Demographic survey_ family members (Alberta), 2, April 8, 2020
- Appendix B_Demographic survey_Key informants, 1, June 25, 2019
- Appendix D-Interview guide_Key informants (Version #2), 2, February 5, 2020
- Powell_Dissertation Proposal, June 25, 2019
- Appendix G- Timeline, 1, June 25, 2019
- Appendix L- Resources and supports_Calgary zone Alberta, 1, August 9, 2019
- Appendix M- Resources and supports_South zone Alberta, 1, August 14, 2019
- Appendix F- Analysis plan, 1, June 25, 2019
- Appendix E-Process for field notes and memos, 1, June 25, 2019

- Appendix K- Resources and supports_Central zone Alberta, 1, August 9, 2019

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA) and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2).

Deliberations of the HREBA-CHC included elements described in Section 50 of the HIA. The Committee found the research to be in accordance with requirements of the Act.

As a requirement of the HIA, if your study uses health information a copy of this certification will be sent to the Office of the Information and Privacy Commissioner (OIPC).

Members of the HREBA-CHC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This approval is subject to the following conditions:

1. It is being granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above. Failure to submit a request will result in the file entering into an expired state, whereby all research must cease.
5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

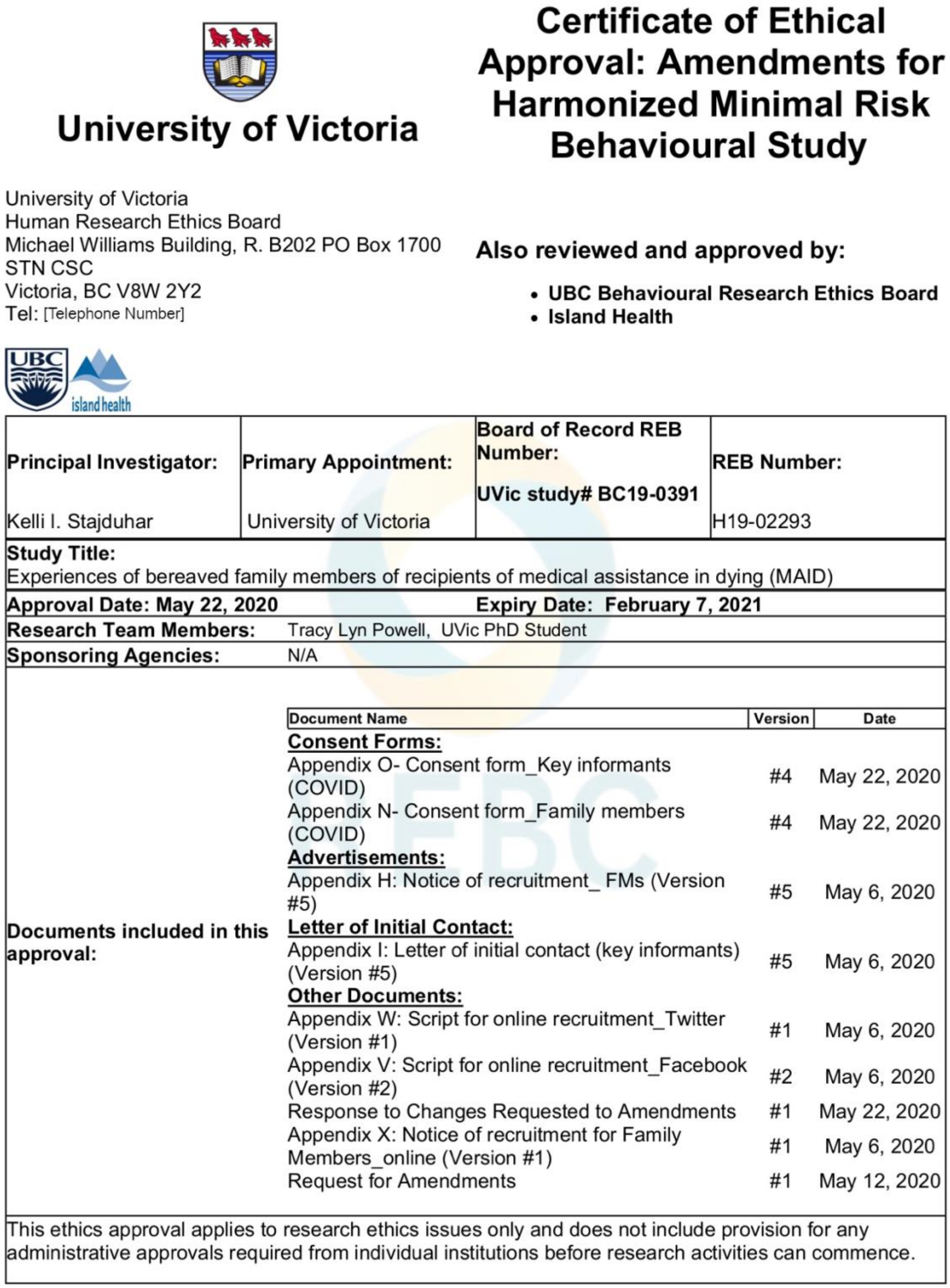
This approval does not guarantee that you will be able to access health records for research purposes. Other institutional or organizational requirements may be in place that you will be required to meet prior to initiating your research. These include approvals for the allocation of resources in support of your study. Inquiries regarding these additional approvals should be directed to the appropriate institutional or organizational body.

Please accept the Committee's best wishes for success in your research.

Approved on behalf of CHC by,	**Date:**
Cyne Johnston , HREBA-CHC	14-Apr-2020

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix H: University of Victoria Certificate of Ethical Approval: Amendments for Harmonized Minimal Risk Behavioural Study



University of Victoria

Certificate of Ethical Approval: Amendments for Harmonized Minimal Risk Behavioural Study

University of Victoria
Human Research Ethics Board
Michael Williams Building, R. B202 PO Box 1700
STN CSC
Victoria, BC V8W 2Y2
Tel: [Telephone Number]

Also reviewed and approved by:

- **UBC Behavioural Research Ethics Board**
- **Island Health**

Principal Investigator:	**Primary Appointment:**	**Board of Record REB Number:** **UVic study# BC19-0391**	**REB Number:**
Kelli I. Stajduhar	University of Victoria		H19-02293

Study Title:
Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Approval Date: May 22, 2020 **Expiry Date: February 7, 2021**

Research Team Members: Tracy Lyn Powell, UVic PhD Student

Sponsoring Agencies: N/A

Documents included in this approval:

Document Name	Version	Date
Consent Forms:		
Appendix O- Consent form_Key informants (COVID)	#4	May 22, 2020
Appendix N- Consent form_Family members (COVID)	#4	May 22, 2020
Advertisements:		
Appendix H: Notice of recruitment_ FMs (Version #5)	#5	May 6, 2020
Letter of Initial Contact:		
Appendix I: Letter of initial contact (key informants) (Version #5)	#5	May 6, 2020
Other Documents:		
Appendix W: Script for online recruitment_Twitter (Version #1)	#1	May 6, 2020
Appendix V: Script for online recruitment_Facebook (Version #2)	#2	May 6, 2020
Response to Changes Requested to Amendments	#1	May 22, 2020
Appendix X: Notice of recruitment for Family Members_online (Version #1)	#1	May 6, 2020
Request for Amendments	#1	May 12, 2020

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2014).

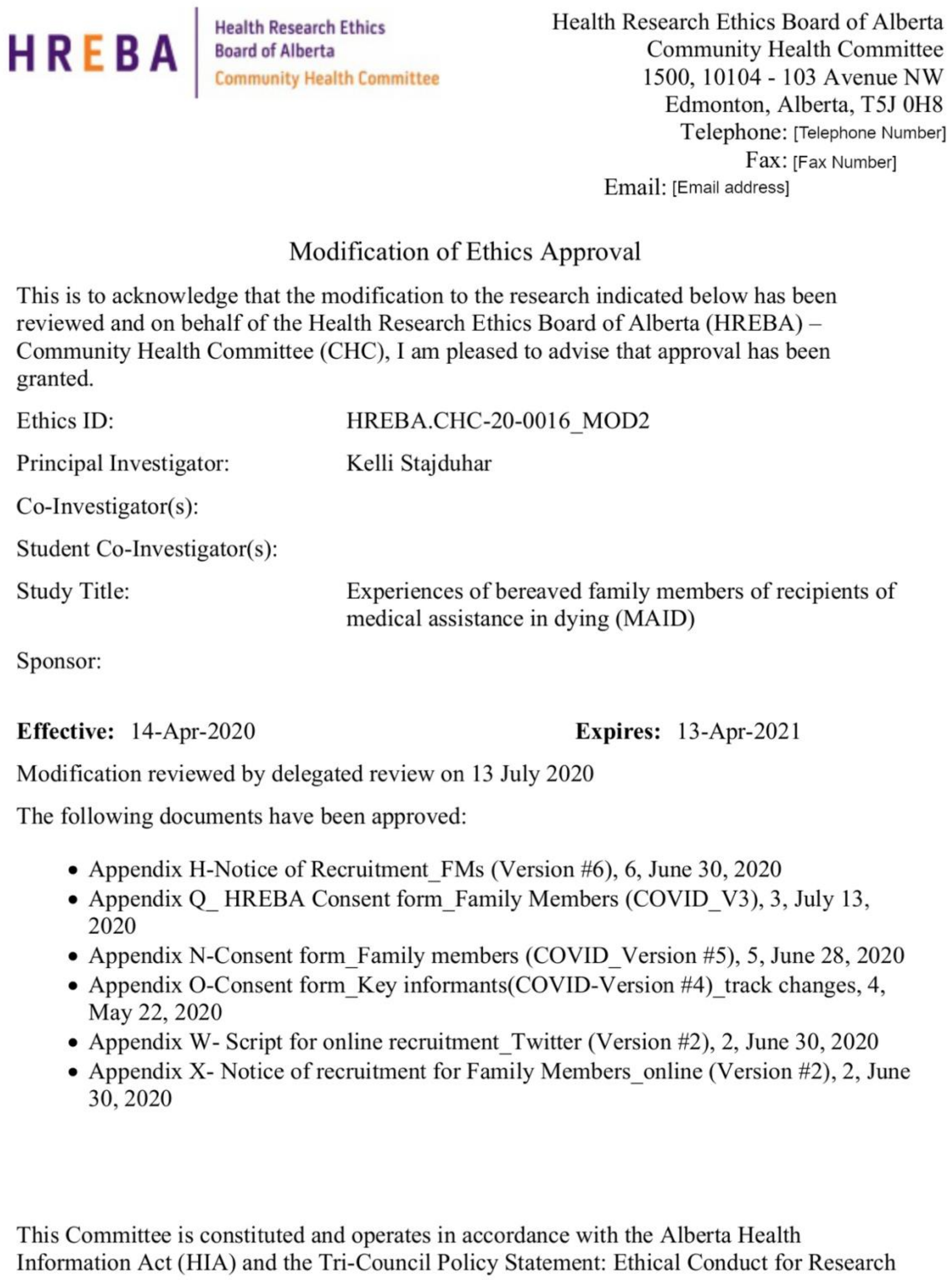
The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

This study has been approved either by the Board of Record's full REB or by an authorized delegated reviewer.

REBC

Appendix I: Health Research Ethics Board of Alberta Certification of Ethical Approval



HREBA
Health Research Ethics
Board of Alberta
Community Health Committee

Health Research Ethics Board of Alberta
Community Health Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: [Telephone Number]
Fax: [Fax Number]
Email: [Email address]

Modification of Ethics Approval

This is to acknowledge that the modification to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Community Health Committee (CHC), I am pleased to advise that approval has been granted.

Ethics ID: HREBA.CHC-20-0016_MOD2

Principal Investigator: Kelli Stajduhar

Co-Investigator(s):

Student Co-Investigator(s):

Study Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Sponsor:

Effective: 14-Apr-2020 **Expires:** 13-Apr-2021

Modification reviewed by delegated review on 13 July 2020

The following documents have been approved:

- Appendix H-Notice of Recruitment_FMs (Version #6), 6, June 30, 2020
- Appendix Q_ HREBA Consent form_Family Members (COVID_V3), 3, July 13, 2020
- Appendix N-Consent form_Family members (COVID_Version #5), 5, June 28, 2020
- Appendix O-Consent form_Key informants(COVID-Version #4)_track changes, 4, May 22, 2020
- Appendix W- Script for online recruitment_Twitter (Version #2), 2, June 30, 2020
- Appendix X- Notice of recruitment for Family Members_online (Version #2), 2, June 30, 2020

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA) and the Tri-Council Policy Statement: Ethical Conduct for Research

Involving Humans (TCPS 2).

Members of the HREBA-CHC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

Please note that the approval of this modification does not change the effective or expiry dates of this study as indicated above.

Please accept the Committee's best wishes for success in your research.

Approved on behalf of CHC by,	**Date:**
Cyne Johnston , HREBA-CHC	14-Jul-2020

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix J: Facebook Post

Hi there, I’m Tracy Powell and I’m working on my PhD at the School of Nursing at the University of Victoria. I’m also a nursing educator at Mount Royal University in Calgary. Are you a bereaved family member who has had a significant other receive medical assistance in dying (MAID)? I’d like to talk with you about your experience and how it’s impacted you personally. If you are interested, please contact me privately at [email address] or [telephone number] for further information.

Please feel free to share the information about this research within your community and contacts.

Thank you,
Tracy

Appendix K: Twitter Post

Calling all bereaved FMs on Vancouver Island, BC or Central, Calgary, South zones in Alberta who have had a loved one receive #MAID. I would like to hear your story for my PhD research. Read ⬇ for more info @DWDCanada @cancersociety @WellspringCAN @BridgeC14 @CAMAPCanada

(*The notice of recruitment* (*Appendix M: Notice of Recruitment of Family Members) will be attached to the Tweet)*

Appendix L: Invitation to Participate in Research

Invitation to participate in a research study:

Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Are you a family member of someone who died through MAID?

Did your family member who received MAID live on Vancouver Island *or* the Central, Calgary or South areas of the province of Alberta?

Do you live on Vancouver Island or in the province of Alberta?

If so, this study may be of interest to you!

Purpose of the study:

Tracy Powell, a doctoral candidate in the School of Nursing at the University of Victoria and a nursing educator at Mount Royal University in Calgary, is seeking to understand your experience and perspective of being a family member who has had a significant other end their life through medical assistance in dying (MAID).

What is required:

Participation in this study would require you to be interviewed by Tracy (by video conference or telephone), and to complete a demographic questionnaire.

Who can participate:

To participate, you should be 19 years of age and over; able to speak and read English; able to consent to participate; reside on Vancouver Island, BC or in the Central, Calgary, or South areas of Alberta; are a family member of an individual who received MAID, and, the MAID event occurred on Vancouver Island, BC or in the Central, Calgary, or South areas in the province of Alberta. Involvement is voluntary.

Are you interested in more information or want to participate?

Please contact Tracy Powell directly at [email address] or [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply).

*If you are reading this poster online, and are interested in this study, to maintain confidentiality, do not post your interest publicly, instead, contact Tracy directly: [email address] or [telephone number]

Appendix M: Notice of Recruitment

Notice of Recruitment:

"Bereaved family members of recipients of medical assistance in dying (MAID)"

Tracy Powell, a doctoral candidate at the University of Victoria School of Nursing and a nursing educator at Mount Royal University in Calgary, Alberta, is conducting a research project to understand the experiences of bereaved family members who have had a significant other receive medical assistance in dying (MAID). Family members known to be primary caregivers for loved ones during serious or terminal illness, and research indicates that family members also experience challenges which may become even more complex if assisted dying becomes the choice of their significant other.

This is an invitation for bereaved family members of recipients of MAID to participate in this research. The purpose of this study is to understand the experience and perspective of bereaved family members who have had a significant other end their life through MAID, and to describe how MAID implementation, policies, guidelines and processes in different provinces may have influenced these experiences. This study is focused on experiences of bereaved family members in the province of Alberta and British Columbia.

The information gathered from this study may be used to inform doctors, nurses and social workers who are involved in MAID and palliative care, as well as, health care administrators, support and advocacy groups. There is also the potential that information from this study will inform supportive interventions, policy, and programs for bereaved family members like you, who have had a significant other participate in MAID. Findings may also be published in academic or peer reviewed papers and presented at professional conferences.

Participation in this study is strictly voluntary and requires informed consent. Acceptance or refusal to participate in this study will in no way affect care that you or your family receives from the health care system. Participation in this study would require you to be interviewed by me and for you to complete a demographic questionnaire.

Demographic questionnaire

The purpose of the questionnaire is to describe the participants. The questions in the questionnaire will focus on your gender; age; marital status; ethnicity; education level; employment status; relationship to the deceased; underlying medical condition of your significant other; date of death of your significant other; location of the death (hospital, home, long-term care/nursing home, hospice, or other); if the MAID event was in the desired location or setting; if palliative care services were involved prior to MAID;

where you lived in relation to where your significant other resided in the period before the death; what health care provider(s) were present at the MAID event; if you have seen the medical death certificate of your significant other, and whether it was completed using terms you expected. If you choose to participate, the questionnaire will be completed after you sign an informed consent and prior to the interview. The questionnaire will be sent to you via email or hard-copy through Canada Post. The questionnaire will take approximately 10 minutes to complete and any information that you provide will not be identified to you, as your name will not be on any documents.

Interview

The purpose of the interview is to explore your specific experience related to MAID, as well as, understanding the broader factors that may have influenced your experience and perspectives. If you choose to participate, a one-on-one interview via a video or telephone call, using the program Zoom will be set up. The interview will be either with or without the video and can be used on a computer or cell phone. The interview will be conducted at a time of your choice and I can guide you through the Zoom technology prior to the interview. The interview will take about 60 to 150 minutes (1.0 to 2.5 hours). All interviews will be audio recorded and transcribed. Your name and any other identifying information that might be present in the audio recording will be removed from the typed transcript. Prior to your involvement, we will go over the informed consent process.

To be considered for this study, you should be 19 years of age or over; able to speak and read English; able to consent to participate; reside in British Columbia or in the province of Alberta; are a family member of an individual who received MAID, and, the MAID event occurred in British Columbia or in the province of Alberta.

If you would like more information about this study and/or are interested in participating, please contact me directly at [email address] or [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply). I can review the informed consent process and once you confirm your wish to proceed, arrange for you to receive the consent form, and we can establish a time to complete the questionnaire and conduct the interview. At the time of the interview, I will review the informed consent form with you.

Thank you for taking the time to consider this invitation to be involved.

Sincerely,
Tracy L. Powell, RN, PhD(*c*)

School of Nursing

University of Victoria

Kelli I. Stajduhar, RN, PhD (Supervisor)

Professor, School of Nursing

Research Affiliate, Institute on Aging & Lifelong Health (IALH), University of Victoria

Scientist, End of Life Program Fraser Health

Appendix N: Participant Consent Form

Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

PARTICIPANT CONSENT FORM

Family Member

You are invited to participate in a study titled ***experiences of bereaved family members of recipients of medical assistance in dying*** (***MAID)*** that is being conducted by Tracy Powell.

Tracy Powell is a doctoral candidate in the School of Nursing at the University of Victoria, and nursing educator at Mount Royal University in Calgary, Alberta. Consent for this research is being sought by the researcher, who will answer questions you have about the research now, or later in the researcher process. Tracy can be contacted at [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply) and emailed at [email address].

As a graduate student, Tracy is required to conduct research as part of the requirements for completion of a doctoral degree in Nursing, and as such, the document (known as a dissertation) that will be produced from this research will be available to the public. The research is being conducted under the supervision of Dr. Kelli Stajduhar, Professor in the School of Nursing at the University of Victoria. The supervisor can be contacted at telephone [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply) or email address [email address].

Background and Purpose of the Study

You are invited to participate in a research study. Your participation must be free and voluntary. You are free to withdraw at any time.

Family members are known to be primary caregivers for loved ones during serious or terminal illness. During this trajectory, research indicates that family members experience challenges which may become even more complex if assisted dying becomes the choice of their significant other.

In Canada, assisted dying became an end-of-life option for eligible individuals in 2016, and since legalization, there has been variability noted across jurisdictions regarding medical assistance in dying (MAID) implementation, as well as in the associated policies, processes, and guidelines. The purpose of this study is to understand the experience and perspective of bereaved family members who have had a significant other end their life through MAID, and to describe how MAID implementation, policies, guidelines and processes in different provinces may have influenced these experiences.

Location of Research

This research is primarily being conducted on Vancouver Island, British Columbia (BC) and in Alberta (Central, Calgary and South zones). Research may also be conducted in other regions throughout BC and Alberta.

Number of Participants

We plan to interview approximately 15-20 family members from each of the provincial settings. We expect to interview between 30-40 bereaved family members in total.

What is Required if I Participate?

If you decide to participate, you will participate in a one-on-one interview via a video or telephone call, using the UVic-hosted version of Zoom. You will receive a unique password ID number from the researcher prior to the interview. You will log in using the number you received to gain access to the interview. The interview will be either with or without the video and can be used on a computer or cell phone. You are free to turn off your camera or mute your microphone if it is not needed. The interview will last approximately 60 to 150 minutes (1.0 to 2.5 hours). A facilitator will use a series of guiding questions and engage in a conversation with you regarding your experience when your significant other died through MAID. Interview questions will ask you to tell about: your experience as your significant other went through the MAID process; your perspectives on your significant other's choice for MAID; the MAID process and how it impacted your experience; and your experience since your significant other's death. The interview facilitator may ask additional questions in order to seek clarification or get you to elaborate on certain parts of your story.

The interview will be arranged at a time of your convenience, and will take place online using program Zoom, at a location of your choosing. The interview will be audio recorded for accuracy and typed by the transcriptionist who is hired for the project. Only audio of the interview will be saved and sent for transcription, any video of the interview will be not be saved.

You will also be asked to complete a demographic questionnaire. The questions in the questionnaire will focus on your gender; age; marital status; ethnicity; education level; employment status; relationship to the deceased; underlying medical condition of your significant other; date of death of your significant other; location of the death (hospital, home, long-term care/nursing home, hospice, or other); if the MAID event was in the desired location or setting; if palliative care services were involved prior to MAID; where you lived in relation to where your significant other resided in the period before the death; what health care provider(s) were present at the MAID event; if you have seen the medical death certificate of your significant other, and whether it was completed using terms you expected. The questionnaire will be completed prior to the interview. The questionnaire will take approximately 10 minutes to complete. Any information that you provide will not be identified to you, as your name will not be on any documents.

What are the Possible Risks or Inconveniences of Participating?

You may be exposed to the following risks and inconveniences:

- Psychological or emotional risk due to the personal, private and possibly intense experience of MAID and as a result of retelling your experience.
- Inconvenience due to time commitment.

To reduce these risks, the following steps will be taken:

- You do not have to answer any question you do not wish to answer. There are no right or wrong answers, we are seeking your opinion and insights. If at any time you find the discussion or telling of your experiences upsetting, you are welcome to stop the interview temporarily to compose yourself or withdraw from the interview all together without consequence. We can also offer you further support through a list of available resources which we will provide to you in hard copy form, at the time of the interview.
- The interview will be scheduled at a time of your choosing to reduce inconveniences as much as possible.

What are the Possible Benefits of Participating?

There may or may not be direct benefits to you from taking part in this study. We hope that the information learned from this study can be used to inform MAID practitioners, health care providers, health care administrators, health and social care educators, and advocacy groups about the experience of MAID; and that the information may be used to inform supportive interventions, policy, and programs for family members who have had a significant other participate in MAID.

Do I Have to Take Part?

You are free to participate or not. Participating in this study does not waive any of your legal rights to research related harm. If you do decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you do withdraw from the study, we will ask you if we can still use your collected data.

Will I be Paid for Taking Part?

You will not be provided with any payments or coverage of costs for participating in this study.

On-Going Consent

If new information becomes available, or if this project takes place over a longer period of time, we will ask you to renew your consent to participate. Sometimes a research project will recruit a subgroup of participants to perform other research activities. If this occurs, you will be provided with another consent form describing the new research activities and requesting your consent.

Confidentiality & How my Personal Information will be Used

Your confidentiality will be protected within limits of the law. Only the audio portion of the Zoom interview will be collected and used. To increase the protection of your identity and personal information, you will use the unique password ID number to access the interview.

The interview will be transcribed by a hired, professional transcriptionist and your name will be replaced with a unique identification number. In the event that names or identifying details about individuals, facilities, or organizations are provided during your interview, the transcriptionist will replace this information with pseudonyms. Interviews will be audio recorded. The recordings will be destroyed by the Primary Research Contact once the transcripts have been verified.

You are consenting to the use of the UVic-hosted Zoom service to complete the interview. Please be aware that Zoom servers are located outside of Canada, and Zoom stores *users' names and usage data outside of Canada.* Recordings of Zoom meetings are not stored on Zoom servers. UVic has contracted with Zoom to have all content stored on servers inside Canada, however, the implementation of the Canadian servers will not be completed until approximately mid-May 2020. Note that any study related videos sent outside of Canadian borders may increase the risk of disclosure of information because of the laws in those countries.

Until Canadian servers are confirmed, the use of the UVic-hosted version of Zoom is permitted by the *Freedom of Information and Protection of Privacy Act* (FIPPA) with consent by you, the participant attending the interview meeting.

Future Use of Data

Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar and Tracy Powell, research ethics approval will be sought before any secondary analysis is done with this data. The data will also be de-identified before used in the future. Data will be stored securely at Mount Royal University and in compliance with the highest standard of data management practices.

Disposal of Study Documents and Recordings

Additional documentation created during the study will be disposed of in the following manner:

Data Source	**How Destroyed**	**When Destroyed**
Completed consent forms, completed demographic questionnaires	Shredded	Five years after study completion.
Audio recordings	Erased/digital override	Immediately following verification of transcript.
Field notes/personal memos/interview notes	Shredded	One year after study completion.

Sharing of Study Results

We can inform you of the progress of the study throughout, and a summary of the study results will also be provided to you, upon request. Results of this study may be presented at academic and scientific conferences and at presentations to community members, including individuals and family members who are dealing with end-of-life issues and/or contemplating MAID; or for bereaved family members of

MAID who were not study participants. We will also engage with non-profit organizations which support individuals and family members related to MAID, palliative and end-of-life care.

Who Should I Contact if I Need More Information or Help?

The contact information for the Principal Investigator is:

Kelli Stajduhar, RN, PhD, Professor

Address: Institute on Aging & Lifelong Health, School of Nursing, University of Victoria

Phone Number: [telephone number]

Email: [email address]

If you have any questions or want further information about the study, you can contact:

Tracy L. Powell, RN, PhD(c)

Address: University of Victoria

Phone Number: [telephone number]

Email: [email address]

For questions or concerns about your rights as a research participant, please contact research ethics at the University of Victoria at [telephone number] or [email address].

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of Victoria

Study: Experiences of bereaved family members of recipients of medical assistance in dying (MAID).

PARTICIPANT CONSENT

My signature on this consent means:

- I have read and understood participant information and consent form.
- I understand that I will be using a Zoom video or telephone call to complete the interview, and it is entirely voluntary.
- I have the opportunity to ask questions and have had satisfactory response to my questions.
- I understand that I am completely free to refuse to participate or to withdraw from this study at any time and will in no way affect the present or future medical care that I may receive.
- I understand that all the information collected will be kept confidential and that the results will only be used for research purposes.
- I understand that the recording will be transcribed verbatim and my identity and personal information will be removed from the transcriptions.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no direct benefit from this study.
- I understand that the interview session will be recorded and saved for the purpose of review.
- I will receive a copy of this consent for my record.

I consent to participate in the study.

Participant's Name (Please Print):	Date:
____	_______________________
Person Obtaining Informed Consent (Please Print):	Signature:
____	_________________________

A copy of this consent form will be given to you, and a copy will be kept by the researcher.

The statements below are optional. Please tell the primary research contact to check those that apply to you.

We are asking to collect your email address in the event we need to clarify or discuss any of your interview answers in more detail. We are also asking to collect your email to notify you of publications and presentations about the study. Although you may not be aware of this fact, emails sent to some webmail services (e.g. Gmail, Hotmail, etc.), may be stored/routed outside of Canada (for example, in the United States). Due to the fact that future emails will contain personal information about you, including your name, the *Freedom of Information and Protection of Privacy Act* (*FIPPA)* requires that we obtain your consent before we continue. Tracy Powell will only send your personal information to the email address you have provided to her. All of the information which you provide to us will be kept completely confidential. Providing your email address means that you voluntarily agree and give your consent for the researcher to email your personal information to you.

☐ I give permission for the researcher to follow up with me privately by phone or email to clarify any of my interview answers or discuss any questions in more detail.

Email address: ___________________________________

Phone number: ___________________________________

☐ I would like to receive notification of publications and presentations about this study:

Email address: ____

☐ Same email address as above (if applicable).

Appendix O: Informed Consent Form

Informed Consent Form for Participation in a Research Study

Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Family Member

Researcher:	Kelli Stajduhar, RN, PhD, FCAHS Professor, Institute on Aging & Lifelong Health and School of Nursing, University of Victoria Phone Number: [telephone number] Email: [email address]
Student Co- Investigator:	Tracy L. Powell, RN, PhD(c) University of Victoria Phone Number: [telephone number] Email: [email address]
Funder(s)/Sponsor:	N/A

WHY AM I BEING ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being invited to participate in a research study because you are a family member who had a significant other receive medical assistance in dying (MAID) in Alberta, Canada. Family members are known to be primary caregivers for loved ones during serious or terminal illness. During this period, research shows that family members experience challenges which may become even more complex if assisted dying becomes the choice of their significant other. There is also information to suggest that since MAID legalization, there has been variability noted across provinces and territories regarding MAID implementation, as well as, in the associated policies, processes, and guidelines.

The purpose of this research study is to build an understanding regarding the experience and perspective of bereaved family members who have had a significant other end their life through MAID, and to describe how MAID implementation, policies, guidelines and processes in different provinces may have influenced the experience.

This study is primarily being conducted in Alberta (Central, Calgary and South areas of the province) and on Vancouver Island, British Columbia (BC).Research may also be conducted in other regions throughout BC and Alberta.

This consent form provides information about the study to assist you with making an informed decision. The student co-investigator will discuss this study with you and will answer any questions you may have. You are encouraged to ask questions. When all your questions have been answered to your satisfaction, you can decide if you want to be in the study or not.

Taking part in this study is voluntary. You may choose whether or not you take part. If you choose to participate, you may leave the study at any time without giving reason or without penalty. Deciding not to take part or deciding to leave the study early will not result in any penalty, or effect current or future care.

If you decide to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form for your personal records.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Up to 40 people will take part in this part of the study focusing on bereaved family members. Up to 20 of the people will be bereaved family members from Alberta, primarily in the Central, Calgary and South areas of the province; and up to 20 bereaved family members will take part primarily from Vancouver Island, BC.

WHAT WILL HAPPEN DURING THIS STUDY?

If you decide to participate, you will participate in a one-on-one interview via a video or telephone call, using the University of Victoria (UVic) hosted version of Zoom. You will receive a unique password ID number from the researcher prior to the interview. You will log in using the number you received to gain access to the interview. The interview will be either with or without the video and can be used on a computer or cell phone. You are free to turn off your camera or mute your microphone if it is not needed. The interview will last approximately 60 to 150 minutes (1.0 to 2.5 hours). In the interview, the student co-investigator will use a series of guiding questions and engage in a conversation with you regarding *your experience* when your significant other went through the process and had MAID. Interview questions will ask you to tell about: your experience as your significant other went through the MAID process; your perspectives on your significant other’s choice for MAID; the MAID process and how it impacted your experience; and your experience since your significant other’s death. The student co-investigator may ask additional questions in order to seek clarification or get you to elaborate on certain parts of your story.

The interview will be arranged at a time of your convenience, and will take place online using program Zoom, at a location of your choosing. The interview will be audio recorded for accuracy and typed by the transcriptionist who is hired for the project. Only audio of the interview will be saved and sent for transcription, any video of the interview will be not be saved.

You will also be asked to complete a demographic questionnaire. The questionnaire will be completed prior to the interview. The questionnaire will take approximately 10 minutes to complete. The questions in the questionnaire will focus on your gender; age; marital status; ethnicity; education level; employment status; relationship to the deceased; underlying medical condition of your significant other;

the month and year when your loved one died ; location of the death (hospital, home, long-term care/nursing home, hospice, or other); if the MAID event of your significant other was in the desired location or setting; if palliative care services were involved prior to MAID; where you lived in relation to where your significant other resided in the period before the death; what health care provider(s) were present at the MAID event; if you have seen the medical death certificate of your significant other, and whether it was completed using terms you expected.

Any information that you provide will not be identified to you, as your name will not be on any documents.

This study is part of a PhD program and should take 4 years to complete. The results should be known in within 2 years of completion of data collection.

WHAT ARE MY RESPONSIBILITIES SHOULD I DECIDE TO PARTICIPATE IN THIS STUDY?

If you choose to participate in this study, you will be expected to:

- Participate in a one-on-one interview
- Complete a demographic questionnaire

WHAT WILL HAPPEN IF I CHOOSE TO WITHDRAW FROM THE STUDY EARLY?

You can choose to end your participation in this research study (called early withdrawal) at any time without having to provide a reason and without penalty. If you choose to withdraw early from the study without finishing all data collection, you are encouraged to contact the student co-investigator, Tracy Powell at [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply) or email at [email address]. The researcher may also withdraw you from the study if she feels it is in your best interest.

If you do withdraw from the study, we will ask you if we can still use your collected data, but no additional information will be collected after you withdraw your permission.

WHAT ARE THE RISKS/DISCOMFORTS OF PARTICIPATING IN THIS STUDY?

You may be exposed to the following risks and inconveniences:

- Psychological or emotional risk due to the personal, private and possibly intense experience of MAID and as a result of retelling your experience.
- Inconvenience due to time commitment.

To reduce these risks, the following steps will be taken:

- You do not have to answer any question you do not wish to answer. There are no right or wrong answers, we are seeking your opinion and insights. If at any time you find the discussion or telling of your experiences upsetting, you are welcome to stop the interview temporarily to compose yourself or withdraw from the interview all together without consequence. We can also offer you further support through a list of available resources which we will provide to you in hard copy form, at the time of the interview.
- The interview will be scheduled at a time and location of your choosing to reduce inconveniences as much as possible.

WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that the information learned can be used to inform MAID practitioners, health care providers, health care administrators, health and social care educators, and advocacy groups about the experience of MAID; and that the information may be used to inform supportive interventions, policy, and programs for family members who have had a significant other receive MAID.

HOW WILL MY PERSONAL INFORMATION BE KEPT PRIVATE?

If you decide to participate, the researcher and student co-investigator will only collect information needed for this study. Each participant will be assigned a unique identification number (e.g., Family member 1 (FM-01) during the collecting of data and this unique identification number will be maintained throughout the study.

You are consenting to the use of the UVic-hosted Zoom service to complete the interview. Please be aware that Zoom servers are located outside of Canada, and Zoom stores *users' names and usage data outside of Canada.* Recordings of Zoom meetings are not stored on Zoom servers. UVic has contracted with Zoom to have all content stored on servers inside Canada, however, the implementation of the Canadian servers will not be completed until approximately mid-May 2020. Note that any study related videos sent outside of Canadian borders may increase the risk of disclosure of information because of the laws in those countries.

Until Canadian servers are confirmed, the use of the UVic-hosted version of Zoom is permitted by the *Freedom of Information and Protection of Privacy Act* (FIPPA) with consent by you, the participant attending the interview meeting.

The researcher and student co-investigator will do everything that they can to make sure that your data is kept private/confidential. Interviews will be audio recorded and only the audio portion of the Zoom interview will be collected and used. To increase the protection of your identity and personal information, you will use the unique password ID number to access the interview. Each interview will be transcribed by the professional transcriptionist hired for this project, and your name will be replaced with the unique identification number on this document. In the event that names or identifying details about individuals, facilities, or organizations are provided during your interview, the transcriptionist will replace this information with pseudonyms. Throughout the study, electronic data will be contained in a password protected computer. Paper copies of documents (e.g., consent form, demographic questionnaire, physical documents) will be kept in a locked filing cabinet at a secure location in Mount Royal University, the institution where the student co-investigator is employed.

No data relating to this study that includes your name will be released nor will it be published by the researcher or student co-investigator. Sometimes, by law, the researcher may have to release information including names and therefore absolute confidentiality cannot be guaranteed. However, every effort will be made to make sure that your information is kept confidential.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your information kept confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information. At no time will specific comments be connected to any participant unless an agreement is obtained beforehand.

Audio-recordings in this study will be stored in a secure location and accessed only by members of the research team. The audio-recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed/digitally erased by the student co-investigator. Field notes and personal memos will be kept at the secure location for one year after study completion, then will be shredded. Completed consent forms and demographic questionnaires will be kept at the secure location for five years after study completion, then will be shredded or digitally erased.

After the study is done, we will still need to securely store your data that was collected as part of the study. Electronic data from this study will continue to be stored in a password protected computer and will be retained for future graduate students and further secondary analysis by the researcher, Dr. Stajduhar, and the student co-investigator, Tracy Powell. Research ethics approval will be sought before any secondary analysis is done with this data. The data will also be de-identified before used in the future. Data will be stored securely at Mount Royal University and in compliance with the highest standard of data management practices. We will keep data and study records stored for 5 years after the end of the study.

WILL THERE BE COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

Costs for participating in this study may include long-distance telephone charges (depending on your location); and, gas, transit, or parking costs depending on where the interview takes place.

You will receive no reimbursement or coverage for costs for participating in this study.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

We can inform you of the progress of the study throughout.

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. If new information becomes available, or if this project takes place over a longer period of time, we will ask you to renew your consent to participate. Sometimes a research project will recruit a subgroup of participants to perform other research activities. If this occurs, you will be provided with another consent form describing the new research activities and requesting your consent.

You have the right to be informed of the results of this study once the entire study is complete. A summary of the study results will also be provided to you, upon your request. If you would like to be informed of the results of this study, please contact the student co-investigator, Tracy Powell.

IS THERE ANY CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest to declare.

WHO DO I CONTACT FOR QUESTIONS RELATED TO THIS STUDY?

If you have questions about taking part in this study or want further information about the study, you can contact:

Tracy L. Powell, RN, PhD(c)

Address: University of Victoria
Phone Number: [telephone number]
Email: [email address]

Kelli Stajduhar, RN, PhD, FCAHS
Professor
Address: Institute on Aging & Lifelong Health
School of Nursing, University of Victoria
Phone Number: [telephone number]
Email: [email address]

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta.

Telephone: [telephone number]
Toll Free: [telephone number]

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UNDERSTANDING AND SIGNATURES PAGE

	Yes	No
Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits and risks/discomforts of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand that a Zoom video or telephone call will be used to complete the interview	☐	☐
Do you understand that you are free to leave the study at any time, without out having to give reason or without penalty?	☐	☐
Do you understand that we will be collecting information about you for use in this study only?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?	☐	☐
Do you feel that you had enough time and opportunity to consider the information provided to you by way of asking questions, having conversations with others and considering your options?	☐	☐

If a potential participant has answered “no” to any question above, please make sure to go over the relevant information with them until they do understand it. ***Only once they are comfortable with all the information can you accept their decision to participate in the study.***

You consent to participate in the study.

Participant’s Name (Please Print): ________________________ Date:_______________

Person Obtaining Informed Consent (Please Print): ________________________________

Signature: ____

STUDY TEAM ACKNOWLEDGEMENT

I believe the person providing consent understands what is involved in this research study and has freely decided to participate.

Signature of Person Conducting the Consent Discussion	Printed Name	Date

You will be given a copy of this signed and dated consent form prior to participating in this optional research.

The statements below are optional. Please tell the student co-investigator to check those that apply to you.

We are asking to collect your email address in the event we need to clarify or discuss any of your interview answers in more detail. We are also asking to collect your email to notify you of publications and presentations about the study. Although you may not be aware of this fact, emails sent to some webmail services (e.g. Gmail, Hotmail, etc.), may be stored/routed outside of Canada (for example, in the United States). Due to the fact that future emails will contain personal information about you, including your name, the Freedom of Information and Protection of Privacy Act requires that we obtain your consent before we continue. Tracy Powell will only send your personal information to the email address you have provided to her. All of the information which you provide to us will be kept completely confidential. Providing your email address means that you voluntarily agree and give your consent for the researcher to email your personal information to you.

☐ I give permission for the researcher to follow up with me privately by phone or email to clarify any of my interview answers or discuss any questions in more detail.

Email address: ___________________________________

Phone number: ___________________________________

☐ I would like to receive notification of publications and presentations about this study.

Email address: ____

☐ Same email address as above (if applicable).

Appendix P: Letter of Initial Contact-Key Informant

Letter of Initial Contact-Key Informant

Tracy Powell, a doctoral candidate at the University of Victoria School of Nursing and a nursing educator at Mount Royal University in Calgary, Alberta, is conducting a research project to understand the experiences of bereaved family members who have had a significant other receive medical assistance in dying (MAID). Family members are known to be primary caregivers for loved ones during serious or terminal illness, and research indicates that family members also experience challenges which may become even more complex if assisted dying becomes the choice of their significant other.

You have been identified as someone who could offer key insights into this research study and this is an invitation to you to participate. The purpose of this study is to understand the experience and perspective of bereaved family members who have had a significant other end their life through MAID, and to describe how MAID implementation, policies, guidelines and processes in different provinces may have influenced these experiences. This study is focused on the experiences of bereaved family members in Central, Calgary or Central zones in the province of Alberta or on Vancouver Island, British Columbia.

Participation in this study is strictly voluntary and requires informed consent. Acceptance or refusal to participate in this study will in no way affect your employment or position. Your confidentiality will be protected in this study, however, a limit to confidentiality may result if you choose to participate during work hours, and inform your manager or supervisor about your participation. Participation in this study would require you to be interviewed by me and, prior to this, for you to complete a demographic questionnaire. Please accept my invitation to share your specific experience and knowledge.

Demographic questionnaire

The purpose of the questionnaire is to describe the participants. The questions in your questionnaire include gender, age, education level, occupation, role related to end-of-life care/MAID, and when you became connected to MAID. If you choose to participate, the questionnaire will be completed prior to the interview. The questionnaire will take 3-5 minutes to complete and any information that you provide will not be identified to you, as your name will not be on any documents. Prior to your involvement, we will go over the informed consent process and you will need to sign the consent form.

Interview

The purpose of the interview is to explore your specific experience and knowledge about implementation, policies and procedures related to MAID as well as, your understanding of broader factors that may influence the experience and perspectives of family members. If you choose to participate, a one-on-one interview via a video or telephone call, using the program Zoom will be set up.

The interview will be either with or without the video and can be used on a computer or cell phone. The interview will be scheduled a time that is convenient for you. The interview will take about 60 to 90 minutes (1.0 to 1.5 hours). All interviews will be audio recorded and transcribed. Your name and any other identifying information that might be present in the audio recording will be removed from the typed transcript. Prior to your involvement, I will go over the informed consent process.

Whether or not you choose to participate in this interview will in no way effect your employment or position.

The information gathered from this study may be used to inform doctors, nurses and social workers who are involved in MAID and palliative care, as well as, health care administrators, support and advocacy groups. There is also the potential that information from this study will inform supportive interventions, policy, and programs for family members who have had a significant other participate in MAID. Findings may also be published in academic or peer reviewed papers and presented at professional conferences.

If you would like more information about this study and/or are interested in participating, please contact me directly at [email address] or [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply). I can review the informed consent process and once you confirm your wish to proceed, arrange a place and time to conduct the interview. At the interview, I will review the informed consent form with you.

Thank you for taking the time to consider this invitation to be involved.

Sincerely,

Tracy L. Powell, RN, PhD(*c)*

School of Nursing

University of Victoria

Kelli I. Stajduhar, *RN, PhD* (Supervisor)

Professor, School of Nursing

Research Affiliate, Institute on Aging & Lifelong Health (IALH), University of Victoria

Scientist, End of Life Program Fraser Health

Appendix Q: Participant Consent Form – Key Informant

Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

PARTICIPANT CONSENT FORM

Key Informant

You are invited to participate in a study titled ***experiences of bereaved family members of recipients of medical assistance in dying*** (***MAID)*** that is being conducted by Tracy Powell.

Tracy Powell is a doctoral candidate in the School of Nursing at the University of Victoria, and nursing educator at Mount Royal University in Calgary, Alberta. Consent for this research is being sought by the researcher, who will answer questions you have about the research now, or later in the researcher process. Tracy can be contacted at [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply) and emailed at [email address].

As a graduate student, Tracy is required to conduct research as part of the requirements for completion of a doctoral degree in Nursing, and as such, the document (known as a dissertation) that will be produced from this research will be available to the public. The research is being conducted under the supervision of Dr. Kelli Stajduhar, Professor in the School of Nursing at the University of Victoria. The supervisor can be contacted at telephone [telephone number] (Note: this may be a long-distance number depending on your location and therefore long-distance charges may apply) or email address [email address].

Background and Purpose of the Study

You are invited to participate in a research study. Your participation must be free and voluntary. You are free to withdraw at any time.

Family members are known to be primary caregivers for loved ones during serious or terminal illness. During this trajectory, research indicates that family members experience challenges which may become even more complex if assisted dying becomes the choice of their significant other.

In Canada, assisted dying became an end-of-life option for eligible individuals in June 2016, and since legalization, there has been variability noted across jurisdictions regarding medical assistance in dying (MAID) implementation, as well as, in the associated policies, processes, and guidelines. The purpose of this study is to understand the experience and perspective of bereaved family members who have had a significant other end their life through MAID, and to describe how MAID implementation, policies, guidelines and processes in different provinces may have influenced these experiences.

Location of Research

This research is being conducted on Vancouver Island, British Columbia (BC) and in Alberta (Central, Calgary and South zones).

Number of Participants

We plan to interview approximately 10-15 key informants from each of the provincial settings. We expect to interview between 20-30 key informants in total.

What is Required if I Participate?

If you decide to participate, you will participate in a one-on-one interview via a video or telephone call, using the UVic-hosted version of Zoom. You will receive a unique password ID number from the researcher prior to the interview. You will log in using the number you received to gain access to the interview. The interview will be either with or without the video and can be used on a computer or cell phone. You are free to turn off your camera or mute your microphone if it is not needed. The interview will last approximately 60 to 90 minutes (1.0 to 1.5 hours).

A facilitator will use a series of guiding questions and engage in a conversation with you regarding your experience and knowledge about implementation, policies and procedures related to MAID, as well as, your understanding of broader factors that may influence the experience and perspectives of family members. Interview questions may ask you: about your experience with family members in relation to MAID; the kinds of things that you have noted as impacting family members in relation to MAID and what could enhance or ease their experience; if your colleagues ever discuss issues related to family members and MAID (and if so, how the discussions have come about and what was the essence of the discussion); if you perceive MAID processes in your area being enacted as the legislation and policy is outlined; and what could be improved related to MAID processes.

The interview will be arranged at a time of your convenience (for instance, during work hours) and will take place online using the program Zoom, at a location of your choosing (e.g., at your work site). The interview will be audio recorded for accuracy and typed by the transcriptionist who is hired for the project. Only audio of the interview will be saved and sent for transcription, any video of the interview will be not be saved.

You will also be asked to complete a demographic questionnaire. The questions in the questionnaire will focus on your gender, age, education level, occupation, role related to end-of-life care/MAID, and when you became connected to MAID. The questionnaire will be completed prior to the interview. The questionnaire will take approximately 3-5 minutes to complete and any information that you provide will not be identified to you, as your name will not be on any documents.

What are the Possible Risks or Inconveniences of Participating?

You may be exposed to the following risks and inconveniences:

- Psychological or emotional risk as a result of retelling your experiences related to MAID, or due to the possibly intense experience of MAID.
- Inconvenience due to time commitment.

To reduce these risks, the following steps will be taken:

- You do not have to answer any question you do not wish to answer. There are no right or wrong answers, we are seeking your opinion and insights. If at any time you find the discussion or telling of your experiences upsetting, you are welcome to stop the interview temporarily to compose yourself or withdraw from the interview all together without consequence. We can also offer you further support through a list of available resources which we will provide to you in hard copy form, at the time of the interview.
- The interview will be scheduled at a time of your choosing to reduce inconveniences as much as possible.

What are the Possible Benefits of Participating?

There may or may not be direct benefits to you from taking part in this study. We hope that the information learned from this study can be used to inform MAID practitioners, health care providers, health care administrators, health and social care educators, and advocacy groups about the experience of MAID; and that the information may be used to inform supportive interventions, policy, and programs for family members who have had a significant other participate in MAID.

Do I Have to Take Part?

You are free to participate or not. If you decide not to participate your employment status will not be affected in any way. Participating in this study does not waive any of your legal rights to research related harm. If you do decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you do withdraw from the study, we will ask you if we can still use your collected data.

Will I be Paid for Taking Part?

You will not be provided with any payments or coverage of costs for participating in this study.

On-Going Consent

If new information becomes available, or if this project takes place over a longer period of time, we will ask you to renew your consent to participate. Sometimes a research project will recruit a subgroup of participants to perform other research activities. If this occurs, you will be provided with another consent form describing the new research activities and requesting your consent.

Confidentiality & How my Personal Information will be Used

Your confidentiality will be protected within limits of the law. A limit to confidentiality may result if you choose to participate during work hours, and inform your manager or supervisor about your participation. Only the audio portion of the Zoom interview will be collected and used. To increase the protection of your identity and personal information, you will use the unique password ID number to access the interview.

The interview will be transcribed by a hired, professional transcriptionist and your name will be replaced with a unique identification number. In the event that names or identifying details about individuals, facilities, or organizations are provided during your interview, the transcriptionist will replace this information with pseudonyms. Interviews will be audio recorded. The recordings will be destroyed by the Primary Research Contact once the transcripts have been verified.

You are consenting to the use of the UVic-hosted Zoom service to complete the interview. Please be aware that Zoom servers are located outside Canada, and Zoom stores *users' names and usage data outside of Canada*. Recordings of Zoom meetings are not stored on Zoom servers. UVic has contracted with Zoom to have all content stored on servers inside Canada, however, the implementation of the Canadian servers will not be completed until approximately mid-May 2020. Note that any study related videos sent outside of Canadian borders may increase the risk of disclosure of information because of the laws in those countries.

Until Canadian servers are confirmed, the use of the UVic-hosted version of Zoom is permitted by the *Freedom of Information and Protection of Privacy Act* (FIPPA) with consent by you, the participant attending the interview meeting.

Future Use of Data

Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar and Tracy Powell, research ethics approval will be sought before any secondary analysis is done with this data. The data will also be de-identified before used in the future. Data will be stored securely at Mount Royal University and in compliance with the highest standard of data management practices.

Disposal of Study Documents and Recordings

Additional documentation created during the study will be disposed of in the following manner:

Data Source	**How Destroyed**	**When Destroyed**
Completed consent forms, completed demographic questionnaires	Shredded	Five years after study completion.
Audio recordings	Erased/digital override	Immediately following verification of transcript.
Field notes/personal memos/interview notes	Shredded	One year after study completion.

Sharing of Study Results

A summary of the study results will be provided to you upon request. We will also offer to present the findings to your health care team. Results of this study may be presented at academic and scientific conferences and at presentations to community members, including individuals and family members who are dealing with end-of-life issues and/or contemplating MAID; or for bereaved family members of MAID who were not study participants. We will also engage with non-profit organizations which support individuals and family members related to MAID, palliative and end-of-life care.

Who Should I Contact if I Need More Information or Help?

The contact information for the Principal Investigator is:

Kelli Stajduhar, RN, PhD, Professor

Address: Institute on Aging & Lifelong Health, School of Nursing, University of Victoria

Phone Number: [telephone number]

Email: [email address]

If you have any questions or want further information about the study, you can contact:

Tracy L. Powell, RN, PhD(c)

Address: University of Victoria

Phone Number: [telephone number]

Email: [email address]

For questions or concerns about your rights as a research participant, please contact research ethics at the University of Victoria at [telephone number] or [email address].

island health

University of Victoria

Study: Experiences of bereaved family members of recipients of medical assistance in dying (MAID).

PARTICIPANT CONSENT

My signature on this consent means:

- I have read and understood participant information and consent form.
- I understand that I will be using a Zoom video or telephone call to complete the interview, and it is entirely voluntary.
- I have the opportunity to ask questions and have had satisfactory response to my questions.
- I understand that I am completely free to refuse to participate or to withdraw from this study at any time.
- I understand that all the information collected will be kept confidential and that the results will only be used for research purposes.
- I understand that the recording will be transcribed verbatim and my identity and personal information will be removed from the transcriptions.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no direct benefit from this study.
- I understand that the interview session will be recorded and saved for the purpose of review.

I will receive a copy of this consent for my record.

I consent to participate in the study.

Participant's Name (Please Print): ____________________________ Date _________________

Person Obtaining Informed Consent (Please Print): ____________________________________

Signature: ____

***A copy of this consent form will be given to you, and a copy will be kept by the researcher*.**

The statements below are optional. Please tell the primary research contact to check those that apply to you.

We are asking to collect your email address in the event we need to clarify or discuss any of your interview answers in more detail. We are also asking to collect your email to notify you of publications and presentations about the study. Although you may not be aware of this fact, emails sent to some webmail services (e.g. Gmail, Hotmail, etc.), may be stored/routed outside of Canada (for example, in the United States). Due to the fact that future emails will contain personal information about you, including your name, the *Freedom of Information and Protection of Privacy Act* (FIPPA) requires that we obtain your consent before we continue. Tracy Powell will only send your personal information to the email address you have provided to her. All of the information which you provide to us will be kept completely confidential. Providing your email address means that you voluntarily agree and give your consent for the researcher to email your personal information to you.

☐ I give permission for the researcher to follow up with me privately by phone or email to clarify any of my interview answers or discuss any questions in more detail.

Email address: ___________________________________

Phone number: ___________________________________

☐ I would like to receive notification of publications and presentations about this study:

Email address: ____

☐ Same email address as above (if applicable).

Appendix S: Demographic Questionnaire (Family Member)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Please answer all questions to the best of your ability. This information will provide additional information about you. All information will be anonymous.

ID# __________

What gender do you identify with? ______________

What is your age (in years)? _____________

Please specify your ethnicity: ___________________________

What is the highest degree or level of school you have completed?

☐ Below High School
☐ High School Diploma
☐ College Diploma
☐ Baccalaureate Degree
☐ Post-Graduate Degree
☐ Other__________

What is your marital status? ____________________________

What is your current employment status?

☐ Retired
☐ Part-time
☐ Other (Casual, contract)
☐ Unemployed
☐ Full-time

What was your employment status when your loved one had their MAID event?

ID# __________

Where did your loved one die? (e.g. hospital, home, long-term care/nursing home, hospice, or other)

☐ Hospital ☐ Home ☐ Long-term care/nursing home

☐ Hospice ☐ Other________________________________

Was this location or setting chosen by your loved one?

☐ Yes

☐ No

If no, please explain: ____

What health care provider(s) were present at the MAID event?

☐ Physician ☐ Registered nurse (RN) ☐ Social worker

☐ Nurse Practitioner ☐ Spiritual care provider ☐ Other______________

Were palliative care services involved prior to MAID?

☐ Yes

☐ No

If no, please explain: ____

Where did you live in relation to where your significant other lived in the time leading up to their death?

Appendix T: Demographic Questionnaire (Family Member) (Alberta)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Please answer all questions to the best of your ability. This information will provide additional information about you. All information will be anonymous.

ID# __________

What gender do you identify with? _______________

What is your age (in years)? ______________

Please specify your ethnicity: _____________________________

What is the highest degree or level of school you have completed?

☐ Below High School ☐ High School Diploma ☐ College Diploma

☐ Baccalaureate Degree ☐ Post-Graduate Degree ☐ Other__________

What is your marital status? ______________________________

What is your current employment status?

☐ Retired ☐ Part-time ☐ Other (Casual, contract)

☐ Unemployed ☐ Full-time

What was your employment status when your loved one had their MAID event?

ID# __________

Where did your loved one die? (e.g. hospital, home, long-term care/nursing home, hospice, or other)

☐ Hospital ☐ Home ☐ Long-term care/nursing home

☐ Hospice ☐ Other_______________________________

Was this location or setting chosen by your loved one?

☐ Yes

☐ No

If no, please explain: ____

What health care provider(s) were present at the MAID event?

☐ Physician ☐ Registered nurse (RN) ☐ Social worker

☐ Nurse Practitioner ☐ Spiritual care provider ☐ Other______________

Were palliative care services involved prior to MAID?

☐ Yes

☐ No

If no, please explain: ____

Where did you live in relation to where your significant other lived in the time leading up to their death?

Appendix U: Demographic Questionnaire (Key Informants)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Please answer all questions to the best of your ability. This information will provide additional information about you. All information will be anonymous.

ID# ___________

What gender do you identify with? _______________

What is your age (in years)? ______________

What is the highest degree or level of education?

☐ Below High School ☐ High School Diploma ☐ College Diploma

☐ Baccalaureate Degree ☐ Post-Graduate Degree ☐ Other___________

What is your profession/occupation? _______________________________________

What is your role related to MAID/ end-of-life care? ___________________________

When did you become connected to MAID?

☐ Before implementation (prior to June 2016)

☐ At implementation (June 2016)

☐ During the first year of legalization (July 2016 to June 2017)

☐ During the second year of legalization (July 2017-June 2018)

☐ In the past year (since July 2018)

☐ Other___________

Appendix V: Interview Guide (Family Member)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Introduction: Thank you for being willing to meet today and to participate in this discussion and the research about the experiences of family members of MAID recipients. I am Tracy Powell, a doctoral candidate in the School of Nursing at the University of Victoria, and a nurse educator at Mount Royal University in Calgary. I am a nurse with a background in caring for people with cancer and other life limiting illnesses.

In this project I am looking for *your* personal perspective and I would like to understand your experience – in your own words, and with all the uniqueness of you and your family. This is, of course, a personal and emotional subject and this is particularly why I wanted to meet with you personally, and to take our time. If you need anything – a drink of water, a short break or otherwise, during the interview please don't hesitate. It is also your right to stop the interview at any time and to withdraw from the study for any reason. If you decide to withdraw from the study, you will be given the choice of allowing your data to be included in the study or not.

Before you begin, I would like to remind you that the interview is being audio-recorded and will be transcribed by Angela McNally, who is hired for the project. Angela McNally has signed an oath of confidentiality related to her work on this project.

*Review consent form.

Interview questions:

Can you tell me a little bit about yourself and how MAID came to be part of your experience?

Can you describe a bit more about your specific experience as your significant other went through the MAID process?

> *Probe:* Begin each with Please …
>
> Tell me your level of involvement and responsibility you had in the MAID process
>
> Tell me about your family and if there were tensions among members when your loved one chose MAID
>
> Tell me about the most challenging part of your experience
>
> Tell me about the most beneficial part of the experience
>
> Tell me about any support you received during the experience

Can you tell me about your perspectives on your significant other's choice for MAID?

> *Probe:* Begin each with Please …
>
> Tell me about any moral and ethical issues you had

Tell me about your perspective on death as a result of the EOL process your significant other underwent

Can you tell me about the MAID process and how it impacted your experience?

Probe: Begin each with Please …

Tell me about your loved one's process with MAID eligibility criteria

Tell me about the MAID process as you experienced it, and if it was as you expected

Tell me about the location of your loved one's death

Tell me if the location influenced your experience at the time of the death or after

Tell me about a situation/occurrence during the MAID process stuck with you the most

Tell me about your experience with health care professionals and the MAID team

Tell me to what extent were palliative care services discussed or offered to your significant other

Tell me if there is anything you would change about EOL care or MAID (including the process, legislation, eligibility criteria) based on your experience

Can you tell me about your experience since your significant other's death?

Probe: Begin each with Please …

Tell me about your life since going through MAID with your significant other

Tell me how the death was disclosed to family, friends and members of your community

Tell me would you change related to supports and services for family members who have a loved one choose MAID

Summary:

Is there anything you would like to talk about before we end the interview?

Would I be able to contact you if I have additional questions?

Are there any documents, that you know of, that pertain to what you have discussed with me today? (If response is yes) Would be willing to share them with me?

Would you like to be kept up-to-date on the progress of the study and be provided with a summary of the findings following completion of the study? (If yes, confirm how and method of contact).

Closing:

Thank you for taking the time to participate in this study, and for being willing to discuss your experience.

I want to remind you that you are still able to withdraw from the study without any problems, but it would need to be done prior to when I analyze the data, and to do this, you would just need to contact me and let me know.

This discussion today may have been of a sensitive nature for you and it may have brought up feelings and emotions that may cause you distress. If this happens, please contact your health care provider, and there are also other resources that are available in this (provide them with the resource list for their area) information sheet.

Appendix W: Bereavement Resources and Supports on Vancouver Island, British Columbia

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Talking about your experience related to MAID and the death of your significant other may cause some emotional reactions. If you feel your physical or emotional health is affected, it is recommended that you make an appointment to see **your family physician/nurse practitioner**.

If this is not possible (for whatever reason), the following is a list of resources that you may wish to contact if you feel you may need bereavement or grief support in your community:

If you or someone you know is in crisis, please call the **24-hour Vancouver Island Crisis Line**:

- [telephone number]
- www.vicrisis.ca or go to your nearest hospital emergency department.

The **Victoria MAiD Bereavement Support Group** meets the 1st and 3rd Thursday of each month 3:00–4:30 P.M. Victoria Health Unit 1947 Cook St., Victoria, BC. For information contact the Clinical Specialist at [telephone number]

Hospice Societies on Vancouver Island

Hospice Societies on Vancouver Island also offer a range of bereavement supports

Please check the one closest to you for additional resources and specific information.

- Alberni Hospice Society www.albernihospice.ca
- Campbell River Hospice Society www.crhospice.org
- Comox Valley Hospice Society www.comoxhospice.com
- Cowichan Valley Hospice Society www.cowichanvalleyhospice.org
- Nanaimo Community Hospice Society www.nanaimohospice.com
- Oceanside Hospice Society www.oceansidehospice.com
- Pacific Rim Hospice Society www.pacificrimhospice.ca
- Saltspring Hospice Society www.saltspringhospice.org
- Sooke Hospice Society www.sookehospice.com
- Victoria Hospice Society www.victoriahospice.org

Online Bereavement Resources and Supports

Victoria Hospice provides booklets and pamphlets about many aspects of grief and bereavement which can be accessed online at: www.victoriahospice.org/patients-families/useful-brochures.

BC Bereavement Helpline is a resource for people to find bereavement support within their own community.

- www.bcbh.ca phone
- [telephone number]

Bridge C-14 provides compassionate support to families throughout their journey with MAiD.

- www.bridgec14.org

Canadian Association of MAiD Assessors and Providers

- www.camapcanada.ca

Canadian Virtual Hospice "Ask A Professional" is a resource that offers a way to submit questions to health care providers, including grief counsellors.

- www.virtualhospice.ca

Compassionate Friends is a peer support group for parents who have experienced the death of a child (of any age).

- www.tcfcanada.net

Dying with Dignity Canada is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

Contact: Nino Sekopet, personal support program.

- [telephone number] or [email address]

KidsGrief.ca is an interactive network of information and support for parents and caregivers supporting bereaved children and youth.

- www.kidsgrief.ca

Learning Through Loss offers grief and loss education and supportive programs for youth.

- www.learningthroughloss.org

MyGrief.ca is an interactive network of information and support for people dealing with life-threatening illness and loss.

- www.mygrief.ca

Appendix X: Bereavement Resources and Supports in Alberta (Central Zone)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Talking about your experience related to MAID and the death of your significant other may cause some emotional reactions. If you feel your physical or emotional health is affected, it is recommended that you make an appointment to see **your family physician/nurse practitioner**.

If this is not possible (for whatever reason), the following is a list of resources that you may wish to contact if you feel you may need bereavement or grief support in your community:

Health Link

A telephone service, which provides free 24/7 nurse advice and general health information for Albertans.

- Call 811; https://www.albertahealthservices.ca/info/Page12630.aspx

If you or someone you know is in crisis, please call the **24-hour Mental Health Help Line** in Alberta:

- [telephone number] (Toll free)
- https://www.albertahealthservices.ca/findhealth/Service.aspx?id=6810&serviceAtFacilityID=1047134 *or* go to your nearest hospital emergency department.

Bereavement Support Program Provided by Alberta Health Services (Central Zone):

Drayton Valley Hospital and Care Centre

4550 Madsen Avenue, Drayton Valley, Alberta T7A 1N8

- [telephone number]

Red Deer Regional Hospital Centre

3942 50A Avenue, Red Deer, Alberta T4N 4E7

- [telephone number]

Rimbey Hospital and Care Centre

5228 50 Avenue, Rimbey, Alberta T0C 2J0

- [telephone number]

Rocky Mountain House Health Centre

5016 52 Avenue, Rocky Mountain House, Alberta T4T 1T2

- [telephone number]

Sundre Hospital and Care Centre

709 1 Street NE, Sundre, Alberta T0M 1X0

- [telephone number]

Red Deer Hospice Care provided by Red Deer Hospice Society

99 Arnot Avenue, Red Deer, Alberta T4R 3S6

- [telephone number]

Online Bereavement Resources and Supports:

Alberta Health provides information and videos about many aspects of grief and bereavement which can be accessed online at: https://www.albertahealthservices.ca/info/Page13161.aspx

Bridge C-14 provides compassionate support to families throughout their journey with MAiD.

- www.bridgec14.org

Canadian Association of MAiD Assessors and Providers

- www.camapcanada.ca

Canadian Virtual Hospice “Ask A Professional” is a resource that offers a way to submit questions to health care providers, including grief counsellors.

- www.virtualhospice.ca

Compassionate Friends is a peer support group for parents who have experienced the death of a child (of any age).

- www.tcfcanada.net

Dying with Dignity Canada is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

Contact: Nino Sekopet, personal support program.

- [telephone number] or [email address]

KidsGrief.ca is an interactive network of information and support for parents and caregivers supporting bereaved children and youth.

- www.kidsgrief.ca

Learning Through Loss offers grief and loss education and supportive programs for youth.

- www.learningthroughloss.org

MyGrief.ca is an interactive network of information and support for people dealing with life-threatening illness and loss.

- www.mygrief.ca

Appendix Y: Bereavement Resources and Supports in Alberta (Calgary Zone)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Talking about your experience related to MAID and the death of your significant other may cause some emotional reactions. If you feel your physical or emotional health is affected, it is recommended that you make an appointment to see **your family physician/nurse practitioner**.

If this is not possible (for whatever reason), the following is a list of resources that you may wish to contact if you feel you may need bereavement or grief support in your community:

Health Link

A telephone service, which provides free 24/7 nurse advice and general health information for Albertans.

- Call 811; https://www.albertahealthservices.ca/info/Page12630.aspx

If you or someone you know is in crisis, please call the **24-hour Mental Health Help Line** in Alberta:

- [telephone number] (Toll free)
- https://www.albertahealthservices.ca/findhealth/Service.aspx?id=6810&serviceAtFacilityID=1047134 *or* go to your nearest hospital emergency department.

Bereavement Support Programs (Calgary Zone**):**

Grief support program provided by **Alberta Health Services**

Bob Glasgow Grief Support Centre, Third Floor

1820 Richmond Road SW, Calgary, Alberta, T2T 5C7

- [telephone number]

Calgary Chapter - Dying with Dignity Canada

Contact: June Churchill (June is a retired social worker)

- [email address]
- [telephone number]

When you contact June she will establish a time to meet with you.

Grief support program provided by **Compassionate Friends of Canada**

Calgary First Evangelical Free Church

732-55 Avenue SW, Calgary, Alberta T2V 0G3

- [telephone number]

Online Bereavement Resources and Supports

Alberta Health provides information and videos about many aspects of grief and bereavement which can be accessed online at: https://www.albertahealthservices.ca/info/Page13161.aspx

Bridge C-14 provides compassionate support to families throughout their journey with MAiD.

- www.bridgec14.org

Canadian Association of MAiD Assessors and Providers

- www.camapcanada.ca

Canadian Virtual Hospice "Ask A Professional" is a resource that offers a way to submit questions to health care providers, including grief counsellors.

- www.virtualhospice.ca

Compassionate Friends is a peer support group for parents who have experienced the death of a child (of any age).

- www.tcfcanada.net

Dying with Dignity Canada is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

Contact: Nino Sekopet, personal support program.

- [telephone number] or [email address]

KidsGrief.ca is an interactive network of information and support for parents and caregivers supporting bereaved children and youth.

- www.kidsgrief.ca

Learning Through Loss offers grief and loss education and supportive programs for youth.

- www.learningthroughloss.org

MyGrief.ca is an interactive network of information and support for people dealing with life-threatening illness and loss.

- www.mygrief.ca

Appendix Z: Bereavement Resources and Supports in Alberta (South Zone)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Talking about your experience related to MAID and the death of your significant other may cause some emotional reactions. If you feel your physical or emotional health is affected, it is recommended that you make an appointment to see **your family physician/nurse practitioner**.

If this is not possible (for whatever reason), the following is a list of resources that you may wish to contact if you feel you may need bereavement or grief support in your community:

Health Link

A telephone service, which provides free 24/7 nurse advice and general health information for Albertans.

- Call 811; https://www.albertahealthservices.ca/info/Page12630.aspx

If you or someone you know is in crisis, please call the **24-hour Mental Health Help Line** in Alberta:

- [telephone number] (Toll free)
- https://www.albertahealthservices.ca/findhealth/Service.aspx?id=6810&serviceAtFacilityID=1047134 *or* go to your nearest hospital emergency department.

Distress Centre

- [telephone number]; www.distresscentre.com
- 24-hour crisis line, counselling and intervention services; Online counselling is available from 5-10pm daily

Bereavement Support Programs (South Zone):

Lethbridge

1107- 2A Avenue N, Lethbridge, Alberta T1H 0E6

- [telephone number]

Lethbridge Family Services General Bereavement Group

- For more information, please contact the Intake Office: [telephone number]

Lethbridge Mental Health Clinic

200 – 5 Avenue South

- Phone: [telephone number]   Fax: [fax number]

TUESDAYS & WEDNESDAYS from 12:30 to 3:00 or FRIDAYS from 9:00 to 11:00. Bring Alberta Health card, and a list of medications you are presently taking.

On Our Own- Lethbridge, Lethbridge Senior Citizens Organization (LSCO)

500 – 11 Street South Lethbridge

- For more information, call [telephone number]

A support group for widows, widowers and divorcees. Meet for a social hour every Wednesday in the LSCO Dining Room at 2:00 pm; there is also the opportunity for the recently bereaved to meet separately and share their grief

MDM Community Centre

2802-222 Street, Bellevue, Alberta T0K 0E0

- [telephone number]

Alberta Health Services – Addictions & Mental Health Services

2 – 346 3 St. S.E. (Provincial Building), Medicine Hat, Alberta

- [telephone number] *No fee

Medicine Hat

1 Dunmore Road SE, Medicine Hat, Alberta T1A 1Z5

- [telephone number]

Online Bereavement Resources and Supports:

Alberta Health provides information and videos about many aspects of grief and bereavement which can be accessed online at: https://www.albertahealthservices.ca/info/Page13161.aspx

Bridge C-14 provides compassionate support to families throughout their journey with MAiD.

- www.bridgec14.org

Canadian Association of MAiD Assessors and Providers

- www.camapcanada.ca

Canadian Virtual Hospice "Ask A Professional" is a resource that offers a way to submit questions to health care providers, including grief counsellors.

- www.virtualhospice.ca

Compassionate Friends is a peer support group for parents who have experienced the death of a child (of any age).

- www.tcfcanada.net

Dying with Dignity Canada is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

Contact: Nino Sekopet, personal support program.

- [telephone number] or [email address]

KidsGrief.ca is an interactive network of information and support for parents and caregivers supporting bereaved children and youth.

- www.kidsgrief.ca

Learning Through Loss offers grief and loss education and supportive programs for youth.

- www.learningthroughloss.org

MyGrief.ca is an interactive network of information and support for people dealing with life-threatening illness and loss.

- www.mygrief.ca

Appendix AA: Interview Guide (Key Informants)

Research Title: Experiences of bereaved family members of recipients of medical assistance in dying (MAID)

Introduction:

Thank you for being willing to meet today and to participate in this discussion and the research about the experiences of family members of MAID recipients. I am Tracy Powell, a doctoral candidate in the School of Nursing at the University of Victoria, and a nurse educator at Mount Royal University in Calgary. I am a nurse with a background in caring for people with cancer and other life limiting illnesses.

In this project I am looking for *your* personal perspective and I would like to understand your experience – in your own words, and with all the uniqueness of you and your role in health and community care related to MAID. This is, of course, a personal and emotional subject and this is particularly why I wanted to meet with you personally, and to take our time. If you need anything – a drink of water, a short break or otherwise, during the interview please don't hesitate. It is also your right to stop the interview at any time and to withdraw from the study for any reason. If you decide to withdraw from the study, you will be given the choice of allowing your data to be included in the study or not.

Before you begin, I would like to remind you that the interview is being audio-recorded and will be transcribed by Angela McNally, who is hired for the project. Angela McNally has signed an oath of confidentiality related to her work on this project.

*Review consent form.

In-depth interview questions for key informants:

Questions might include:

1. To begin, please tell me a little bit about yourself and your involvement with MAID?
2. What has been your experience with family members in relation to MAID?
3. What are the kinds of things that you have identified as impacting family members in relation to MAID? What could enhance or ease their experience?
4. Do your colleagues ever discuss issues related to family members and MAID? If so, how have they come about? Could you comment generally on the discussions?
5. From your perspective, are MAID processes in your area being enacted as the legislation and policy is outlined? What do you think could be improved?

Summary:

Do you have any additional comments or questions?

Would I be able to contact you if I have additional questions?

Are there any documents that you know of that pertain to what you have discussed and would be willing to share with me?

Closing:

Thank you for taking the time to participate in this study, and for being willing to discuss your experience. I want to remind you that you are still able to withdraw from the study without any problems, but it would need to be done prior to when I analyze the data, and to do this, you would just need to contact me and let me know.

Aspects of this discussion today may have brought up feelings and emotions that may cause you distress. If this happens, please contact your health care provider, and there are also other resources that are available in this (provide them with the resource list for their area) information sheet.

Appendix BB: Documents as Part of Data Collection

1. Alberta Health Services. (n.d.-a). *Health professionals: Medical assistance in dying*. https://www.albertahealthservices.ca/info/Page14381.aspx
2. Alberta Health Services. (n.d.-b). *Medical assistance in dying.* https://www.albertahealthservices.ca/info/page13497.aspx
3. Alberta Health Services. (2016). *Medical assistance in dying: What are my options?*
4. Alberta Health Services. (2019). *Record of request for medical assistance in dying* (No. HSP11175). https://cfr.forms.gov.ab.ca/Form/HSP11175.pdf
5. Alberta Health Services. (2019, January 23). *What is medical assistance in dying* (*MAID)?* https://www.albertahealthservices.ca/news/features/2019/Page14894.aspx
6. Alberta Health Services. (2021). *2020-21 report to the community: AHS map and zone overview*. https://www.albertahealthservices.ca/assets/about/publications/ahs-ar-2021/zones.html
7. Alberta Health Services. (2021). *Medical assistance in dying* (Policy # HCS-165-01). https://extranet.ahsnet.ca/teams/policydocuments/1/clp-med-assist-in-death-hcs-165-01.pdf
8. Alberta Health Services. (2021). *MAID Care Coordination Service*. https://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-coordination-service.pdf
9. Alberta Health Services. (2021). *How to access MAID Services*. https://www.albertahealthservices.ca/assets/info/maid/if-maid-how-access-medical-assistance-in-dying-in-alberta.pdf
10. Bill C-7, *An Act to amend the Criminal Code* (*medical assistance in dying)*. (2021). 2nd Session, 43rd Parliament. https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent
11. Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other acts* (*medical assistance in dying)*. (2016). 1st Session, 42nd Parliament. https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent
12. Carter v. Canada, 2015 1 SCR 331. https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do
13. Covenant Care. (2016). *Responding to requests for medical assistance in dying*. https://covenantcare.ca/wp-content/uploads/2016/05/responding-to-requests-for-medical-assistance-in-dying-may-24-2016.pdf
14. Covenant Health. (2018). *Responding to requests for medical assistance in dying.* https://www.covenanthealth.ca/media/124082/medical-assistance-in-dying-vii-b-440-december-3-2018-final.pdf
15. Criminal Code, RSC 1985, c C-46 [Canada]. https://www.canlii.org/en/ca/laws/stat/rsc-1985-c-c-46/latest/
16. Department of Justice Canada. (2020, October 5). *Government of Canada reintroduces proposed changes to medical assistance in dying legislation*. https://www.canada.ca/en/department-justice/news/2020/10/government-of-canada-reintroduces-proposed-changes-to-medical-assistance-in-dying-legislation.html

17. Dying with Dignity Canada. (n.d.). *Navigating a request for medical assistance in dying*. https://www.dyingwithdignity.ca/end-of-life-support/navigating-a-request-for-medical-assistance-in-dying/
18. Government of British Columbia. (n.d.). *Medical assistance in dying.* https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying
19. Government of British Columbia. (2021, June). *Regional health authorities*. https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/regional-health-authorities
20. Government of Canada. (2022, December 28). *Monitoring System for Medical Assistance in Dying in Canada.* https://www.canada.ca/en/health-canada/services/publications/health-system-services/monitoring-system-medical-assistance-dying.html
21. Health Canada. (2017, April 26). *Interim update on medical assistance in dying June 17 to December 31, 2016.* https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html
22. Health Canada. (2017, October 6). *Second interim report on medical assistance in dying in Canada.* https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-sep-2017.html
23. Health Canada. (2018, June). *Third interim report on medical assistance in dying in Canada.* https://www.canada.ca/content/dam/hc-sc/documents/services/ publications/health-system-services/medical-assistance-dying-interim-report-june-2018/medical-assistance-dying-interim-report-june-2018-eng.pdf
24. Health Canada. (2019, April). *Fourth interim report on medical assistance in dying in Canada.* https://www.canada.ca/content/dam/hc-sc/documents/services/ publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf
25. Health Canada. (2020, July). *First annual report on medical assistance in dying in Canada 2019*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf
26. Health Canada. (2021, June 30). *Second annual report on medical assistance in dying 2020*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2020/annual-report-2020-eng.pdf
27. Health Canada. (2022, July). *Third annual report on medical assistance in dying in Canada 2021*. https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2021/annual-report-2021.pdf
28. Health Canada. (2023, March 14). *Interim update on medical assistance in dying in Canada June 17 to December 31, 2016*. https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html

29. Island Health. (n.d.). *Learn about health: Medical assistance in dying* (*MAiD).* https://www.islandhealth.ca/learn-about-health/medical-assistance-dying/medical-assistance-dying
30. Island Health. (2019, April 23). *Medical assistance in death* (*MAiD): A guide to support patients & families.* https://www.islandhealth.ca/sites/default/files/MAiD/documents/maid-bereavement-guide-patients-families.pdf
31. Province of British Columbia. (n.d.-a). *Medical assistance in dying*. https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying
32. Province of British Columbia. (n.d.-b). *Provincial Health Services Authority*. https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/provincial-health-services-authority
33. Province of British Columbia. (2023, January 1). *Medical assistance in dying – information for health-care providers*. https://www2.gov.bc.ca/gov/content/ health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying/information-for-providers
34. Province of British Columbia, Ministry of Health. (2023b). *Medical assistance in dying- Request for medical assistance in dying. https://www2.gov.bc.ca/assets/gov/health/ forms/1632fil.pdf*
35. Province of British Columbia, Ministry of Health. (2023c). *HLTH 1632 – Request for MAiD:* Instructions *for completion: Medical assistance in dying*. https://www2.gov.bc.ca/assets/gov/health/forms/1632_instructions.pdf
36. Truchon v. Canada, 2019 QCCS 3792. https://www.canlii.org/fr/qc/qccs/doc/2019/2019qccs3792/2019qccs3792.html

Appendix CC: Process for Recording Supplementary Field Notes and Personal Memos

Process proposed during data collection and analysis
Structure within notes/memos
▪ Date and time of interview ▪ Location and under what conditions did the interview occur ▪ What personal assumptions did I bring to the interview? ▪ How well did I ask the questions, including probing questions? ▪ How was the rapport?
▪ Chronicle reflections and observations from the interview ▪ How was the quality of the information? ▪ What was most significant from the interview? ▪ Concepts from the interview ▪ Record observations
▪ Summarize each interview ▪ Itemize and reflect on emerging themes *&/or* links to the literature ▪ Create notes that allow the questioning or re-questioning of participants (i.e., data clarification, elaboration, and evaluation)
Possible inductive/analytic questions
Focus on moving beyond what is self-evident; Trust your mind and ask.
◊ What emerged? ◊ What was created? ◊ Why is this here? ◊ Why not something else? ◊ What does it mean, what is its role? ◊ I wonder … ◊ Have I seen this elsewhere? ◊ What am I missing/not seeing? ◊ What else might there be?

◊ What ideas are starting to form that address my research questions?

◊ What is their story telling me?

◊ Things I learned that surprised me?

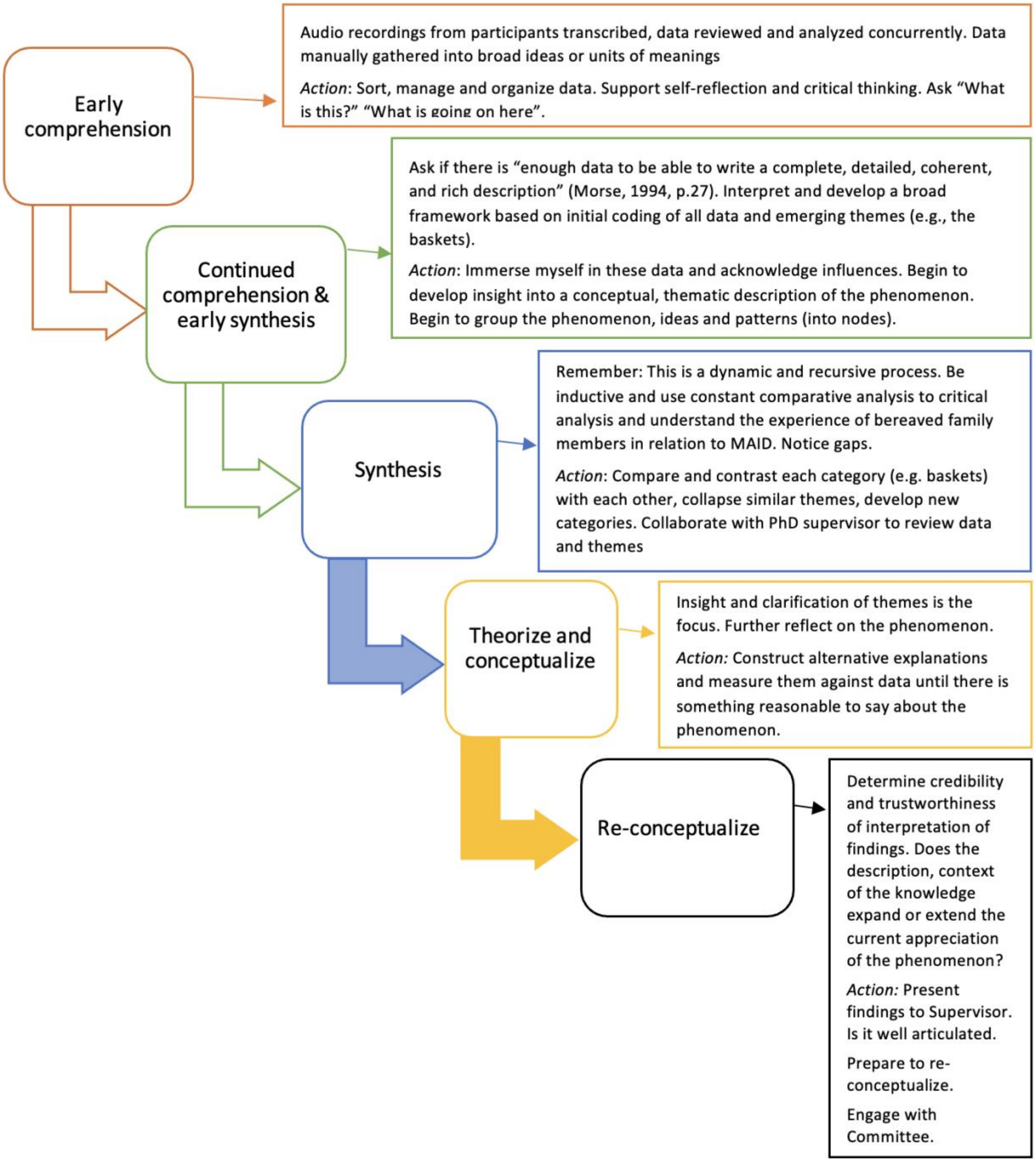
◊ Is this different/similar than what I expected? Why?

◊ Are these things related? How?

Note. Modified from (Patton, 2015)

Patton, M. Q. (2015). *Qualitative research and evaluation methods* (4th ed.). SAGE.

Appendix DD: Plan for Data Analysis



Audio recordings from participants transcribed, data reviewed and analyzed concurrently. Data manually gathered into broad ideas or units of meanings

Action: Sort, manage and organize data. Support self-reflection and critical thinking. Ask "What is this?" "What is going on here".

Ask if there is "enough data to be able to write a complete, detailed, coherent, and rich description" (Morse, 1994, p.27). Interpret and develop a broad framework based on initial coding of all data and emerging themes (e.g., the baskets).

Action: Immerse myself in these data and acknowledge influences. Begin to develop insight into a conceptual, thematic description of the phenomenon. Begin to group the phenomenon, ideas and patterns (into nodes).

Remember: This is a dynamic and recursive process. Be inductive and use constant comparative analysis to critical analysis and understand the experience of bereaved family members in relation to MAID. Notice gaps.

Action: Compare and contrast each category (e.g. baskets) with each other, collapse similar themes, develop new categories. Collaborate with PhD supervisor to review data and themes

Insight and clarification of themes is the focus. Further reflect on the phenomenon.

Action: Construct alternative explanations and measure them against data until there is something reasonable to say about the phenomenon.

Determine credibility and trustworthiness of interpretation of findings. Does the description, context of the knowledge expand or extend the current appreciation of the phenomenon?

Action: Present findings to Supervisor. Is it well articulated.

Prepare to re-conceptualize.

Engage with Committee.

Note: This figure represents the data analysis plan that was undertaken for this study. The concurrent and iterative process in data collection and analysis approach is based on "Emerging from the data: The cognitive process of analysis in qualitative inquiry," by J. M. Morse, 1994, In J.M. Morse (Ed.), Critical issues in qualitative research methods (pp. 23-43). SAGE Publications.

Appendix EE: Pl Overview of Descriptive Findings