GOOD GRIEF? THE IMPACT OF MEDICAL ASSISTANCE IN DYING (MAiD) ON GRIEVING EXPERIENCES IN RURAL SOUTHERN ALBERTA

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DEDICATION

To my Oma and Opa, Gisela and Walter Raiser – although I was not fortunate enough for our lives to overlap, I have thought of you often throughout this project. Oma, you were ahead of your time in your wish for assistance in dying, and I hope you would be proud to know that this option now exists.

To my grandparents, André and Louise Trottier, whose deaths during my work on this project formed my first and most profound experience of grief so far – remembering your unwavering love, support, and sincere interest in my work has brought comfort during the most emotionally challenging parts of this research. My grief for your absence has shaped how I approached the stories of grief shared by my participants; even after your passing, you continue to inspire me to accomplish my goals. How I wish you were here to share in this achievement and how I wish we keep on loving each other.

ABSTRACT

Medical Assistance in Dying (MAiD) has introduced new ethical, clinical, and social considerations in Canada's healthcare system since its legalization in 2016. While research has explored the legal, policy, and practical implications of MAiD, less is known about the grief experiences of those closely involved in the process—particularly within rural communities. This thesis explores the grief experiences of patients, family members, and healthcare professionals involved in MAiD within a rural Southern Alberta context. Using a reflexive thematic analysis of qualitative interview data, this study investigates how participants described grief and what factors influenced their experiences.

Through this analysis, I generated three primary themes: (1) MAiD as a means to avoid a 'bad death'; (2) bureaucratic processes and institutional policies that complicate the MAiD experience and related grief; and (3) the role of stigma and secrecy in shaping grief and limiting access to support. While many participants identified MAiD as enabling a more dignified and controlled end-of-life experience, the grief that followed was not always straightforward. Experiences were shaped by personal and professional relationships, the perceived legitimacy of MAiD within communities, and systemic barriers—including final consent policies and restrictions in faith-based facilities.

This research contributes to growing evidence that grief related to MAiD can be multifaceted and influenced by more than the nature of death itself. Findings underscore the importance of considering how rurality, cultural context, and stigma intersect to shape bereavement. The thesis concludes with recommendations for improving policy, support services, and future research, especially regarding the role of rural social norms and institutional restrictions in the experience of MAiD-related grief.

ETHICS STATEMENT

Work described within this thesis received research ethics approval from the University of Alberta Research Ethics Board, Project Name: “Medical Assistance in Dying: Ethical and Policy Issues in Rural Southern Alberta”, Protocol number: Pro00103469_AME1, September 9, 2021.

USE OF GENERATIVE AI

Throughout the process of writing this thesis, I occasionally used a generative artificial intelligence, ChatGPT, as a tool to help in refining sentence structure and clarity, and to provide secondary proof reading of drafts for instances of typos, spelling mistakes, and grammatical errors. Generative AI tools were not used to generate any content presented within this thesis, nor to aid in analyses. All ideas, interpretations, and conclusions presented within this thesis are my own. In other words, I used ChatGPT as a writing support tool to refine my explanation of findings and concepts rather than as a content generator.

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Finally, to my family and chosen family—my parents, Dan and Sandy Trottier, my sibling Nicolas, my chosen-sister Michelle, and my partner Zach—thank you. I could likely write an additional 100 pages on the ways you have each supported me through this process over the past few years, but instead I will say: thank you for your patience, understanding, flexibility, and love. This journey has been a challenging one for us all, and I am beyond grateful for the unwavering support you have offered throughout. I could not have done this without you.

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LIST OF ABBREVIATIONS

AHS	Alberta Health Services
DSM	Diagnostic and Statistical Manual of Mental Disorders
MAiD	Medical Assistance in Dying
MD-SUMC	Mental Disorder as the Sole Underlying Medical Condition
NP	Nurse practitioner
PAS	Physician assisted suicide
PAD	Physician assisted death
PGD	Prolonged grief disorder
PTSD	Post-traumatic stress disorder
VAD	Voluntary assistance in dying

CHAPTER 1: INTRODUCTION

Introduction

In this thesis, I explore grief experiences related to medically assisted death among patients, family members, and healthcare professionals in Southern Alberta. Medical assistance in dying (MAiD) was legalized in Canada in 2016, allowing eligible adults to hasten their death with assistance from physicians and nurse practitioners (Government of Canada, 2023a). Current legislation allows for Canadian adults with a serious and incurable condition that causes enduring and intolerable suffering—excluding those of a psychiatric nature—to receive MAiD (Department of Justice Canada, 2024). Since its legislation, the Canadian MAiD program has been accessed by over 60,000 eligible patients and provided by over 2,000 unique practitioners (Health Canada, 2024a). Although MAiD is legal in all Canadian jurisdictions, utilization varies across provinces and territories. In 2023, MAiD accounted for approximately 5% of all deaths across Canada (ranging from 1.1% in Newfoundland and Labrador to 7.1% in Québec), and about 2.8% in Alberta (Health Canada, 2024a; Statistics Canada, 2024).

The death of a loved one is almost always accompanied by experiences of grief. Despite this, the way that grief is experienced varies widely due to a variety of factors including individual characteristics, social and cultural norms, and the method by which death occurred (Zisook & Shear, 2009). The introduction of assisted dying programs around the world has led to substantial research on how assisted death-related grief is experienced (Andriessen et al., 2020; Coelho et al., 2021; Frolic & Oliphant, 2022; Gamondi et al., 2015, 2019; Hashemi et al., 2021; La Brooy et al., 2024; Serota, Atkinson, et al., 2023; Srinivasan, 2019; Trouton et al., 2020; Yan et al., 2022; Zisook & Shear, 2009). Thus far, these investigations have shown mixed results, with some suggesting similar experiences of grief among those bereaved by assisted- and unassisted-death, while others suggest a more positive experience among those bereaved by MAiD (Andriessen et al., 2020; Gamondi et al., 2015; Yan et al., 2022).

The purpose of this thesis was to investigate the grief experiences of individuals impacted by and/or involved in MAiD provision within rural communities across Southern Alberta.

Overview of Thesis Document

This thesis is organized into three chapters: an introduction (Chapter 1), a study manuscript (Chapter 2), and an integrative discussion and conclusion (Chapter 3). In Chapter 1, I introduce the study topics, review key literature, outline my positionality, and provide details on my analytic process. Chapter 2 presents the core manuscript of my project, which includes a condensed literature review and methods section, detailed study findings, and preliminary discussion and recommendations. In Chapter 3, I expand upon these discussion points and recommendations, concluding with my reflections on the research process.

Terminology

The language used within literature on the topics of assisted dying programs and grief varies greatly, influenced by region, recency of publication, and the disciplinary lens through which findings are presented (Riisfeldt, 2023; Zisook & Shear, 2009). Terms for assisted dying vary various jurisdictions, the most common of which include ‘euthanasia’, ‘physician-assisted dying’ (PAD), ‘physician-assisted suicide’ (PAS), ‘voluntary assistance in dying’ (VAD), and MAiD, among others (Mroz et al., 2020). For clarity and in alignment with Canadian legislation, I use the acronym ‘MAiD’ and its derivatives (‘[medical] assisted dying’, ‘[medically] assisted death’, etc.) throughout this thesis (Government of Canada, 2023a).

The terms ‘grief’, ‘bereavement’, and ‘mourning’ are commonly used within the literature; while these terms are related, they refer to distinct aspects of the experience of loss. Bereavement refers to the objective experience of the loss of a loved one, typically through death, while mourning refers to the outward expression of the reaction to such loss (Abi-Hashem, 1999; Northcott & Wilson, 2022). While various definitions of ‘grief’ exist, Wolfelt (1988, as cited in Abi-Hashem, 1999) defines grief as both a process and an outcome related to significant loss; Abi-Hashem expands upon this, describing grief as “a phenomenological experience” which involves “a mixture of feelings, thoughts, sensations, movements, and behaviours” (1999, p. 310). Throughout this thesis, I adopt this framing of grief as an expansive and multifaceted experience that encompasses emotional, cognitive, physical, and behavioural responses to loss rather than a singular emotion or discrete reaction. While these terms are most commonly used and understood in the context of loss via death, grief can occur following non-death losses, including the end of relationships, job loss, and significant declines in health or ability (Sweetman & O’Donnell, 2020).

Descriptions of grief within the literature are often separated into three primary categories: uncomplicated (or ‘normal’) grief, complicated grief, and clinical grief (PDQ Supportive and Palliative Care Editorial Board, 2002). Respectively, these categories refer to grief experiences that are expected and ease over time (uncomplicated grief), those which are more intense, prolonged, or impactful to daily functioning than expected (complicated grief), and especially severe forms of complicated grief that constitute diagnosis of Prolonged Grief Disorder (PGD) classified within the Diagnostic and Statistical Manual of

Mental Disorders 5th text-revised edition (DSM-5-TR) and the International Classification of Diseases 11th edition (ICD-11; (American Psychiatric Association, 2022; Cacciatore & Francis, 2022; PDQ Supportive and Palliative Care Editorial Board, 2002; World Health Organization, 2022). These categories, while likely useful for assessment and resource provision, contradict the expansive and multifaceted framing of grief that I have adopted throughout this work, which I perceive as more continuous than categorical. Thus, discussions of 'complicated grief' or factors which 'complicate the grief experience' throughout this thesis should be understood as subjective rather than categorical descriptions of participants' experiences with grief.

Finally, throughout this thesis, I refer to 'good' and 'bad' experiences of death and grief. My use of these terms is not intended as a value judgment on individuals' personal or emotional processes of grieving, nor do they imply a binary classification of experiences. Instead, these terms are used to illustrate and reflect participants' narratives of how broader structures, including institutional policies, healthcare systems, and societal perspectives, influenced the experience of death and bereavement. Throughout this thesis, my use of the term 'good death' should be understood as a dying experience that aligns with individuals' beliefs, values, and wishes for end-of-life that is supported by policies and environments that minimize harm and foster dignity. Similarly, the term 'good grief' refers to experiences of bereavement that involve adaptive coping, meaning making, and/or are described by participants as a relatively positive experience. Accordingly, the terms 'bad death' and 'bad grief' refer to those experiences which do not align with end-of-life beliefs, values, or wishes, and which foster maladaptive or harmful responses to the loss. I have used these terms to concisely illustrate how various macro- and meso-level structures can both positively (moving towards 'good') and negatively (moving towards 'bad') shape experiences of dying and grief, rather than to pass judgment on how individuals experience death or express their grief.

Background

Canadian Culture of Death and Dying

The fact that we will die is one of very few certainties in life. Despite this, death remains a challenging topic to engage with in Canadian society (Banjar, 2017; Northcott & Wilson, 2022). While dying has been an inevitable conclusion to the human lifecycle for as long as we have existed, advances in medicine over the past century have been accompanied by a shift in how we perceive and engage with the concept of death as a society. Prior to the mid-20th century, death in Canadian culture was generally perceived as a natural, unalterable occurrence (Northcott & Wilson, 2022). However, scientific advances and medical innovations allowing us to extend the human life have transformed our collective perceptions towards death, reframing what was once viewed as an inevitable, natural conclusion to life, into an unfamiliar, frightening experience that should be avoided for as long as possible (Banerjee, 2007). The discomfort around death within Canadian society can be observed in the language we use around death, dying, and the deceased (using terms like 'passed away' in place of 'died'); our cultural fixation with youthfulness; a focus on death as an undesirable, treatable, and even preventable health outcome and the subsequent use of aggressive life-sustaining or -prolonging medical interventions; and the social rituals we engage following the death of a loved one (Banerjee, 2007; Banjar, 2018; Northcott & Wilson, 2022). Although the introduction of MAiD in Canada may be an early indicator of a cultural shift related to death and dying (perhaps towards understanding death as a natural occurrence that can be supported but not avoided), death-denial and deathilliteracy within our society undoubtedly plays a role in how the MAiD program has been implemented and utilized. While I do not directly examine Canadian cultural attitudes towards death and dying as a factor influencing experiences of grief within this thesis, it is important to acknowledge that the experiences and issues discussed throughout occur within and are shaped by this broader cultural context.

Assisted Dying in Canada: The MAiD Program

In June of 2016, the Canadian government passed legislation for eligible adults to receive MAiD, allowing physicians and nurse practitioners to actively assist in a patient's death (Government of Canada, 2023a). At present, Canada is among eight other countries (Belgium, Colombia, Luxembourg, Netherlands, New Zealand, Portugal, Spain, and Switzerland), six Australian states (New South Wales, Queensland, South Australia, Tasmania, Victoria, and Western Australia), and eleven jurisdictions in the United States (Washington D.C., California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington State) to allow active assistance in death (World Federation of Right to Die Societies, n.d.).

Specific MAiD laws vary by jurisdiction. Currently, Canada is one of only a few regions to allow clinicians to prescribe lethal substances for a patient to self-administer (self-administered MAiD; legal in all Canadian jurisdictions except Quebec) and to directly administer a lethal substance to induce a patient's death (clinician-administered MAiD; Emanuel et al., 2016; Health Canada, 2023). In addition, Canadian legislation currently excludes Canadians experiencing mental illness as the sole underlying condition leading to their suffering from MAiD eligibility until March 2027 (Bill C-39; Health Canada, 2024a,b). Additional details on the Canadian MAiD program and its eligibility and exclusion criteria are available through the Canadian Department of Justice and Canadian Parliament (Department of Justice Canada, 2021, 2024; Nicol & Tiedemann, 2018).

National MAiD Utilization

From its legalization in 2016 through the end of 2023, MAiD has been accessed by over 60,000 Canadians, accounting for about 5% of all mortality across the country (Health Canada, 2024a). In 2023, over 15,000 Canadians died by MAiD; these patients were an average of 78 years old, slightly more likely to be male (52%), and most commonly reported cancer as their underlying condition (64%; Health Canada, 2024a). The most common sources of suffering among MAiD recipients included loss of ability to participate in meaningful activities, inability to perform activities of daily living, loss of dignity, and inadequate control of pain (Health Canada, 2024a). In 2023, there were 2,200 clinicians engaged in MAiD provision in Canada (94.5% physicians, 5.5% nurse practitioners), who engaged in an average of 7 assisted deaths each (Health Canada, 2024a). Most MAiD recipients had received palliative care prior to their assisted death (75%), which is a holistic end-of-life care approach designed to address physical, social, emotional, psychological, and spiritual needs of patients with serious illness (Government of Canada, 2023b; Health Canada, 2024a). As noted earlier, both clinician- and self-administered MAiD deaths are permitted across jurisdictions in Canada, excluding the province of Quebec where self-administration is prohibited (Health Canada, 2024a). Despite this, the vast majority of MAiD services are clinician-administered, with just seven self-administered MAiD deaths recorded in 2023(Health Canada, 2024a).

Provincial Utilization in Alberta

Given the Alberta-specific focus of this project, I briefly summarize MAiD policy and outcomes specific to Alberta as these factors vary across the Canadian provinces and territories. Alberta was one of the first jurisdictions in Canada to introduce comprehensive guidelines for assisted dying, which involves a single, centrally coordinated system for referrals, patient access, and reporting (Frolic & Oliphant, 2022; Silvius et al., 2019). A total of 3,914 MAiD deaths have occurred in Alberta between 2016 and 2023, representing approximately 80% of all MAiD requests received province-wide (Health Canada, 2024a). In 2023, 977 Alberta residents received MAiD; these patients were similar to those nationally, with an average of 75 years old (78 years old nationally), more likely to be male (52% provincially and nationally) and suffering from a cancer-related underlying condition (63% provincially and 64% nationally; Health Canada, 2024a). In 2022, family medicine practitioners (60% provincially; 68% nationally) and nurse practitioners (19% provincially; 9% nationally) were most likely to provide MAiD services for Albertans, compared to physicians in other specialties (Health Canada, 2023). The setting of MAiD deaths in Alberta in 2022 was roughly equivalent to those nationally, occurring most often within a private residence (36% provincially vs. 40% nationally) or a hospital (31% provincially vs. 30% nationally; Health Canada, 2023). Compared to national data, a higher proportion of MAiD deaths in Alberta occurred in urban settings (84% provincially vs. 71% nationally) than in rural settings in 2022 (16% provincially vs. 29% nationally; Health Canada, 2023). With approximately 82% of Albertans residing in urban areas, the distribution of Alberta MAiD deaths is relatively proportionate to the population of Albertans across urban and rural areas (82% and 18% respectively; Statistics Canada, 2021).

MAiD in Rural Canada

According to 2021 Census data, nearly one-in-five Canadians (17.8%) reside in rural communities, defined as areas with less than 1,000 residents and fewer than 400 inhabitants/km^2 (Statistics Canada, 2022). Despite this, literature exploring the niche impacts of rurality on MAiD provisions specifically within Alberta is limited (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Manduca-Barone et al., 2022). Thus, despite the Alberta-specific focus of this project, I have chosen to include work investigating the impact of rurality on MAiD across Canada broadly. For clarity, I have specified the geographic region of each study reviewed in the following paragraphs.

Access to health care services in rural communities has been a long-standing problem within Canada (Wilson et al., 2020). Despite accounting for nearly 20% of the population, rural communities in Canada are serviced by just 8% of practicing physicians and 11% of registered nurses (Schiller, 2017; Wilson et al., 2020). In addition, rural Canadians are more likely to experience premature all-cause mortality, as well as mortality due to cardiovascular disease, diabetes, injury, and suicide (Canadian Institute for Health Information [CIHI], 2006; Kondro, 2006). Data from Statistics Canada shows that between 2012 and 2016, the rate of mortality by preventable and treatable causes per 100,000 was positively associated with the degree of remoteness where one resides, with those living in remote and very remote areas experiencing about 1.5x higher rates of mortality from preventable and treatable causes (Statistics Canada, 2019).

Disparities in health outcomes and access to services have generated concern among some scholars pertaining to the impact MAiD may have on rural residents. One such concern is that the disproportionate distribution of MAiD providers across rural and urban settings has led to lack of access to such services for those in rural and remote areas of the country (Schiller, 2017; Wilson et al., 2020). In contrast to urban settings, rural communities often rely on a sole clinician (or a small team of clinicians) to provide health services (Wilson et al., 2009). Not only can this pose a challenge for continuity of services in the case of clinician relocation or retirement, but it can impose a difficult decision for clinicians on whether to engage in or abstain from the provision of MAiD (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Wilson et al., 2009). For instance, a rural healthcare provider who conscientiously objects to providing MAiD may inadvertently remove access to such services for their entire community, particularly when they are the sole provider eligible to provide MAiD (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Pesut, Thorne, Schiller, et al., 2020). On the other hand, a provider who chooses to participate in the MAiD program risks breaking trust with patients who are opposed to the practice, thereby limiting access to other essential health and end-of-life services (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Byrnes et al., 2022).

Another concern among scholars is that MAiD may be accessed by rural patients in lieu of adequate access to alternate life-preserving or end-of-life care options (Brassolotto, Manduca-Barone, & Sedgwick, 2023). For example, geographic isolation of rural communities from urban centres (where the most robust health and end-of-life care options are available) may influence a rural patient's decision to access MAiD if it is more geographically accessible than other end-of-life options (Collins & Leier, 2017). Cultural differences in the perspectives of a "good death" between rural and urban Canadians, summarized in work by Wilson and colleagues (2009), may further complicate the decision for rural Canadians on travelling to urban centres to access end-of-life options. In general, rural Canadians tend to place more importance on remaining within their home and home communities at the end of their lives than do urban-based Canadians (Wilson et al., 2009). Thus, in cases where rural palliative care is less accessible than assisted death services, rural Canadians may feel that their only choice to experience a "good rural death" is to forego palliative care in favour of MAiD (Brassolotto, Manduca-Barone, & Sedgwick, 2023; CIHI, 2019; Pesut & Thorne, 2019; D. M. Wilson et al., 2009).

In addition to accessibility issues and the importance of remaining within one's home in the dying process, the tight-knit nature of rural communities and the issue of dual roles among rural healthcare providers introduces privacy and confidentiality concerns. Rural providers often reside within the communities in which they work, taking on dual roles as healthcare professionals as well as community members, neighbours, and friends of those they treat (Brassolotto et al., 2021). Brassolotto and colleagues (2021) highlight key benefits of dual roles, including opportunities for reciprocity, enhanced patient-centered care, and heightened trust and support between providers and patients (see also Manduca-Barone et al., 2022). However, this role duality can also pose challenges, particularly in the provision of MAiD. The intersection of professional and personal relationships with patients may mean that a provider's decision to provide (or refrain from providing) MAiD services is likely to spread quickly throughout the community, possibly breaking trust among patients who disagree with the provider's decision, and negatively impacting personal relationships (Brassolotto et al., 2021; Coombs et al., 2022; Manduca-Barone et al., 2022). This can also pose a threat to patient confidentiality in cases where community members know that a patient has died after accessing medical services from a clinician known to provide MAiD. Not only can this impact the grieving process for the deceased's loved ones, but it could potentially cause turmoil between community members due to disagreements about MAiD (Manduca-Barone et al., 2022).

Canadian perspectives and perceptions.

Public perspectives on MAiD vary widely among Canadians (Pennings & Reid, 2020). There has been substantial work done to summarize expert and public opinion related to specific aspects of the Canadian MAiD program, including the current exclusions of mature minors (Campbell et al., 2023; Liu et al., 2023; Patton & Dobson, 2021; Singh et al., 2020) and individuals suffering solely from mental illness (Bahji & Delva, 2022; Bastidas-Bilbao et al., 2023; Dembo et al., 2018; Hawke et al., 2024; Montreuil et al., 2020), as well as some investigation into perspectives on advanced MAiD requests (Bravo et al., 2018; Byram et al., 2021; Harris, 2021; Variath et al., 2022b). Although these works are important in the consideration of MAiD eligibility expansions, they fall outside the specific scope of this project. Thus, I have chosen to review and summarize findings from studies investigating perspectives specifically related to the Canadian MAiD program in its current state (excluding mature minors and individuals suffering solely from mental illness and disallowing advanced requests; Government of Canada, 2023a).

General public. Two surveys of Canadians have been conducted to understand the general public's acceptance of the MAiD program (Hawrelak et al., 2022; Pennings & Reid, 2020). The first, conducted in 2020 among a random sample of 1,500 Canadian adults, suggests that most Canadians are in favour of MAiD; just 19% report being opposed to the program, while 33% were enthusiastically supportive (Pennings & Reid, 2020). The remaining 48% report being cautious supporters of the program, which Pennings and Reid (2020) describe as being generally in favour but holding reservations about aspects of the program including a concern for those with mental illness or disabilities. In Alberta, the proportion opposed to MAiD is significantly higher at 32% (Pennings & Reid, 2020). Participants opposed to the program were more likely to be religious, visible minorities, or immigrants to Canada. Although the authors did not state so explicitly, it is possible that the high degree of religiosity in Alberta may play a role in this difference.

The second survey of Canadians' perspectives on MAiD was conducted in 2022 among a sample of 438 undergraduate students in Alberta (Hawrelak et al., 2022).

Respondents were presented with four scenarios of patients requesting MAiD: an 85-year-old patient with terminal illness ('old and terminal'), an 85-year-old patient with mental illness ('old and mental illness'), an 18-year-old patient with terminal illness ('young and terminal'), and an 18-year-old patient with mental illness ('young and mental illness'). After reading through each scenario, respondents were asked to indicate whether they believed that the patient's best outcome was to a) be denied MAiD, b) be granted self-administered MAiD, c) be granted clinician-administered MAiD, or d) for terminal patients to be removed from life-sustaining treatments (Hawrelak et al., 2022). Overall, more than half of respondents endorsed MAiD provision (self- or clinician-administered) for at least one scenario indicating a general support of the program among this sample. However, support for MAiD varied by patient age and illness; while over 90% of respondents supported MAiD for the 'old and terminal' patient, less than 60% were in support for the 'young and mentally ill' patient (Hawrelak et al., 2022). High self-reported religiosity was associated with lesser support for MAiD across all scenarios, while respondents who reported previously discussing MAiD with family members or friends showed higher levels of support overall (Hawrelak et al., 2022). Altogether, Canadians seem to broadly support the MAiD program, with variation dependent upon both personal- and patient-related factors (Hawrelak et al., 2022; Pennings & Reid, 2020).

Health care professionals. There has been substantial work to describe the perspectives of Canadian healthcare professionals on MAiD, including physicians, medical students, and nurses. Among physicians, most (ranging from 63% among spinal surgeons to 72% among psychiatrists) were in favour of the legislation, indicating support for patients to obtain MAiD and physicians to participate in the program (Leck et al., 2020;

Rousseau et al., 2017). In terms of active involvement in the process, between 37% and 60% said they were willing to advise, assess, or refer prospective MAiD patients as needed (Chandhoke et al., 2020; Leck et al., 2020; Spicer et al., 2017; Wong et al., 2019). Willingness to participate in the prescription or administration of lethal substances showed the greatest variation. Leck and colleagues (2020) found that fewer than 4% of participating physicians could see themselves actively involved in providing MAiD but did not specify between self- or clinician-administered. Other studies suggest that physicians were generally more willing to prescribe a lethal substance than to administer it themselves; between 30% - 35% were willing to prescribe a lethal substance, while about 25% were willing to administer it to a patient (Chandhoke et al., 2020; Wong et al., 2019).

Three studies investigated the attitudes and perceptions of medical students and trainees regarding MAiD (Bator et al., 2017; Falconer et al., 2019; McCarthy & Seal, 2019). Of over 2,000 Canadian trainees surveyed, approximately 90% supported the legalization of the MAiD program, while 60-70% were willing to support self-administered MAiD for their patients (Bator et al., 2017; Falconer et al., 2019; McCarthy & Seal, 2019). In line with findings from the general public and physicians, high degrees of religiosity were associated with lower levels of support for MAiD (Bator et al., 2017; Falconer et al., 2019; McCarthy & Seal, 2019). Overall, findings indicate that medical students and trainees view MAiD more positively compared to experienced physicians. Although higher levels of training were associated with more positive attitudes towards MAiD, this association was not explained by age (Bator et al., 2017; McCarthy & Seal, 2019). McCarthy and Seal (2019) suggest the possibility that longstanding relationships with patients may negatively impact experienced physicians' willingness to engage in MAiD. Another possible factor is the relative novelty of MAiD legalization; thus, incoming physicians are more likely to have encountered the topic during their training than senior physicians, leading to higher levels of acceptance among the younger cohort (McCarthy & Seal, 2019). While the factors influencing this generational change in perspectives have not yet been investigated, high acceptance among incoming physicians is likely to increase accessibility to MAiD in the coming years.

Canadian nurses' perspectives on MAiD have also been explored (Beuthin et al., 2018; Bruce & Beuthin, 2020; Freeman et al., 2020). In a qualitative study of 17 Canadian nurses (LPNs, RNs, and NPs), 88% of participants said that MAiD had a positive impact in how they viewed their profession, while just 12% were opposed to the practice. The nurses in this study noted that providing MAiD aligned with professional values including holistic care, nonjudgment, advocacy, and supporting a patient-defined 'good death' (Beuthin et al., 2018). Another study reported similar results, with just 15% of nurses identifying as conscientious objectors (Pesut, Thorne, Storch, et al., 2020). Finally, a cross-sectional study of nurses working in palliative care settings in Ontario showed less than 50% support for providing MAiD within hospice care settings (Freeman et al., 2020). However, this is not to say that palliative care nurses in Ontario are not generally supportive of MAiD. Three-quarters of nurses support individuals' right to decide their own death, and when asked what should occur if a hospice patient requested MAiD, nearly all nurses were in support of transferring the patient to access assisted death care (Freeman et al., 2020). Across studies, nurses who support MAiD provision cite reasons including its crucial place in holistic care practices, avoiding patients' prolonged suffering, and advocating for patients and their choices, while those opposed most commonly cited religious or spiritual beliefs (Beuthin et al., 2018; Pesut, Thorne, Storch, et al., 2020). Regardless of personal willingness to directly engage in MAiD, nurses were primarily concerned with patient care and therefore were generally understanding of MAiD’s place in healthcare (Beuthin et al., 2018).

Controversy and stigma. Despite its legal status, MAiD remains a controversial topic among experts and the general public in Canada (Downie & Schuklenk, 2021). While the biological process of dying affects all individuals regardless of social status, structures within our modern societies have contributed to disproportionate morbidity and mortality for disadvantaged groups (Wright & Shaw, 2019). Advocates for MAiD in Canada argue that access to such services uphold our Charter right to autonomy in life and death and helps to mitigate prolonged and unnecessary suffering of those with advanced or terminal illness (Department of Justice Canada, 2021; Dugdale et al., 2019). In contrast, those unsupportive of the MAiD program commonly cite objection on the grounds of religion as observed in the association between high religiosity and opposition to assisted death within the literature, which is presumed to be due to the opposition to hastening of death among most major religions (Pew Research Center, 2013). A number of non-faith-based arguments against MAiD have been presented as well, including the ‘slippery slope’ argument which posits that as we become more comfortable with assisting death for those suffering from terminal and irremediable illness, we risk enacting ever-more permissive criteria leading to legalizing MAiD for anyone and any reason (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Braverman et al., 2017; Disability Rights Education & Defense Fund, n.d.; Downie & Schuklenk, 2021; Pullman, 2023; Reggler, 2017; Sulmasy et al., 2016; Wright & Shaw, 2019). Other non-faith-based arguments against MAiD include the ‘it offends me’ argument, which states that the act of wilfully ending ones own life inherently devalues human life; the ‘pain can be alleviated’ stance, which argues that the existence of effective palliative care and pain management options renders MAiD unnecessary; and the ‘physician integrity and patient trust’ argument, which highlights concerns around MAiD practices as contradictory to physicians’ oath and the impact this may have on patient trust (Sulmasy et al., 2016).

These disagreements, particularly regarding the morality and ethics involved with assisted death programs, has sparked political tension and controversy between groups in favour and opposed to MAiD. As is often the case with politically charged topics, arguments made on both sides of the MAiD debate have quickly reached the general public by way of news and social media regardless of the validity or plausibility of the claims. This widespread of often unfounded or invalid claims related to MAiD has led to bilateral stigmatization of patients with advanced illness and healthcare providers, oftentimes regardless of their decision to participate in MAiD (Pesut, Thorne, Schiller, et al., 2020; Shen & Wellman, 2019; Sulmasy et al., 2016; Thurley, 2023). For instance, patients who choose to access MAiD may be viewed as ‘weak-willed’ or ‘quitters’ who are looking for an ‘easy way out’, while providers may be viewed as ‘doctors of death’ or as being engaged in eugenic practices (Shen & Wellman, 2019; Thurley, 2023). On the other hand, terminal patients who choose not to apply for MAiD may feel some degree of stigma related to burdening their loved ones or caregivers, while physicians who conscientiously object may feel stigmatized by MAiD-engaged colleagues (Pesut, Thorne, Schiller, et al., 2020; Sulmasy et al., 2016). For those closely involved in or impacted by MAiD-related decisions, this undoubtedly feels like being stuck between a rock and hard place with no clear solution to the debate (Pesut, Thorne, Schiller, et al., 2020). While I do not aim to influence readers’ perspectives on this controversy, it is important to consider how these arguments against MAiD may influence the decision-making process of prospective MAiD patients.

To my knowledge, the impact of stigma on the decision to access MAiD among Canadians has not yet been explored. However, an investigation on prospective use of palliative care services highlights the impact of negative stereotypes on healthcare and end-of-life care decisions (Shen & Wellman, 2019). Specifically, study respondents who held negative stereotypes of those who chose palliative care options (i.e., as quitters, hopeless, or weak-willed) were less likely to indicate willingness to use palliative care options in the future compared to those who did not endorse such stereotypes (Shen & Wellman, 2019). Additionally, there is some preliminary evidence to suggest that experiences of grief related to MAiD deaths may be less severe than for unassisted death. Of two studies investigating this, one found that participants perceived MAiD grief to be less maladaptive than non-MAiD grief, while the other found no significant difference between the groups (Philippkowski et al., 2021; Singer et al., 2023). Recently, Crumley et al. (2023) described that family members of MAiD patients in Canada reported unexpected experiences of guilt, judgment and/or secrecy around their loved one's MAiD death. Although inconclusive, these results present the possibility that stigma surrounding MAiD may contribute to perceptions of less severe grief and subsequently fewer available resources for those bereaved by MAiD deaths (Singer et al., 2023).

Further, a recent review by Byrnes, Ross and Murphy (2022) suggests that fear of being 'found out' as a MAiD provider, a lack of emotional support for MAiD providers, and internalised stigma about providing MAiD served as barriers in clinicians' decision to engage in MAiD-related care. Thus, it is possible that the controversy surrounding MAiD in Canada has led to fewer clinicians taking part in the provision of these services, introducing access barriers for patients seeking end-of-life options. While it is not yet clear whether the controversial nature of MAiD in Canada has influenced prospective MAiD patients, it is plausible that stigma and the resulting barriers to access and expectations of grief could play a role in their end-of-life decisions.

Grieving Death

As human beings, each of us will eventually experience the loss of a loved one due to death during our lives, and subsequently experience some degree of grief related to that loss. Grief, defined primarily as the “emotional/affective process of reacting to the loss of a loved one through death” (“Definitions of Terms: Grief”, para. 1) is a universal human experience following significant loss (PDQ Supportive and Palliative Care Editorial Board, 2002). Despite its universality, the way that grief is actually experienced can vary widely, which has led many scholars to theorize on the mechanisms and presentations of different types of grief (Boerner et al., 2015; Bonanno & Kaltman, 2001; Rawlings, 2023; M. S. Stroebe & Schut, 2001). Although there is no clear consensus on the various types of grief we may experience, scholars have generally agreed on a few types that are relevant to this work (Chochinov, 1989; Rawlings, 2023). In the following paragraphs, I will summarize existing literature on three key forms of grief, including normal or uncomplicated grief, and two forms of complicated grief: disenfranchised (ambiguous), and anticipatory grief (Coelho & Barbosa, 2017; Doka, 1999; Lombardo et al., 2014; Rando, 1988; Stefano et al., 2021; Thompson & Doka, 2017). Another form of grief that is widely debated in the literature but that I will not address in depth within this work was first presented as a condition for further study in the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) under the name ‘Persistent Complex Bereavement Disorder’, and more recently added to the DSM-5 text revision (DSM-5-TR) as ‘Prolonged Grief Disorder’

(PLG; American Psychiatric Association, 2022). Information on PLG and other theorized forms of grief can be found within existing literature (Belitsky & Jacobs, 1986; Bonanno & Kaltman, 2001; Bowlby, 1980; Chochinov, 1989; Parkes, 1965; Rando, 1992; Shear et al., 2001; Stefano et al., 2021; Wagoner & de Luna, 2021; Worden, 2018).

Uncomplicated (or "Normal") Grief

Even in its uncomplicated form, experiences of grief vary widely across individuals and cultures (Zisook & Shear, 2009). Generally, the experience of uncomplicated grief is one that leads to adjusting to life without the lost loved one, does not usually require formal support to manage, and is often experienced alongside positive emotions such as relief, peace, or happiness (Zisook & Shear, 2009). While these experiences vary based on individual characteristics of the bereaved and the context of the loss, uncomplicated grief can involve experiences of strong emotions, sleep and appetite disturbances, existential questioning, and a lack of energy or ability to engage in activities beyond those of daily living. Over time, however, these experiences become less intense and more sporadic, eventually integrating into the reality of ongoing life (Shear, 2022). Shear (2022) describes uncomplicated grief as a process which, when observed broadly, resembles a journey down a bumpy road that eventually leads to the acute pain of grief transforming into a muted, background sensation throughout everyday life (Shear, 2022). In contrast, complicated grief refers to experiences in which such a transformation does not occur.

Complicated Grief: Anticipatory and Disenfranchised Grief

Complicated grief, as described by Shear (2022), refers to a grief experience that does not follow a trajectory of uncomplicated grief, often presenting with much more intense emotions, a longer process towards acceptance and integration, or causing a severe impairment to one's daily activities (Shear, 2022). Considerable debate among scholars exists around whether complicated grief can be classified as a syndrome; for example, Shear (2022) argues that the specific symptoms associated with complicated grief, such as incessant existential questioning, ruminating, and unrelenting negative emotions, qualify it as a specific syndrome uniquely distinct from uncomplicated grief and anxiety or mood disorders (Shear, 2022). Further, a study by Simon et al. (2013) suggests that approximately 7% of bereaved people experience complicated forms of grief as defined by the persistent complex bereavement disorder criteria in the DSM-5, which ultimately result in greater risk of adverse health outcomes including suicidality, depression, and post-traumatic stress disorder (PTSD; Simon, 2013). In contrast, scholars such as Cacciatore and Frances (2022) argue against the inclusion of complicated grief as a diagnostic syndrome, citing the low threshold of diagnostic criteria, a lack of empirical evidence for reliability and validity, and the danger of pathologizing the heterogenous expression of grief (Cacciatore & Francis, 2022). While I do not aim to stake claim to either side of this debate, this discussion is important to consider in understanding the expressions of grief across various individual characteristics and circumstances of death.

Disenfranchised (ambiguous) grief. One form of complicated grief that is present in the literature on MAiD is disenfranchised (or ambiguous) grief. This term, first coined by Doka (1989) and developed further by Attig (2004), refers to experiences of grief that are not socially accepted or acknowledged. Doka has proposed five general categories in which elements of grief can be disenfranchised, which Attig later summarized. First, experiences of grief may be disenfranchised on the basis of the relationship between the griever and the deceased, whether the relationship is considered to be non-traditional or lacking closeness (Attig, 2004). Examples of this may include grieving the loss of an exspouse, a same-sex intimate partner, or a co-worker. Next, the loss itself may be disenfranchised when the death is not socially viewed as a legitimate or significant loss, such as in cases of miscarriage, death of an incarcerated loved one, or of a pet (Attig, 2004). The third element by which grief may be disenfranchised is characteristics of the griever themselves. This can occur when the individual who has experienced a loss is not deemed capable of grieving, such as young children, those with neurological or development disabilities, or the elderly (Attig, 2004). The circumstances surrounding one's death is the fourth element by which grief can be disenfranchised. In cases where the death is due to stigmatized or controversial means (e.g., suicide, drug poisonings, violent crime involvement, or stigmatized disease), the griever may be less able or likely to seek or be offered support from those around them due to the stigma or other societal influences (Attig, 2004). The final category proposed by Doka is disenfranchised *expressions* of grief; generally, this occurs when the way an individual grieves is not viewed as appropriate, whether emotions displayed are thought to be lacking or very intense (Attig, 2004).

Anticipatory grief. The second form of grief relevant to the topic of MAiD is called anticipatory grief (also referred to as pre-loss grief), first described by Lindemann (1944) as an experience of grief occurring in *anticipation* of a loss (Lindemann, 1944; Toyama & Honda, 2016; Treml et al., 2021; Worden, 2018). Although grief occurs prior to and following any loss (i.e., it is not restricted to death-related losses alone), I have chosen to focus this section specifically on the experiences in anticipation of death (Lindemann, 1944). Like other forms of grief (uncomplicated and complicated alike), experiences of anticipatory grief vary widely across individuals, affected by individual characteristics of the griever and their loved one and the context of the impending death (Rando, 1988). This form of grief is unique as it can be experienced by the end-of-life patient themselves in the time leading up to their death, an experience which has recently been termed ‘self-mourning’ (Plant, 2022). Although the existing literature on experiences of self-mourning is scarce, it may play an important role in both a patient’s experience of death, as well as the grief experiences of those around them.

A common misconception about anticipatory grief is that by starting the grieving process before a loss, much of the ‘grief work’ will be accomplished by the time of the loss, thereby acting as an adaptive coping mechanism in reducing the intensity or duration of the post-loss grief experience (Fulton, 2003). Substantial research has investigated the validity of this assumption (Coelho et al., 2021; Coelho & Barbosa, 2017; Majid & Akande, 2021; Marshall et al., 1997; Nielsen et al., 2016; Reynolds & Botha, 2006; Rogalla, 2020; Treml et al., 2021). Published reviews of this work have summarized mixed findings. Many studies report an association between high levels of pre-loss grief and worse post-loss outcomes (including heightened depressive symptoms, stress, avoidance, and complicated grief); however, it is unclear whether this association is confounded by individual characteristics of the griever such as previous life stressors, prior depressive symptoms, or the responsibilities of caring for a loved one nearing death (Majid & Akande, 2021; Nielsen et al., 2016). In contrast, some studies have reported positive impacts of anticipating a loved one’s death, suggesting that the ability to prepare for such a loss may reduce the likelihood of poor post-loss outcomes (Rogalla, 2020; Schulz et al., 2015). These studies however did not focus specifically on anticipatory *grief*, rather on anticipation of loss more generally. Thus, at present it is not clear the role that experiencing anticipatory grief may play on post-loss outcomes.

Grieving MAiD

The introduction of assisted dying programs around the world has brought forth curiosity about how experiences of grief may differ for those bereaved by assisted and unassisted (or 'natural') death (Andriessen et al., 2020; Beuthin et al., 2022; Frolic et al., 2020; Gamondi et al., 2019; Hashemi et al., 2021; La Brooy et al., 2024; Serota, Atkinson, et al., 2023; Srinivasan, 2019; Trouton et al., 2020; Yan et al., 2022). There is a breadth of literature exploring professional and grief-related experiences of MAiD among loved ones and healthcare providers, both generally and for patients with specific underlying conditions (Andriessen et al., 2020; Calati et al., 2021; Gamondi et al., 2019; Ward et al., 2021; Wibisono et al., 2022; Yan et al., 2022). As the focus of my thesis was to explore experiences of grief related to the current MAiD program in Canada, I have chosen to summarize only studies that focus explicitly on experiences of MAiD-related grief within the confines of the Canadian MAiD eligibility criteria. In other words, I have omitted literature which focuses solely on any of the following: 1) non-grief related experiences of MAiD; 2) grief experiences related to MAiD for patients with mental illness as the sole underlying condition; and 3) experiences of grief related to MAiD for patients younger than 18 years old. Despite substantial literature on professional and personal experiences and perspectives of professional healthcare providers in the MAiD field, to my knowledge none of these studies focus specifically on experiences of grief (Serota, Hubert, et al., 2023; Wibisono et al., 2022). Thus, the following section highlights experiences of MAiD-related grief among friends and family members of MAiD patients.

MAiD-Related Grief Among Family Members and Loved Ones

Three systematic reviews of grief experiences following the loss of a loved one to

MAiD have been conducted, summarizing relevant articles published between 1995 and 2022 (Andriessen et al., 2020; Gamondi et al., 2019; Yan et al., 2022). Included in these reviews are 38 primary analyses from four countries (Canada n = 14; Netherlands n = 9; USA n = 8; Switzerland n = 6; and Australia n = 1) and 6 literature reviews with considerable overlap in included articles. Findings from these three reviews suggest a few key contributing factors in the grief experience of loved ones.

First, relationships and the degree of acceptance and involvement of loved ones throughout the MAiD process seems to play a significant role in how grief is experienced (Andriessen et al., 2020; Gamondi et al., 2019; Yan et al., 2022). Acceptance of the patient's choice to access MAiD is generally associated with a more positive or adaptive grieving process, while direct involvement in the process leads to mixed experiences (Andriessen et al., 2020; Gamondi et al., 2019; Yan et al., 2022). For instance, involvement in decision-making and facilitation of MAiD leads to feelings of fulfilling the patient's last wishes for some, while others experience feelings of guilt in facilitating the death of their loved one (Andriessen et al., 2020; Gamondi et al., 2019; Yan et al., 2022).

Concerns around judgment and criticisms regarding the method of death was another key factor in how participants grieved. Many participants indicated anxiety or fear around disclosing the nature of their loved one's death due to the highly controversial nature of the topic, with some evidence for a correlation between social disapproval (and perhaps disenfranchised grief) and increased experiences of post-loss PTSD and complicated grief (Andriessen et al., 2020; Gamondi et al., 2019; Wagner et al., 2012; Yan et al., 2022). It is plausible that stigma around MAiD may inhibit grievers from accessing bereavement supports, leading to poorer coping and adjustment to life after loss (Srinivasan, 2019).

Another influential factor in the experience of grief was the preparation and anticipation of death. Involvement in the preparatory processes for MAiD were both helpful and hindering. For some, the opportunity to plan out the patient's final days, have a set date for the end of the patient's suffering, and prepare for a final goodbye was comforting for loved ones (Andriessen et al., 2020; Gamondi et al., 2019; Yan et al., 2022). In contrast, many participants experienced frustration and anxiety with the logistics of the process, citing barriers such as lack of clarity around the program, and difficulties identifying and accessing participating providers (Yan et al., 2022). Further, the length of eligibility assessments appears to be a point of contention; decisions made too quickly were often deemed problematic and too permissive while lengthier decisions were viewed as unnecessarily prolonging the patient's suffering (Gamondi et al., 2019; Yan et al., 2022). Selecting an appropriate location for their loved one's passing constituted another logistical barrier for participants. Although a home death may be a more comfortable setting for dying than a hospital, family and friends may want to avoid associating their home with death or feel that their home could not best accommodate the procedure (Yan et al., 2022).

In all, the findings of these reviews suggest that loved ones of MAiD patients generally regarded their experience as a positive one, citing factors including starting the healing process early, avoiding the need for more intensive care options, and mitigating prolonged suffering for their loved one (Yan et al., 2022). These factors seem to contribute to an overall equal or more positive grief experience for those bereaved by MAiD deaths compared to unassisted death, despite individual and cultural variance (Andriessen et al., 2020).

More recent work by La Brooy et al. (2024) supports and extends these findings. In their study of grief-bereavement experiences of family members following assisted death in Australia, participants similarly emphasized the importance of honouring their loved one's wishes and maintaining strong emotional bonds throughout the dying process. The opportunity to prepare for their loved one's death and create meaningful rituals was described as helpful in the process of navigating their grief, while challenges related to their role in facilitating their loved one's death added complexity to the experience (La Brooy et al., 2024). These findings offer further evidence to support the idea that both meaningful involvement in the dying process and broader societal context can significantly shape the experience of MAiD-related grief.

Literature Summary

Overall, the literature suggests that 1) the majority of healthcare workers and the general public in Canada are in support of the Canadian MAiD program; 2) access to and implications of the program likely differ between urban and rural contexts; and 3) grief associated with death by MAiD does not seem to differ significantly from non-MAiD grief. However, a number of gaps exist at the intersects of these topics.

First, while there exists a breadth of literature on experiences of grief among loved ones bereaved by MAiD and the professional perspectives and experiences of healthcare providers who work with MAiD clients, the grief experiences of providers and patients themselves has yet to be explored. Given the often-longstanding personal relationships between patients and providers, it is pertinent to examine how healthcare providers may experience provider-grief after the loss of a patient to MAiD, and the factors that may influence those experiences. Further, the possibility of patients' experiences of 'self-mourning' ahead of their own death may present important considerations for provision of end-of-life grief resources for patients as well as their loved ones (Plant, 2022).

Similarly, existing literature highlights factors associated with health and end-of-life care within rural settings, with substantial literature exploring rurality as a social construct and distinct aspect of cultural identity (Brassolotto et al., 2021; Brassolotto, Manduca-Barone, & Sedgwick, 2023; CIHI, 2006; Keating et al., 2011). Despite this, it remains unclear how social, cultural, and geographic factors associated with rurality may impact experiences of grief. Given the unique considerations for health and end-of-life care within rural settings, as well as the distinct social networks often present within rural communities, insight regarding the rural grief experience may inform strategies to better support individuals through grief across various settings.

Finally, scholars have explored perceptions and stigma related to MAiD broadly, with a handful of studies investigating the impact of MAiD-related stigma on experiences of grief (Philippkowski et al., 2021; Singer et al., 2023). While distinct cultural, social, and political aspects of rurality may play a role in how MAiD-related stigma exists within rural communities, there are key questions which have yet to be explored. First, it remains unclear whether MAiD-related stigma is related to rural social, cultural, and geographic factors, and if so, whether this impacts how the stigma is perceived and experienced within rural communities. If rurality does play a role in the experience of stigma related to MAiD, it is unclear how rural-specific experiences of stigma may influence MAiD availability and utilization within rural settings. Finally, should rural-specific stigma regarding MAiD exist, how it may further impact the rural experience of MAiD-related grief has also yet to be explored.

Research Objectives

Based on my review of the existing literature, I sought to explore the concepts of grief and stigma related to MAiD death among individuals closely involved or impacted by MAiD within rural Southern Alberta through this thesis. To facilitate this exploration, I developed two primary and four secondary research questions to guide my analysis, which I describe in the following section. These questions are as follows:

1. How do participants (patients, family members, and healthcare professionals) implicitly and explicitly describe experiences of grief and/or perceptions of community members' grief related to MAiD death in rural Southern Alberta?
    a. What factors influence these grief experiences?
2. What role does stigma play in patients', family members', and healthcare professionals' experiences of grief related to MAiD death in rural Southern Alberta?
    a. How do participants describe the source of MAiD-related stigma?
    b. How, if at all, does the source and experience of stigma related to MAiD vary across participant groups?
    c. Which rural factors, if any, influence the experience of MAiD-related stigma and associated grief experiences?

In the following section, I briefly describe the methods used to explore these questions, provide context around my positionality as a researcher with respect to the methods used and the topics of grief and MAiD, and discuss my epistemological assumptions and orientation to my data. Additional details about the analytic methods used are presented in the Methods section of Chapter 2.

Methodology

Analytic Approach

To explore my research questions, I adopted an inductive reflexive thematic approach, described by Braun and Clarke (2022), to conduct a secondary analysis of interview transcript data from participants with first-hand experiences with the MAiD program in rural Southern Alberta. Braun and Clarke (2022) describe this approach as "an accessible and robust method" to qualitative analysis that involves developing and interpreting patterns of meaning across a dataset (p. 4). I followed Braun and Clarke's (2022) iterative six-phase approach to reflexive thematic analysis, which includes 1) data familiarization, 2) coding, 3) generating preliminary themes, 4) reviewing and developing themes, 5) refining, defining, and naming themes, and 6) describing, explaining, and evidencing thematic findings. Prior to beginning data familiarization, I embarked on what I conceptualize as 'Phase 0' of this process: reflecting on my personal experiences, values, and training to understand my positionality as the researcher within this project.

Reflexive Researcher Positionality

Although I have several years of experience in health research, this thesis marked my first time leading a qualitative study from design through to analysis and interpretation. My previous work has been grounded almost entirely in quantitative methods, where objectivity, replicability, and generalizability are emphasized as the cornerstones of 'good' research. As a result, approaching this project from a qualitative, constructivist perspective felt unfamiliar, and at times uncomfortable. I frequently found myself instinctively quantifying patterns in the data and seeking a clear, step-by-step approach to coding and interpretation. The lack of predetermined structure, alongside the ability to tolerate ambiguity and uncertainty, required a significant adjustment from my previous experience conducting research. This project also marked my first experience conducting primary research on a topic with which I had limited prior academic or personal experience. I was raised and have lived the majority of my adult life in urban and semi-urban environments, and while I have experiences with grief related to the death of loved ones, these losses did not involve MAiD. Considering my position relative to the topic allowed me to anticipate how my role as an ‘outsider researcher’ (Braun & Clarke, 2022) may influence how I approached and interpreted my data. As such, I kept a notebook at my desk to record personal and tangential thoughts that arose during my analysis, and to reflect on these thoughts following each analysis session. To navigate challenges related to my lack of methodological and topical experience throughout the process, I regularly reviewed Braun and Clarke’s publications on reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2021, 2022), and sought out academic literature and media sources on MAiD and grief to further immerse myself in the topics. Finally, regular meetings with my supervisor provided helpful feedback on my process and analytic outputs from preliminary codes to finalized themes and reminded me to lean into my subjectivity as a researcher rather than resist it.

The practice of reflecting on my personal experiences, values, and training was crucial in understanding my positioning as a researcher within this study and helped to inform my orientation to the data and approach to coding. While I began this project relatively naïve to specific aspects of MAiD, rural health scholarship, and qualitative research practices—which I believe position me as an ‘outsider researcher’—I am well versed in the broader contexts in which this work is situated. My academic training in psychology and public health alongside personal experiences of loss, grief, and a healthcare service user have served as the lens through which I interpreted the data from my ‘outside’ perspective.

Data Orientation and Coding Approach

Two commonly adopted orientations to analysing data in reflexive thematic analysis are experiential and critical orientations (Byrne, 2022; Clarke, 2021). Experiential orientations tend to prioritize the participant's own description and meaning of an experience, placing emphasis on the participant's thoughts, feelings, and beliefs around it. In contrast, critical orientations to analysis strive to extend beyond a descriptive understanding of these as a reflection of the individual's experience, assuming that these thoughts, feelings, and beliefs are a part of rather than reflective of the experience (Byrne, 2022). For this research, I chose to adopt a mixed orientation to my analysis. Practically, this involved first taking on an experiential approach in familiarising myself with the data and generating initial codes (phases 1 and 2 of Braun and Clarke's [2022] six-phase approach). To do this, I engaged a semantic approach to coding, in which I labelled (using the comments feature of Microsoft Word) excerpts based on the meaning explicitly described within them. For example, in excerpts where participants described feeling sad about the loss of a loved one, but also relieved that their loved one was no longer suffering, I applied the codes "sad" and "relieved" which I eventually refined to "mixed/competing emotions: sadness and relief". This experiential orientation and semantic coding approach allowed me to gain an understanding of participants' experiences through their perspectives and honour their explicit descriptions of the thoughts, feelings, and beliefs they had in relation their MAiD experience.

Once I had completed one round of semantic coding across the dataset, I re-read each transcript through a more critical lens to assess how participants' descriptions may relate to the social, cultural, and political context of the experiences. In practice, this involved a latent approach to coding, through which I theorized about the meanings, assumptions, and ideas that may underlie participants' descriptions. In other words, this process involved considering why participants described their experiences in the ways they did and how that may be implicated in their continued experience of reflecting and adapting to new thoughts and feelings that arise even after their active involvement with MAiD. I revisited each transcript multiple times to add and refine codes based on new perspectives I developed throughout the coding process until I felt confident that my codes adequately represented the meanings I interpreted across the dataset. This mixed approach to inductive coding provided me with a thorough understanding of participants' experiences in their own words, as well as the opportunity to critically assess how their previous experiences, relationships, and social, cultural, and political context may have shaped (and been shaped by) their perspective towards the MAiD experience.

Generating, Revising, and Defining Themes

To generate preliminary or 'candidate' themes, I began to visually organize the codes I had compiled in earlier phases according to patterns of meaning using an online whiteboard tool (Miro). This process resulted in the development of four categories of codes which I presented to my supervisory committee: 1) Protecting Others from Unnecessary Harm; 2) Personal and Professional Rural Relationships; 3) Contradictory Emotions and Beliefs; and 4) The Cycle of Stigma and Secrecy. We discussed these categories, the codes within them, and the excerpts that informed their development as a group, with each member of my supervisory committee offering valuable feedback to challenge and refine my interpretation and categorization of the data. Following this meeting, I revisited my whiteboard with their feedback in mind, restructuring the organization of my codes in various ways. When I was conceptually satisfied with the structure, I compared each new theme within the structure to Braun and Clarke's (2022) basic criterion for candidate themes:

1. "Is this pattern a *viable* theme – a pattern that has an identifiable central organising concept, as well as different manifestations of that idea?" (p. 98),

and their thematic review and development questions (p. 99):

1. "Can I identify boundaries of this theme?"
2. "Are there enough (meaningful) data to evidence this theme?"
3. "Are the data contained within each theme too diverse and wide-ranging?", and
4. "Does this theme convey something important?".

Further refinement, guided by feedback from Dr. Brassolotto, resulted in three final themes which I present in the following chapter.

CHAPTER 2:

GRIEVING MAID: EXPLORING THE INFLUENTIAL FACTORS ON EXPERIENCES OF GRIEF RELATED TO MEDICAL ASSISTANCE IN DYING

Introduction

Since its legalization in 2016, Medical Assistance in Dying (MAiD) in Canada has introduced complex considerations surrounding end-of-life care for patients, families, and healthcare professionals. While MAiD is often framed in terms of its role in providing patients with choice and autonomy, its broader implications – including how it affects experiences of grief – are also important elements of the conversation. In this chapter, I explore the ways in which patients, family members, and healthcare professionals described their experiences of MAiD and associated grief within the context of rural communities in Southern Alberta, Canada. Findings of this study largely align with existing literature on the topic, while offering additional insights into the influences of Canadian and rural Southern Albertan contexts on these experiences. In this chapter, I outline three key findings: (1) participants are drawn to MAiD in order to avoid factors associated with a 'bad death'; (2) bureaucratic policies and processes can complicate the MAiD experience and related experiences of grieving; and (3) stigma around MAiD can contribute to a sense of secrecy among those involved, limiting opportunities for open public discussions and access to grief-related supports. In what follows, I elaborate on these themes, offer illustrative examples from the dataset, and discuss their implications for MAiD-related grief. The findings from this study present an opportunity to explore policies and practices that can better support individuals through the nuances of the MAiD process, and to enhance public education and awareness around the program.

As detailed in Chapter 1, I use the terms ‘good’ and ‘bad’ death or grief experiences throughout this thesis not as value judgments or rigid classifications, but to reflect participants’ descriptions of how institutional, systemic, and social contexts shaped their experiences. A ‘good death’ refers to one that aligns with a person’s values and end-of-life wishes, while ‘good grief’ captures experiences of coping and meaning-making that were described or interpreted as relatively positive. Conversely, ‘bad’ deaths or grief experiences reflect misalignment with values, and/or the presence of barriers that hindered dignity or healing. These terms are used to illustrate how policy and practice can shape experiences of dying and bereavement, not to evaluate individual responses to loss.

Background

MAiD in the Canadian Context

Canadian Legislation

In June 2016, Canada legalized MAiD through an exemption to the Criminal Code, which allowed eligible adults to receive assistance in dying from physicians and nurse practitioners. Canada’s MAiD program permits both clinician-administered MAiD and self-administered MAiD, though the latter is prohibited in Québec and remains rare nationwide (Government of Canada, 2023a; Health Canada, 2024a). To ensure that requests are made voluntarily and that patients meet eligibility criteria, Canadian legislation includes several safeguards, including the requirement for patients to provide final consent immediately before receiving MAiD. In 2021, the law was amended under Bill C-7 to expand MAiD eligibility. Patients eligible for MAiD are now divided between two tracks; patients whose deaths are reasonably foreseeable are considered ‘Track 1’ patients and are eligible to waive the requirement to provide final consent, while ‘Track 2’ patients’ deaths are not reasonably foreseeable and are not eligible to waive the final consent requirement (Health Canada & MAiD Practice Standards Task Group, 2023). In both tracks, patients must be 18 years or older, able to make informed decisions about their health, have a grievous and irremediable medical condition, and make a voluntary, written request for MAiD. With the recent amendments under Bill C-7 and upcoming changes which may allow for individuals suffering solely from mental illness to access MAiD, Canadian legislation for assisted dying is among the most permissive in the world (Konder & Christie, 2019).

Canadian Perspectives and Controversy

Canada, like many other Western nations, has adopted a highly medicalized approach to death and dying, which influences our views on death and, by extension, assisting in the facilitation of death (Banjar, 2017). Perspectives about MAiD in Canada exist along a continuum, ranging from unconditional support to complete opposition (Sedgwick et al., 2024). A breadth of evidence exploring these perspectives suggest that most Canadians are supportive of MAiD under specific circumstances, which vary across individuals and demographic groups (Bator et al., 2017; Beuthin et al., 2018; Bruce & Beuthin, 2020; Chandhoke et al., 2020; Falconer et al., 2019; Freeman et al., 2020; Hawrelak et al., 2022; Leck et al., 2020; McCarthy & Seal, 2019; Pennings & Reid, 2020; Pesut, Thorne, Storch, et al., 2020; Rousseau et al., 2017; Spicer et al., 2017; Wong et al., 2019).

Despite this, passionate advocacy from either end of the continuum has resulted in a high degree of political tension and polarization around the topic (Downie & Schuklenk, 2021). While proponents of the program argue that legislated access to MAiD reduces end-of-life suffering and upholds our Charter right to autonomy in life and death (Department of Justice Canada, 2021; Dugdale et al., 2019), critics have raised concerns about the precedent it may set for healthcare and emphasize the importance of protecting human life (Disability Rights Education & Defense Fund, n.d.; Pullman, 2023; Sulmasy et al., 2016). Additionally, with the expansion of MAiD eligibility introduced under Bill C-7 and potential expansion to allow MAiD for patients suffering solely from mental illness in 2027 (Department of Justice Canada, 2024), there have been critiques from disability rights groups and allies regarding equity considerations (Bernasky et al., 2024; The Vulnerable Persons Secretariat, 2021). Specifically, there are concerns that it is becoming easier to access MAiD than to access disability, income, and mental health supports, thereby promoting an ableist perspective that a disabled life is one not worth living (Bernasky et al., 2024; Brassolotto, Manduca-Barone, & Zurbrigg, 2023; The Vulnerable Persons Secretariat, 2021). At their core, arguments both for and against MAiD demonstrate compassion for and a desire to protect the wellbeing of others. However, polarity in perspectives on how to best respect individuals' nuanced experiences of life and death have resulted in significant controversy and experiences of stigma for Canadians involved in the MAiD program.

Canadian Utilization

To date, more than 60,000 Canadians have accessed MAiD, representing approximately 5% of total mortality nationwide (Health Canada, 2024a). On average, MAiD recipients were 78 years old, and most likely to be male, Caucasian, and under Track 1 of the eligibility criteria (Health Canada, 2024a). While the majority of MAiD deaths occurred in urban areas of the country, proportional rates were higher within rural regions, highlighting key discrepancies in access and utilization between urban and rural populations (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Health Canada, 2024a;

Manduca-Barone et al., 2022).

MAiD in the Southern Alberta Context

Alberta was one of the first provinces in the country to establish centralized MAiD guidelines and has reported just over 5,000 MAiD deaths between 2016 and 2024 (Alberta Health Services, 2024). As of 2022, approximately 16% of MAiD deaths in Alberta occurred in rural settings, roughly aligning with Alberta's population distribution and Canada-wide MAiD utilization across urban and rural communities (Alberta Health Services, n.d.-b; Health Canada, 2023). However, rural residents often face accessibility challenges around MAiD due to geographic isolation from major population centres, which can influence their decision-making process around end-of-life care (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Hewitt et al., 2024; Manduca-Barone et al., 2022; Schiller, 2017; C. R. Wilson et al., 2020). For instance, rural residents may experience greater challenges with accessing specialist services, pain management support, or palliative care.

Further, the dominant conservative values and tight-knit nature that are characteristic of many rural communities in Southern Alberta can present challenges related to patient and provider privacy around MAiD engagement. This can lead to significant implications for individuals' and families' social wellbeing, particularly in light of the controversy surrounding MAiD (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Byrnes et al., 2022; Wilson et al., 2009). These factors, among others, highlight a distinct need to consider the context of place when investigating experiences of MAiD and related grief within a rural context (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Sedgwick et al., 2024).

Grieving MAiD

Grief is a natural, universal response to the death of a loved one, encompassing a wide range of emotional, psychological, and physical reactions which can vary based on individual, cultural, and contextual factors. For many, grief involves navigating intense emotions, seeking meaning through loss, and gradually integrating the experience into their lives (Boerner et al., 2015; Bonanno & Kaltman, 2001; PDQ Supportive and Palliative Care Editorial Board, 2002; Rawlings, 2023; Stroebe & Schut, 2001). Within the context of MAiD, the structured nature of the process can impact the grieving journey, potentially providing opportunities for preparation and closure while still presenting emotional challenges for the bereaved.

Emerging evidence suggests that grief experiences related to MAiD deaths may differ from those associated with unassisted (or 'natural') deaths (Andriessen et al., 2020; Gamondi et al., 2019; La Brooy et al., 2024; Wagner et al., 2012; Yan et al., 2022). For instance, La Brooy et al. (2024) explored the impacts of assisted dying on grief and bereavement in the Australian context. They found that family members of assisted dying patients experienced a sense of meaning from fulfilling their loved ones' wishes; they were able to maintain bonds with the deceased loves ones through unique rituals and advocacy related to assisted dying; and knowing the exact day and time of death enabled them to plan and prepare. Their participants also indicated that assisted deaths present some distinct challenges for grief and bereavement, especially in terms of the impact on familial relationships and the burdens associated with navigating related moral predicaments (La Brooy et al., 2024).

Although high degrees of acceptance, involvement, and preparation for the loved one's death were commonly associated with more adaptive grief experiences, the literature suggests that concerns around judgment, interpersonal and familial conflict, and facing logistical or legislative obstacles can have a negative impact (Andriessen et al., 2020; Gamondi et al., 2019; La Brooy et al., 2024; Serota, Buchman, et al., 2023; Srinivasan, 2019; Wagner et al., 2012; Yan et al., 2022). While these international findings provide key insight into factors that may play a role in how MAiD-related grief is experienced broadly, I aimed to explore MAiD and related experiences of grief within the context of rural Southern Alberta.

Methods

Research Questions

1. How do MAiD patients, family members, and care professionals describe experiences of grief related to MAiD death in rural Southern Alberta?
2. What factors influence how MAiD-related grief is experienced within a Southern Alberta context?

Study Design

For this study I conducted a secondary reflexive thematic analysis of semi-structured interview data collected between September 2021 and April 2022 (Brassolotto, Manduca-Barone, & Sedgwick, 2023). Eligible participants were 18 years or older at the time of consent, able to speak and understand conversational English, lived and/or worked in Southern Alberta, and self-identified as belonging to one of three groups: a) patients who had requested and been approved for MAiD, b) family members of a patient who had previously received MAiD, or c) healthcare professionals directly involved in MAiD assessments and/or provisions. Interview guides were developed and used to encourage discussion about participants' lived and professional experiences with the MAiD program within the context of rural Southern Alberta. While participants were not asked explicitly about grief, discussions around death and loss provided ample opportunity to explore participants' psychological and emotional reactions to MAiD deaths, including implicit descriptions of grief. Interviews were conducted by telephone or Zoom call with participants and transcribed by a third-party transcription service. For further details on data collection and ethical considerations, see Brassolotto, Manduca-Barone and Sedgwick, 2023.

Data Analysis

Using Braun and Clarke's (2019, 2021, 2022) six-phase approach to reflexive thematic analysis, I began by familiarizing myself with the data set through reading, re-reading each transcript, and using the comment feature in Microsoft Word to annotate initial thoughts, curiosities, and potential patterns. Next, I used a semantic coding approach to generate initial codes by noting interesting, insightful, or unexpected statements, before re-visiting each transcript to generate latent codes based on my perception of participants' explicit statements within their broader social, political, and geographic context. For each round of coding, I created a new copy of transcripts which retained the comments I applied in the previous round, adding new comments with revised codes and new ideas, and resolving comments from previous rounds which no longer felt relevant to my analysis. Following my second round of coding, I met with Dr. Brassolotto via Zoom to discuss and revise my initial codes. I then began to categorize my revised codes according to patterns of meaning to form candidate themes, which included (1) Protecting Others from

Unnecessary Harm, (2) Personal and Professional Rural Relationships, (3) Contradictory Emotions and Beliefs, and (4) The Cycle of Stigma and Secrecy. Members of my supervisory committee and I met virtually to discuss these candidate themes and offer feedback which allowed for further refinement. Following this, I shared my revised themes ('Mixed Emotions Contribute Complexity' and 'Stigma and Secrecy Hinder Support Seeking') with my committee for approval via email. Once approved, I began compiling my findings into the first draft of this chapter, during which time I further revised and refined my themes in accordance with Phase Six of Braun and Clarke's (2022) approach to reflexive thematic analysis.

Participant Sample

In total, 29 individuals who lived, worked, or requested MAiD in rural Southern Alberta shared their experience of MAiD and were included in analyses. These included 18 healthcare professionals (62%), including zone directors, ethicists, physicians, nurse practitioners, and registered nurses; 8 family members (28%), including adult children, siblings, and spouses of MAiD patients; and 3 patients who had been approved for MAiD (10%). All participants were supportive of MAiD as an end-of-life healthcare practice at the time of data collection. Nearly all participants were Caucasian (97%), two-thirds were male (66%), and were an average age of 56 (range: 33 – 82 years old). While annual household income varied by participant group, most had completed post-secondary education (90%). Despite popular beliefs about religious opposition to MAiD, 45% of study participants identified as spiritual or religious (21% spiritual; 14% Christian; 10% other religion). Full participant demographics are presented in Table 1.

Table 1
Demographic Characteristics

	Overall Sample N = 29 (100%)	Healthcare Professionals n = 18 (62%)	Family Members n = 8 (28%)	MAiD Patients n = 3 (10%)
Avg. Age	**56**	**48**	**65**	**75**
(range)	(33 – 82)	(33 – 72)	(52 – 77)	(62 – 82)
Gender – n (%)				
Male	19 (66%)	13 (72%)	5 (62.5%)	1 (33%)
Female	10 (34%)	5 (28%)	3 (37.5%)	2 (67%)
Annual Household Income – n (%)				
$150,000 +	13 (45%)	13 (72%)	–	–
$100,000 - $149,999	5 (17%)	3 (17%)	1 (13%)	1 (33%)
$50,000 – $99,999	5 (17%)	2 (11%)	2 (25%)	1 (33%)
<$50,000	1 (3%)	–	–	1 (33%)
Prefer not to disclose	5 (17%)	–	5 (63%)	–
Educational Attainment – n (%)				
Graduate or Professional Deg.	13 (45%)	12 (67%)	1 (13%)	–
Undergraduate Deg./College Dip.	13 (45%)	6 (33%)	6 (75%)	1 (33%)
High School Dip.	2 (7%)	–	–	2 (67%)
Some High School	1 (3%)	–	1 (13%)	–
Professional Group – n (%)				
MAiD Providers (MDs, NPs)	–	8 (44%)	–	–
MAiD Nurses (RNs)	–	7 (39%)	–	–
Other (Ethicists, Directors)	–	3 (17%)	–	–
Race/Ethnicity – n (%)				
Caucasian	28 (97%)	18 (100%)	7 (88%)	3 (100%)
Other	1 (3%)	–	1 (13%)	–
Religious Affiliation – n (%)				
None	16 (55%)	13 (72%)	2 (25%)	1 (33%)
Spiritual	6 (21%)	2 (11%)	4 (50%)	–
Christian	4 (14%)	2 (11%)	1 (13%)	1 (33%)
Other	3 (10%)	1 (6%)	1 (13%)	1 (33%)
Political Affiliation – n (%)				
None	14 (48%)	8 (44%)	5 (63%)	1 (33%)
Conservative	6 (21%)	4 (22%)	1 (13%)	1 (33%)
Liberal	6 (21%)	5 (28%)	–	1 (33%)
Other	2 (7%)	1 (6%)	1 (13%)	–
Prefer not to disclose	1 (3%)	–	1 (13%)	–
Avg. Years in Rural Southern AB	**27**	**20**	**30**	**53**
(range)	(2 – 75)	(2 – 47)	(15 – 50)	(23 – 75)
% of Avg. Age in Rural Southern AB	48%	42%	46%	71%

Compared to the general Alberta population, study participants were statistically different across all demographic measures (Table 2). On average, study participants were 17 years older than the provincial average, less likely to be religious or spiritual, and more likely to have completed post-secondary training, be of Caucasian ethnicity, and report a higher annual household income than the average Albertan resident (Statistics Canada, 2023). Study participants were also less likely to report affiliation with the federal Conservative party when compared to provincial results from the last Canadian federal election (Elections Canada, n.d.; Statista Research Department, 2024).

Table 2

Sample and Provincial Demographic Comparison

	Study Sample (n = 29)	Alberta Population[1] (n = 4,262,635)	Sig. Diff *test statistic, p-value*
Age (avg.)	56 years	39 years	$t = 6.10, p < 0.001$
Gender			$\chi^2 = 5.25, p = 0.02$
Male	66%	50%	
Female	34%	50%	
Annual Household Income			$\chi^2 = 24.15, p < 0.001$
<$50k	4%	21%	
$50,000 - $99,999	21%	31%	
$100,000 - $149,999	21%	22%	
$150,000+	54%	25%	
Educational Attainment			$\chi^2 = 38.90, p < 0.001$
< Highschool diploma	3%	10%	
Highschool diploma	7%	25%	
Post-secondary, ≤ bachelor's degree	45%	55%	
Post-secondary, > bachelor's degree	45%	9%	
Race/Ethnicity[†]			$\chi^2 = 29.04, < 0.001$
Caucasian	97%	72%	
Other	3%	28%	
Religious/Spiritual Affiliation			$\chi^2 = 23.86, p < 0.001$
Christian	14%	48%	
Other	31%	12%	
None	55%	40%	
Political Affiliation[‡]			$\chi^2 = 13.45, p = 0.001$
Conservative	21%	55%	
Liberal	21%	16%	
Other	7%	29%	
None	48%	N/A	
Prefer not to say	3%	N/A	

[1] Proportions calculated using Statistics Canada Census 2021 data (Statistics Canada, 2023).

[†] 'Visible Minority' census data was used for ease of comparison, assuming that 'Not a visible minority' census identities were comparable to 'Caucasian' study identities, and 'Visible minority' census identities were comparable to 'Other' racial/ethnic identities among study participants (Statistics Canada, 2023).

[‡] Canadian census does not report political affiliation. Population-level political affiliation rates were obtained from provincial results of the most recent federal election in 2021 as reported by Statista (Statista Research Department, 2024).

Limitations

This study involved a secondary analysis of qualitative interviews originally conducted as part of a broader research project on experiences of MAiD in rural Southern Alberta. As such, the interview guides used to collect the data used within this thesis were not designed specifically to explore experiences of grief which likely limited the degree to which participants shared about this aspect of the MAiD experience. Further, this analysis draws on the perspectives of a relatively small and geographically specific sample with relatively homogenous views towards MAiD as a practice. As noted above, study participants were significantly more likely to be well educated, high-income earners than the broader Albertan population. As such, findings from this work should not be generalized beyond this context but may be useful in guiding future research among more diverse study samples. Finally, while subjectivity is integral to reflexive thematic analytic approaches (Braun & Clarke, 2022), it is important to acknowledge that the findings, conclusions, and recommendations presented throughout the remainder of this thesis have been largely shaped by my own positionality as a researcher.

Findings

In the absence of interview questions focused on grief, participants rarely spoke about their MAiD-related grief explicitly. However, accounts of their experiences and perceptions throughout the process offered insight into how grief and loss can present for patients, loved ones, and professionals involved in the MAiD program. For instance, patients seeking MAiD, who had accepted that their lives were soon ending, still grieved these endings. Healthcare providers who had supported patients along challenging health journeys sometimes experienced sadness and loss following their involvement in ending a patient's life – describing it as a weighty and profound human experience. Family members grieved their loved ones' pre-terminal lives, as well the loss of future possibilities that would not be realized. Living through the COVID-19 pandemic, participants also grieved the loss of normalcy, social connection, and a healthcare system that was not under severe strain. In short, although this study was not explicitly designed by the investigators to inquire about grief, grief and loss manifested in multiple and meaningful ways.

Through my analysis, I generated three key themes related to participants' grief around MAiD. The first illustrates how the opportunity to avoid aspects of a 'bad death' was often a key factor in the decision to participate in MAiD. MAiD was described as an option to allow patients to die with dignity and without unnecessary suffering, to provide family members the opportunity to prepare for the loss, and to offer healthcare professionals a more pleasant alternative to the oft-traumatic experiences of unassisted patient death.

The second theme describes key challenges of the bureaucratic policies and processes involved in the MAiD program, and the impact these challenges have on individuals' experience of death and grieving. Two key challenges identified by participants were (1) the final consent requirement and (2) the limited end-of-life and palliative care facilities that allow MAiD within rural Southern Alberta. Finally, the third theme describes the role of stigma in how participants experience and process their MAiD-related grief.

Theme 1: Avoiding a 'Bad Death' Through MAiD

The concept of a 'bad death' encompasses experiences of death that involve extensive pain or suffering, a sudden or unexpected death, a prolonged dying process, disregard for a patient's wishes, and/or a lack of dignity for the dying person (Good et al., 2004; D. M. Wilson & Hewitt, 2017). This theme explores how participants' desire to avoid a ‘bad death’ was a key factor in their decision to participate in the program. Overwhelmingly, participants described that the opportunity for a patient to exercise agency in their end-of-life decisions contributed to a positive experience across various stages of the death and dying process. Although these deaths were still, of course, emotionally difficult for patients and their families, the ‘good death’ that MAiD provided mitigated the pain and suffering that patients and families can experience at end of life and created feelings of greater acceptance of the death.

Participant-Identified Factors of a ‘Bad Death’

For many participants, a ‘bad death’ was characterized by negative experiences in the time leading up to a patient’s death, rather than the moment of death itself. Most notably, participants described a terminal decline in the patient’s quality of life prior to their death as indicative of a ‘bad death’ experience. This often involved a loss of control and autonomy, which manifested in a progressive loss of independence or ability to engage in activities of daily living and/or pleasure, a heightened need for comfort or life sustaining care, or enduring chronic and severe pain and/or discomfort in the lead up to death. For example, in anticipating the loss of her independence, Patient 2 noted that “if you can’t even get out of bed in the morning, that’s not right” (Patient 2). Similarly, Patient 1 shared about his aversion to receiving additional care in the event his condition suddenly worsened, describing the need for machines and even continuing care within the context of nursing or respite homes as “bad things” (Patient 1). Regarding pain and discomfort prior to death, another patient shared, “I can’t think of anything worse than … to have somebody be in agony for, you know, I don’t know … how long a time, but I think that’s probably the worst thing that can happen to a person” (Patient 3). Similar views were shared by loved ones and healthcare professionals. For example, a family member bereaved by MAiD shared, “you see so many people that are in assisted living or nursing homes that are just *there* [emphasis added]. There is no quality of their life” (Family Member 8), while a nurse described a loss of dignity and control that could accompany heightened care needs:

> I think again it goes back to that choice and that dignity and that sense of control, because it's such a fearful thing, right? And not only the fear, but I just couldn't imagine laying in a bed having no say that you know I don't want to eat today, no I don't want you to roll me right now. I don't – you know when you're in that much pain and you're in that much suffering and you have no control and somebody just comes in and flips you over, wipes your butt, flips you back. Like it's just not [good]. (Nurse 1)

More than anything else, participants described a loss of control during end-of- life – be it over the ability to engage in pleasurable activities, adequately care for oneself, or alleviate one’s pain – as central to the ‘bad death’ experience. All participants acknowledged that MAiD provided an opportunity for patients to retain at least some control over their end-of-life and death experiences, thereby helping to prevent experiencing a ‘bad death’.

Patients’ Experiences of a ‘Good MAiD Death’

The opportunity to retain agency and control around their end-of-life decisions through MAiD was critical in avoiding a ‘bad death’ and facilitating a ‘good death’ experience among patients. This allowed patients to determine what they were unwilling to endure during the end of their life, and the power to circumvent that experience by initiating a MAiD request. Participants shared that the option to avoid enduring factors associated with a ‘bad death’ contributed significantly to a positive pre-death experience for patients. Specifically, knowing that MAiD was an option for them provided patients with comfort in knowing that they would not have to continue living through pain, suffering, or a loss of independence and ability:

> I think that knowing the possibility that MAiD would be involved all the way along, it kind of could give you more comfort as you went along. Like, if this

> really started to go sideways, or if he was incapacitated either physically or mentally, he didn't have to just linger. (Family Member 8)
>
> He [her brother accessing MAiD] mentioned…, "I don't want to suffer." And he said, "knowing that we can get this in place – knowing that it will be in place gives me comfort to know that I won't have to go there [referring to a place of suffering]." And there was another more minor part, that was… he did not want to be dependent and having us deal with that part of it all. (Family Member 6)
>
> It just comes down to giving somebody the option to do what they really want to do. So, there patients that are terrified of a lingering death, a painful death, of, you know, suffocating and not being able to breathe – just giving them the option to have it – just as an assessment, or to be able to even do the provision for them as well, right? So that they know, and they have control over their situation and just the peace that you see in them when they know that they have that option, and that they've qualified for it. (Provider 8)

These comments illustrate the significant positive impact of providing patients with an opportunity to terminate their life prior to enduring a self-determined threshold of decompensation as they approach death. Each of these excerpts suggests that, even if a patient does not proceed with MAiD, knowing it is an option can alleviate fears about suffering during their final days.

Further, family members and healthcare professionals shared their experiences of the MAiD death of patients and/or loved ones, with one physician describing MAiD-facilitated deaths as the "least traumatic part of [a patient's] whole life" (Provider 5). Others echoed this sentiment, describing the active-dying process through MAiD as "beautiful", "peaceful", and aligned with "everybody's dream of how you would die":

> It's beautiful, it's peaceful, you see the release in the body as they pass away, it's just – it's absolutely amazing – absolutely amazing to me. (Nurse 1)
>
> It was wonderful. It was peaceful. It was easy. It felt exactly like everybody's dream of how you would die, which is quietly and peacefully in your sleep. That's everybody's choice. That's what we all wish for our loved ones. … You know? But it was so peaceful that it looked like he was just, like, really deeply asleep. … It was so gentle that there was no transition. Just a smooth – there was no visible

> transition from life to death: as every one of us would hope to die. (Family Member 3)

These examples highlight how MAiD provides reprieve from the worry of a negative experience during active dying, while likely also alleviating patients' worries about a painful death as they approach their end-of-life. In all, participants consistently and frequently described the important role of MAiD in mitigating a 'bad death' experience for patients, allowing patients and their loved ones to be present in their final days together. This appeared to increase acceptance and reduce negative aspects of anticipatory grief for their coming death among patients, and reduced grief among loved ones related to the patient's suffering or missed opportunities to say goodbye.

Family Members' Experiences of a 'Good MAiD Death'

In addition to impact on patients, the sense of control around a patient's death also had positive implications for the family members of MAiD patients. Many participants described that the planned and controlled nature of MAiD allowed them to spend meaningful time with their loved one prior to their passing. For example:

> We had the morning together and um, every part of that day was so peaceful, because we knew it wasn't going to be a struggle. And we all had our times to say goodbye. I think that's another thing about MAiD, you have the time to say goodbye and say everything you need to say, and um so you don't feel like you left things unsaid before or haven't had the time you needed with your family. So that would be another benefit of MAiD if you could control that because if you were waiting beside someone's bed, you can't always wait or plan that, and so that was so important to both of us. I'm glad MAiD provided us with that. (Family Member 8)

> [My father's MAiD death] was authentic and genuine, and that was exactly what was needed at that time. It brought some closure before he actually physically went and allowed my parents to connect again. And allowed him to say his goodbyes to everyone in his own time. (Family Member 2)

Again, participants spoke of the peacefulness that MAiD facilitated, noting that it provided them with the opportunity to re-connect with their loved one before their death and ensure nothing was left unsaid. The planned nature of MAiD also allowed patients to help their loved ones prepare for their passing in the months, weeks, or days leading up to their death. One patient who had been approved for MAiD on the basis of his terminal cancer diagnosis shared:

> If it comes down to [it and] I get the call that [my cancer has] suddenly gone crazy, I'm going to be trying to help [my wife]. We've got so much stuff here, and that's not something I want to deal with then. I want to deal with it now, saying that "this is kind of what we want if something happened." … Everybody knows my wishes, but I just – it's the family, it's thinking of [my wife]. It's thinking of my buddies, what they're going to go through too. So, that's kind of where I am, so I started the process. … It's going to be tough on people, and people need to know that these are my wishes, and we talked about it. It's not great cards to have, but it's all I got. And I just want to make sure that everybody knows so they don't have to [wonder], "Is this really what he wanted?" Yeah, it is. (Patient 1)

For this patient, the opportunity to help his loved ones prepare for his death was a key consideration in preventing a 'bad death' or 'bad grief' experience for his loved ones. While these preparations included administrative planning such as writing a will and assigning Power of Attorney, it also involved ensuring his loved ones knew and understood his decision to reduce any misgivings they may have otherwise experienced. Together, the opportunity for preparation and closure may have profound positive impacts on participants' experience of grief, as previous work has suggested that a lack of closure following an unexpected, untimely, or painful death of a loved one can contribute to challenging or complicated experiences of grief (Burke & Neimeyer, 2013; Mason et al., 2020).

Finally, MAiD helped to mitigate potential 'bad death' experiences among family members who would traditionally take on caregiving roles through their loved one's end-of-life. While participants rarely spoke about the impact of caring for a terminally ill loved one explicitly, many were familiar with the challenges associated with such responsibility. For example, a family member whose father had died by MAiD shared about the impact on his mother who took on a caregiver role ahead of his death, noting that, "when [my father] died, [my mother] was – there was a part of her life that started, that had been kind of disengaged through always looking after my dad" (Family Member 2). It is not uncommon for family members to dedicate their time to help care of loved ones in need; however, the responsibility often comes at a personal cost to the caregiver (Breen et al., 2018). As a result, caregivers may experience a sense of relief upon the death of their loved one, as Family Member 2 described above. However, this relief can itself become a source of guilt, as caregivers may struggle with the idea that they feel relieved by the loss of a loved one, which may further complicate the experience of grief (Breen et al., 2018; Burke & Neimeyer, 2013). Additionally, while caregiving relationships can be quite meaningful and profound, they can also place strain on the parties involved and their relationship. Thus, not only can the caretaking responsibility take a toll on the individual responsible for giving that care, but it could potentially contribute to second-guessing their choice to do so, further complicating the grief experience. Thus, by allowing patients to initiate their death before requiring the increasing help of a family-caregiver, family members of MAiD patients may be less likely to encounter this perceived aspect of a 'bad death'.

Healthcare Professionals' Experiences of a 'Good MAiD Death'

Several healthcare professionals also described the avoidance of 'bad deaths' as a positive aspect of their involvement in the MAiD program. While the experience of a 'bad death' is common for clinicians, particularly those working in emergency departments, palliative care, nursing homes, and/or other trauma settings, engaging in MAiD provisions can offer a more positive experience related to patient death, and allow them to play a crucial role in fulfilling a patient's end-of-life wishes and enabling them to exercise control over their own death. This is significant, given that patient deaths can be quite painful for healthcare professionals – particularly for rural care providers who may know their patients quite well. For instance, one participant spoke about a feeling of profound loss after providing MAiD for a patient whom he had known and supported for many years:

> I [provided MAiD for] this one patient, and that was tough. He was really sick for three years… So, this guy went three years with all his issues. I delivered his son and now, 20 years later, he's got this God-awful illness; and then that was really tough to do his provision. I went outside and cried on the step and the paramedics then patted my head. That's the only one that really got me in tears, that one. (Provider 4)

Similarly, another physician shared about the grief experienced by family physicians who have cared for patients for many years, saying, "that's one of the joys about real cradle-to-grave care…And it's not easy, I think, for some physicians, but it's never easy when our patients go, you know?" (Provider 7). Despite this recognition of the pain of losing a patient, being able to provide a 'good death' was described as especially meaningful for care providers:

> Pretending in medicine that we can control outcomes always is a fallacy, and I think it's a real human failing to think we're in control of nature in the vast expanse of things, and I think MAiD is one of the few things where we do have an actual level of control. … . I don't want to watch these patients have these bad deaths either. And so, I thought if there's an option I can bring to them – not that anybody is required to choose it in any way – it was something I thought I could help with. Yeah. And [it] is what keeps me going, because I will say, this is part of my work that I do enjoy. (Provider 7)

Healthcare professionals shared that the opportunity to be a part of a patient's life and death in this way was "a very rewarding job to do" (Nurse 5) and allowed them to connect with their patients in a distinctly human way, distinct from other professional experiences. One physician described his role in MAiD as "one of the most human things I've ever done in medicine" (Provider 6), with others describing it as:

> A very rewarding experience as a healthcare provider, that's it's very unique and intimate in that it's not technical, right? That I think that's the fear, that you feel like you're coming in and you're being a technician when you do this, but it's really about the human connection, and so it's very rewarding work. (Provider 1)
>
> It's an honour to be there when life begins and an honour to be there when life ends. And I think the fact, as family doctors, that we get to be part of that true cradle to grave, you know, medicine, quite literally in this circumstance. (Provider 3)

In fact, an ethicist involved in the MAiD program spoke about the desire of frontline care workers to actively and meaningfully engage with their patients on a human level, further highlighting the importance of the human connection on professionals:

> Every provider and team wanted to get to know the patient and their story first and deal with them on a human level, not just on a medical level, and that actually helped them with the provision, because they could – and there's a line there. It wasn't that they wanted to evaluate or judge their motives for choosing MAiD. They just wanted to interact with a human being and appreciate their story. Not just be a medicalised procedure that came in, did something and left. (Other Professional 2)

While the loss of a patient is never an easy experience, healthcare professionals frequently described their experience with MAiD deaths as rewarding, finding comfort in ability to help honour their patient's end-of-life wishes.

Thematic Summary

In all, findings described within this theme highlight how MAiD aids in mitigating the fear and experience of a 'bad death' by allowing patients to exercise control over their end-of-life experience. This agency, alongside the avoidance of unnecessary suffering and an opportunity for meaningful connection before a patient's death not only served to alleviate patient distress, but also to foster acceptance and preparedness among family members, easing their grief. For healthcare professionals, participating in the MAiD program was often described as an emotional yet meaningful experience that allowed them to provide compassionate and holistic patient-centred care. In facilitating a ‘good death’ for patients and their loved ones, healthcare professionals were able to witness and be a part of the experience, which positively impacted their own experience of grief.

Theme 2: Bureaucratic processes and policies can complicate the MAiD and grief experience

While MAiD provided an opportunity to avoid a ‘bad death’ experience, positively influencing the grief experience, participants often encountered challenges within the process that complicated their experience of MAiD and associated grief. Within this theme, I explore participants’ experience of two unexpected challenges brought forth by bureaucratic processes and policies, and their impact on participants’ MAiD and grief experiences. The first of these challenges was the requirement for patients to provide final consent immediately prior to MAiD provision. During data collection, Bill C-7 passed which introduced the opportunity for Track 1 patients to waive the final consent requirement. While some participants had experience with the newly implemented waiver, most participants’ experiences with MAiD occurred prior to the change in legislation when final consent was required for all MAiD provisions. This requirement contributed significant stress to the MAiD experience, as patients faced the possibility of a sudden loss of capacity which would exempt them from MAiD eligibility. The second key bureaucratic challenge was institutional policies that prohibited MAiD in publicly funded Catholic-run health and end-of-life care facilities and required patients to be relocated in order to access the service. These factors, both independently and in conjunction with one another, contributed to uncertainty, stress, and chaos to the end-of-life experience for many participants. Not only did this undermine the aim of MAiD for a ‘good death’ for patients, but it contributed to a lingering sense of frustration and disappointment among family members and healthcare professionals, which often had negative impacts on the experience of grief.

Final consent requirement

Canadian MAiD legislation includes various safeguards which are in place to uphold patient autonomy while ensuring that individuals requesting assistance in dying are making a voluntary, informed, and consistent choice. One of these safeguards is the requirement that patients provide a final consent immediately before receiving MAiD, which plays a critical role in protecting vulnerable populations from being coerced into hastening their death (Department of Justice Canada, 2024). Despite its important role, many participants shared experiences of heightened anxiety due to the requirement, fearing that the patient would suddenly lose their capacity to provide informed consent, thereby becoming ineligible to receive MAiD. As explored in Theme 1, a key aspect that attracted patients to MAiD as an end-of-life option was the opportunity it presented for a peaceful and more predictable death. However, participants frequently shared that the anxiety they experienced around the potential loss of capacity starkly contrasted their intention for a peaceful and dignified end-of-life experience. For example,

> This nonsense that they have to come back just before they give you the injection and if you don’t [consent], if you’re not lucid, it all goes away. So, the peace that – [MAiD] gave him dignity, but it didn’t necessarily give him peace because he was just frightened at the end that he wouldn’t be lucid enough to be able to give his consent. Huge hole in the [process] – the only hole in the process was that, in my mind. (Family Member 2)

> [My father] just kept saying, “what if I can’t consent?” So that’s a huge barrier. That created more fear for him than dying. It created a lot of anxiety for me too, because then what? Then I couldn’t fulfill his wishes for him. (Family Member 1)

These excerpts highlight the role of the final consent requirement in uncertainty during the end-of-life and death experience for both family members and patients. Healthcare professionals also expressed a frustration with the final consent requirement, as illustrated by the following comment from a registered nurse involved in MAiD provisions:

> I've talked with some people that are like, "well, why can't I just wait until my mind goes [to initiate MAiD]? Let me enjoy, let me have all of this, because again, we never know when that's going to change, right? It could be two weeks, it could be two years, so let me have my life with my family. Once my mind goes, then I don't want to live anymore and my eldest son has the … legal ability to say, 'no, let's get MAiD in here, because this was her decision.'" So, I'd like to see things like that changed, because again, we're not respecting a person's wishes at the end of life. And again, so then what is the purpose? What is the purpose of goals of care, of personal directives, or having a will? Because we're not going to respect it anyways. (Nurse 1)

In these examples, not only did the anxiety around the potential loss of capacity undermine the anticipated sense of peace and autonomy of a MAiD death for patients, but it also had a compounding effect for family members and healthcare professionals who described anticipatory guilt and/or frustration at the prospect of not being able to fulfil an individuals' end-of-life wishes. As a result of the final consent requirement, some patients sought out options to alleviate the anxiety and potential suffering they would face by initiating the dying process earlier than they would have otherwise. One participant shared the experience of a friend who had used this option:

> A friend of mine … was diagnosed with Alzheimer's … in his mid-70s. His father died of Alzheimer's, so he knew what he was up against, and so he arranged for … a MAiD service.… He went out, took all his buddies and said, "here's what happened, and on August 3, I'm leaving while I can because of this issue, okay?" Because if you don't have capacity and you wait, and wait, and wait until you've gone past your expiry date in terms of being able to be lucid, then you're done. So that puts extraordinary burden on everybody, you know? The system, and the families and all the rest of it. And he wasn't having any part of that. (Family Member 5)

Rather than wait for a significant decline in his quality of life, this individual opted to preempt his suffering by initiating his MAiD death early. Although this allowed him to access a 'good death' through MAiD, it likely complicated the experience of grief, as both the patient and his loved ones also grieved the extra time he may have had before losing lucidity.

While other examples of pre-empting capacity loss through early initiation of MAiD were not described by participants, the occurrence of similar cases across the country – most notably the case of Audrey Parker – initiated the development of an amendment to MAiD legislation (Dying with Dignity Canada, 2022). This amendment, colloquially known as Audrey's Amendment, opened up a pathway for patients to waive the final consent requirement under certain circumstances (Alberta Health Services, 2021b; Dying with Dignity Canada, 2022; Government of Canada, 2023a). One nurse shared her experience of a patient who signed a waiver prior to his anticipated loss of capacity:

> I went to the provision, as an RN we always ask, you know, "why are we here? What are we doing today?" And he couldn't quite say that without his wife helping coach him [on] what to say. And when I asked him for his consent verbally, again, his wife had to coach him through that. He couldn't quite independently say, "yes, I consent, I'm doing medical assistance in dying today." So, I gave the physician a heads up. I met with her ahead of time saying, "I don't think his cognition is 100%." But she [the physician] sat and tried to get consent, and same thing – it was just not 100% clear. So, we were very grateful, the family was very grateful that we had a waiver in place. Otherwise, it wouldn't have happened, and this poor man would have not got his wish. So, I think it was the perfect instance of why we needed that waiver. (Nurse 5)

This excerpt highlights the positive impact of patient's ability to waive the final consent requirement. However, despite its clear benefit in cases such as the one shared by Nurse 5, some physicians described that there are still challenges within the process. For example, one physician noted the difficulty patients face in selecting a date for their provision – a required step in waiving the final consent requirement:

> The waiver of final consent created, in some ways, more challenges for patients because they have to set a date. And they can set it two months down the road, but many people want to – if they lose capacity – they still want to have MAiD. But they can't do that until they set a date, and they're often not ready for that. (Provider 1)

This may contribute to anticipatory grief for both patients and their loved ones, by specifying the date of the patient's impending death perhaps before they have emotionally prepared to do so. While MAiD can be provided before the specified date should the patient lose capacity, if the patient retains capacity beyond the specified date, the waiver becomes null and the patient will be required to provide final consent before MAiD is administered (Canadian Association of MAiD Assessors and Providers [CAMAP], 2024b). This may complicate the experience, as patients and/or their loved ones may hope that the patient loses capacity and receives MAiD before the waiver expires to avoid the process of completing another waiver and choosing a new date of death. In this way, the waiver of final consent has the potential to complicate the grief experience, either by contributing to loved ones' feelings of guilt and regret for hoping that their loved one would die sooner, or by subjecting patients and their loved ones to multiple instances of selecting the date of their death. While the waiver indeed seems to be beneficial in specific situations, it does not always work as intended, which can be frustrating for healthcare professionals:

> This idea about the [waiver] of final consent is not working as well as it should. [Alberta Health Services] has not fully figured that out. I don't know that anyone fully has. But to me, the whole point of that was, once you look me in the eyes, [and] I know what you want, you're approved, we're happy, everyone's [happy], then the whole point was, "I don't want you to go too early. I want you to go when you're ready, and not go because you're afraid you're going to lose capacity." So, this whole like waiver of final consent thing, I find very fiddly, very silly, very whatever. Like, I think it should be built more in and it shouldn't have to be like – we do it as like, two-week timelines. It's silly. It just doesn't make sense. Whereas I'm [thinking] like, "you're approved. Nothing's going to change about you." (Provider 7)

This excerpt highlights this healthcare professional's perception of the purpose of a Waiver of Final Consent; that is to ensure a patient's request for MAiD is voluntary, well-informed, and aligned with their end-of-life values. Along with potential implications for patients' and loved ones' grief experiences, healthcare professionals may feel that limitations of the Waiver detract from their ability to facilitate a 'good death' for patients, which may have implications on their own experiences of grief.

Overall, the final consent requirement has significantly impacted the end-of-life and grief experience for patients, their loved ones, and healthcare professionals involved in MAiD. While it exists within Canadian legislation as a safeguard to protect patient autonomy and ensure MAiD is always voluntary, many participants described it as a source of stress that undermined the sense of peace and control that they sought through MAiD. The introduction of the Waiver of Final Consent has addressed some of these concerns by allowing patients to avoid the anxiety associated with losing access to MAiD. However, challenges remain particularly around the requirement to set a date for provision and the nullification of the Waiver beyond that date, which can contribute to logistical complications through the end-of-life process and complicate the experience of grief for those involved.

Relocation for provision

The second key bureaucratic challenge participants described was the need to relocate patients for MAiD provisions, which participants deemed to be a particular challenge for rural Southern Alberta borne from policies of Catholic-run palliative and end-of-life care facilities in the South Zone. This poses a challenge for residents of these facilities who wish to die by MAiD and their families since patients must be transferred off-site to receive assistance in dying (Covenant Health, 2022). The daughter of a MAiD patient described the distressing experience of witnessing her father be transferred between hospital and palliative care multiple times to receive MAiD:

> Shortly after [he requested MAiD], he was transferred [from the hospital] to the palliative care [facility]. I have a huge problem with that because less than a week later he was transferred back to the hospital to complete the procedure…. But the transfer to the palliative care unit and the transfer back were agonizing for Dad…. He didn't want to go. He didn't want to go. And it was a great, great weight … on our hearts to see my dad, who has such a high pain threshold and has been so courageous all his life, … beg people to not cause him pain, who – these are the people who are supposed to not be causing him pain. [It] makes me so angry. I just don't know. I just speechless. That's not what I would consider to be effective care. (Family Member 3)

She went on to describe how this undermined her father's original intentions around MAiD, noting:

> The only way we got him to move was he had to be completely knocked out. Completely knocked out. So, there was no opportunity – like, you know how the MAiD process… is very calm, very gentle, you get to say your goodbyes? Well, you know, Dad was comatose by the time he got there [referring to the hospital where he would receive MAiD]. It was the only way he could make the transfer. And even then, it was painful I'm sure, because his face was contorted, but, you know, be probably couldn't feel it. I don't know. (Family Member 3)

This was a significant point of contention for this participant, who shared her frustrations around this situation many times throughout her interview. Alongside the distress of watching her father agonize during his transfers, she felt "conflicted as a Catholic" (Family Member 3) that an organization operating under the same faith-based principles that she held could, "let their patient die alone by not permitting them to die in the bed that they're already in" (Family Member 3). This evoked a sense of abandonment by her church and likely contributed additional complexity to her emotional experience of her father's death. Another family member shared a similar, though seemingly less distressing, experience with transferring their loved one from a Covenant Health facility to access MAiD:

> [My father] was one of the first in Southern Alberta [to receive MAiD]. They

> weren't quite set up for it. So, the space that we had in the hospital [that] was where they do the dialysis for kidney patients – so that was kind of awkward and a little weird, because it was a weird setting for it. (Family Member 4)

While this participant did not describe distress around the transfer itself, she later described how the program has progressed since her father's provision, with "better rooms being offered at the hospital, so it wasn't that clinical kind of setting" (Family Member 4). Alongside the depiction of her father's provision setting as 'weird' and 'awkward', this suggests that the move from his palliative care bed to a make-shift MAiD provision setting at the hospital contributed to lack of comfort or dignity during her father's death. These experiences underscore how this particular policy can exacerbate the already complicated experiences for family members during a loved one's end-of-life.

Participants who were professionally involved in the MAiD program also expressed their frustrations with this policy, and reflected the distress described by Family Member 3 above. For example,

> I have a real problem with Covenant Health… runs parallel to [Alberta Health Services] and gets provincial funding.… So, this is my money funding somewhere that will turn people away from a medically allowable legal procedure. You know? And I really struggle with that. It really, really bothers me. … There's places like Medicine Hat, where our only hospice is now a Covenant facility, there's places like Camrose that, really, their only hospital is a Covenant facility. I don't know what those guys do, and that is really distressing. I have no logic to it. I have nothing. If this is provincially funded, I cannot accept that they won't allow MAiD to happen in the building. … That is really distressing when you're talking about having one hospice and watching people get moved, you know, thrown in an ambulance and staff – that's really rough. It's bad. … It is just the least patient-centred care I think I've witnessed in a long, long time. (Provider 7)

Within this comment, Provider 7 highlights an ethical tension between private institutions' right to implement policies aligned to their values (such as prohibiting MAiD provisions on-site) and patients' right to a peaceful and dignified dying experience. In this way, such policies can contribute to a lack of patient agency at end-of-life, further undermining the original intent behind their request for MAiD. Like the final consent requirement, organizational policies necessitating the relocation of patients to receive MAiD can introduce uncertainty and chaos to what was intended to be a peaceful end-of-life experience, ultimately contributing to complications in the grieving process. Further, Provider 7's mention of rural communities whose sole hospice or hospital is operated by Covenant Health highlights the disproportionate impact of institutional objection in these settings. In such cases, patients may be forced to choose between undergoing a long-distance transfer to access MAiD or remaining in their home community and risking a 'bad death' experience.

Many participants discussed the challenges posed by final consent legislation and organizational policies restricting on-site provision as separate issues complicating their experience of MAiD and grief. However, as one physician notes in the comment below, the intersection of these obstacles can result in a patient losing access to MAiD entirely:

> Because I had one lady, I was trying to do her assessment but I couldn't arouse her enough [from the pain medications]. But yet I had met her before, and so I could tell enough that she knew I was there and what I was there for, but she couldn't – she didn't have the capacity to do an assessment. And she was teary and it was brutal, right? Because I knew at that time we wouldn't be able to do a provision on her because we would have to medicate her so much just to get her from palliative care to the site of provision and then we'd have to reverse it to get consent and that was really hard. Those are the ones I think I struggle with the most. (Provider 8)

While this patient could have had the capacity to provide consent while still in a facility prohibiting on-site provision, the need for additional pain medication to facilitate the transfer to hospital would render her incapacitated, thereby losing her eligibility and access to the program.

Thematic Summary

In all, participants' experiences highlight the significant impact of the bureaucratic policies and processes within the MAiD program on patients, their loved ones, and healthcare professionals. While the final consent requirement is meant to ensure informed decision-making and protection of vulnerable populations from coercion, it can also contribute to stress and uncertainty, undermining the original intentions behind a patient's MAiD request. Similarly, the freedom for private institutions to implement policies in alignment with their mission and values can come at a cost to patients who may face limited alternative options, particularly in rural communities. Independently, these challenges can complicate the end-of-life experience, and when combined, further limit access to MAiD for patients and families who would benefit from the service. The introduction of uncertainty, stress, and chaos during the end-of-life process can negatively impact the grief experience. This may be particularly impactful given participants' expectations of a peaceful death facilitated by MAiD, as they may be less likely to prepare for such challenges.

Theme 3: Stigma around MAiD can contribute to a sense of secrecy among those involved, limiting opportunities for open public discussions and access to grief-related supports

Stigma around MAiD remains pervasive in Canada and plays an important role in the experiences of MAiD-related grief. As noted earlier, MAiD has a history of controversy. Before the coining of the term "medical assistance in dying," MAiD was often described as "euthanasia" or "physician assisted suicide" (de Bruin, 2021; Downie & Schuklenk, 2021). Given the illegality of murder and the cultural stigma around suicide, alongside the opposition of several prominent religions, MAiD was not always popular in public opinion (Brassolotto, Manduca-Barone, & Zurbrigg, 2023; Downie & Schuklenk, 2021; Grove et al., 2022). Additionally, MAiD is still a relatively new healthcare service and many Canadians are not aware of its legality, processes, or safeguards. There is also a fair amount of misinformation in circulation (Choi et al., 2024). As such, I was not surprised to find that many participants wanted to keep their MAiD experiences private.

Participants described a desire for secrecy around their involvement in MAiD as a result of this stigma, fueled by concerns of judgment and ostracization within their personal and/or professional spheres. Patients, family members and healthcare professionals involved in the MAiD program shared their reluctance to disclose their participation in the program, which was intensified by their rural context in which there is limited privacy and anonymity (Brassolotto, Manduca-Barone, & Sedgwick, 2023). Throughout this theme, I discuss key factors contributing the participants' secrecy, the cyclical impact of secrecy on further perpetuating stigma, misinformation, and a lack of awareness around MAiD, and the implications of this on participants' experiences of grief.

While the motivations for secrecy and the individuals from whom participants withheld their involvement varied, nearly all participants described feeling the need to conceal their engagement with MAiD to some degree. Participants discussed several contributing factors to this secrecy, many of which were shaped by the social, political, and geographic context of rural Southern Alberta. Specifically, participants noted that while death is often a sensitive or taboo subject, MAiD carried an additional layer of stigma which discouraged open discussions:

> It's not a mainstream topic that comes up that people are ready to talk about. You know, when we sit down with my buddies – and all of my friends are of a certain age, we've all had to deal with death in our families – but nobody in my group has

> ever said, “yeah, my uncle went, and he went with MAiD.” You know? … We know people that have died, that we find out six months later that they died with MAiD. Well, why did somebody wait six months to tell us about that? Or why did our friends decide not to tell? So, there’s a little bit of stigma attached to that. (Family Member 5)
>
> You can’t really talk about it, right? Or [people] feel like they can’t talk about it. And until some of that stigma goes away, we’re still – we – it’s still a very new program, and until some of that stigma goes away or until that’s removed, yeah, it’s going to be – it’ll be a challenge for people to talk about it. (Family Member 4)

For some patients, concerns about stigma led them to conceal their decision to access MAiD from family members, fearing disapproval or opposition. Participants described instances where family members reacted with anger or distress upon learning about a loved one’s choice. In cases where MAiD had not yet been administered, objecting family members may attempt to prevent their loved one from accessing the service. An ethicist involved in the MAiD program recounted his experiences with this, sharing that there were “a handful of times we definitely had families saying, ‘no, this is a bad idea,’ and would do whatever they could [to prevent it]” (Other Professional 2). Similarly, a former zone director spoke about an interaction with a family who learned after their loved one’s death that they had received MAiD:

> They were angry that the loved one had chosen [MAiD] and not consulted with them. And very clearly, they said, “because we would have talked them out of it.” Well, that’s the reason they’re not involved – because it wasn’t their life to choose any decision-making. (Other Professional 3)

These anecdotes suggest that for some patients, disclosing their decision to family members could detract from their own acceptance of mortality and undermine their efforts to die peacefully. However, this was largely dependent on individual characteristics of the patient and their loved ones, as many family member participants displayed support and compassion for their loved ones throughout the MAiD process.

In fact, some family members who were aware of their loved one's decision to access MAiD supported their loved one by concealing their decision from other family members and friends. For example, when describing the role of MAiD in her father's death, Family Member 4 shared that:

> Most people didn't know about it, actually. It was immediate family only, and some close friends of mine. So, my mom's family is Catholic and would – she still hasn't told them, and that's got to be her story to tell them, so that's up to her. … She has not yet told her family because she's worried about how they would react to that. (Family Member 4)

As illustrated by this participant, family members were selective about who would know about their loved one's MAiD procedure, highlighting the role of family dynamics and individual characteristics in how one may react to learning of a loved one's MAiD death. Family Member 3 shared a similar experience which provided insight into the motivations behind concealing the involvement of MAiD in her father's death:

> Not everybody knew, or still knows to this day [the choices] dad had made. It was really only a very, very small, close-knit group that knew that. And most of Dad's family just is – was very surprised that shortly after he went to hospital he passed away. And all we said was, "his cancer was more advanced than any of us thought," or something like that, you know? So the majority of the family does not know that he had MAiD. [Partly because they might have disapproved], but also because I don't want anybody else to feel conflicted over something that wasn't their decision. You know? It had nothing to do with them, but it can make you feel that way, you know? You might feel like, "oh jeeze, I wish I'd known. I should – I would have said something, or I could have said something." I just didn't want anybody else to feel… badly about it, you know? Or guilty, or anything like that. (Family Member 3)

While her secrecy was initially motivated by concerns that her family would attempt to dissuade her father from choosing MAiD, her continued discretion after his death also shielded them from distress that may complicate their grief. For instance, concealing the role of MAiD in a loved one's death from family members with moral opposition to such practices can prevent them from experiencing additional grief related to misaligned values or concerns about the afterlife. Additionally, the knowledge that a loved one chose to die may add another layer of difficulty to their grief, as they may struggle with accepting his decision to leave. A participant whose father had died by MAiD described her sister's struggle to accept that their father had 'chosen to leave':

> To some extent my sister still, after my dad passed away, was bitter, because she's like, "Well, he chose to leave us. He'd rather take care of himself than be with us." … In her mind, he was being very selfish in choosing to leave us and not stay with us. (Family Member 4)

In these ways, secrecy around a loved one's MAiD procedure can protect against attempts to dissuade their decision and helps to protect their loved ones from experiencing grief related to MAiD in addition to grieving the loss itself.

Beyond the protection of others, family members' secrecy around a loved one's use of MAiD was also often motivated by concerns around conflict or judgement from others. As Family Member 4 described it,

> A lot of people just keep it private because they are scared of the judgment that comes not only on them, but also on the family member who chose it – that there's something wrong with that family member for picking it. (Family Member 4)

However, for many participants, the fear of judgment was accompanied by a fear of repercussions within their social and/or professional lives. A former zone director shared about the social repercussions described to her by individuals bereaved by MAiD, who "expressed that they had lost family, or families were divided – and friends – over them knowing, those people knowing that their family member had gone through MAiD and [that] they had supported them" (Other Professional 3). Patients were also cognizant of the potential backlash towards themselves and their loved ones, which participants described as a particular challenge within their tight-knit rural communities. For example, when describing the difficulty of maintaining anonymity throughout the MAiD process within a rural context, Patient 1 shared:

> I haven't talked a lot about my cancer journey. There's I mean, it's kind of out there now, but I haven't really publicly ever said anything. Only because one of it is what happens if I beat the odds and I go in some kind of remission and I want to work part-time and do stuff, I'm conscious of that a little bit too. And plus, I'm private, so not everybody … needs to know. I don't want anybody to feel sorry for me – I've got great neighbours and people have done amazing things and people *want* [emphasis added] to do things. But the rural one is a challenge, because there isn't the same privacy. (Patient 1)

While noted by participants across all groups, concerns about judgment and repercussions were most prominent among professionals working within the MAiD program. Nearly all participants within this group, and some from the family member and patient groups, described the importance of confidentiality around provider and nurses' involvement, particularly in the small communities of Southern Alberta. When considering taking on a more public-facing role within the program, a physician shared that "people told me, like, 'your kid won't get invited to birthday parties,' stuff like that" (Provider 1), while another described how MAiD providers in smaller towns may gain a reputation within their communities as "the killer doctor" (Provider 4).

To an even greater extent, healthcare professionals described their concerns around the impacts of publicly participating in MAiD on their careers, and by extension, the well-being of patients. For example, one physician who provided palliative and MAiD care to patients shared the backlash she experienced after taking on a more public-facing role within the program:

> There were threats that I should not be able to do palliative care, [that] I should have to leave the team. There were threats the other way, that other palliative care physicians were going to quit if I was going to be doing both roles. (Provider 1)

This experience set a precedent for what other professionals working within the program could face should they choose to publicize their own involvement, which served to further encourage their own secrecy, as well as discourage others from participating entirely. For example, Nurse 2 described hearing colleagues speak negatively about the public-facing physician:

> This doctor, she's been very open, because she was the face of this program when it came out down here, and I think that she took a lot of personal flak for that. And I have a lot of respect for her, because that wouldn't have been the easy road. I think that was a very, very brave and difficult road that she chose, to champion this program in a community where it's not going to be well received. And when it did come out, I mean, we've heard the doctors in the hallways and there was a lot of anger and there was a lot of resentment about this program. So, I think in her being the face of that she probably took a lot of flak from these physicians. And just seeing that, it made you very uncomfortable being loud about [it] down here, because it will affect you. (Nurse 2)

This comment in particular highlights that although many professionals may hold highly positive views of those working in the MAiD program, these too are kept private by supportive colleagues who fear associating themselves publicly with the program and facing similar backlash. Many participants spoke to this point, emphasizing the potential impact that disclosing their involvement could have on their future career options, ability to do their job well, and their overall well-being in the workplace. For example, a physician shared his experience with a colleague calling him a "murderer" for providing MAiD to a mutual patient, which made the experience all the more challenging.

> I had one physician call me to tell me that I was murdering a patient, and it was a mutual patient of ours. And it was really hard, especially because she called me the day of [the patient's provision] and told me she couldn't believe that I was going to go out to her house and murder her. And this was a lady I had known quite well actually … and it was – I thought, you know, "great, now this has happened, and I have to go and provide for this woman and her family who I know, and I have this voice of this other physician in the back of my head." It was hard. (Provider 5)

Some professionals described the secrecy as an intentional part of the program's design to help mitigate some of the negative impacts of role visibility, noting that "it's never been set up in a way here that we have real contact with other staff, and in fact, it's very secretive about who's actually involved with the program" (Nurse 2). Many participants shared that maintaining privacy around their MAiD roles was particularly important in Southern Alberta, where "it's a small pond. We all kind of know each other and your choices can affect your professional opportunities down here if people don't agree" (Nurse 2). There is often significant overlap between professional and social roles in small communities (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Sedgwick et al., 2024), which can further complicate professionals' attempts to keep their role in MAiD private, which Nurse 6 describes in the following comment:

> I have seen many, many times how interrelated the communities are, everybody knows everybody else, and that includes the physicians. And, you know, there are families who know people, and their kids go to the same school. That's just the nature of small town or rural living. (Nurse 6)

Throughout these examples, participants described how tight-knit rural communities and a high degree of overlap between personal and professional relationships can contribute to a higher likelihood of being identified as involved in the MAiD program. Not only can this have a negative impact on the professionals already involved in the program, but it can deter others from participating in MAiD care provision, and prevent professionals, family members, and patients alike from engaging in open conversations about their experiences, contributing to a more complex experience of grief.

Each of these factors contributes to a scarcity of appropriate, accessible resources to support individuals impacted by and involved in MAiD deaths, which can have detrimental impacts on their ability to process and cope with the various emotions related to MAiD and experiences of grief. Family members frequently described the importance of support from others who understand the MAiD process but shared that such support was often difficult to access. For example, Family Member 4 noted that there “isn’t support for the family afterwards” (Family Member 4), and shared the following context:

> It is such a hard thing to explain to people, that your dad or your loved one chose this way to die. And unless you’ve got somebody who’s gone through it, and can appreciate that, you know, you helped them, or you were there for them, or you supported them through this, a lot of people don’t understand that there is still some stigma attached to that of, “Why would you stand by and let that happen?” And especially in Southern Alberta, yeah, I wouldn’t knock [it] for any reason other than that, right? (Family Member 4)

Healthcare professionals echoed this sentiment, noting that “there’s not a lot of grief supports, so after death is really challenging too, and people aren’t comfortable to just go to a regular grief group in Southern Alberta and be honest about that” (Provider 1). Much of the inaccessibility of supports for those bereaved by MAiD hinges on the existence of stigma, which contributed to the discomfort in openly discussing MAiD-related grief among a group of community members who may hold opposition to the program. In light of this, a former zone director shared about a MAiD-specific bereavement program they had facilitated which had to stop during pandemic-related lockdowns.

> [It] was very clear that we needed to have a separate bereavement programme for MAiD families, the survivors, because we created a safe environment [where] they all understood each other. They understood the feelings, they’d walk through each of their personal experiences, whether they knew ahead of time or the night before, or whatever it had been based on the desire of the client, basically, or patient. (Other Professional 3)

Several participants also described a lack of emotional supports for professionals involved in MAiD provision. The secrecy of the program often meant that professionals were “very isolated in [their] experience” (Nurse 2), without a clear path to understanding which of their colleagues, if any, would be supportive of their involvement. Two participants shared that there lacked any formal emotional supports for professionals involved in the program:

> I think that's [referring to MAiD-related supports for professionals] something that could definitely be better – healthcare as a whole, but specifically in these types of roles. All I got told was, "We'll do one shadow provision and see how you feel," is basically what it was. And [the] navigator asked how I felt, and I felt OK, but there's definitely no offering of supports or [directions for] where to reach out should you need support. (Nurse 5)

> No. We certainly have a wee group of us that get together sometimes a couple times a year, and like an email goes out after every provision asking if anybody needs to talk or debrief; nothing really formal but just an informal process. And for me, that's been enough. I haven't needed anything else. But I also have a supportive group of people around me that I have created, right. I think if you were isolated, like if you were someone who was maybe single and didn't have many friends or family around, it could be quite difficult after. (Provider 5)

While one physician described how he has navigated the grief around his experiences through support from loved ones and a therapist he sought out independently, he noted the continued difficulty of navigating stigma-driven backlash related to his work:

> My wife is wonderfully supportive. She's a psychologist and she's made it a lot easier for me, which is really nice. And I have sought out – I have a really good therapist myself, who I see, and I've sought out some help sometimes about processing some of the grief, but now I find it's a lot easier and I have some sort of almost rituals in place to make things easier for myself. But I would say the hardest part has been dealing with fear from people, and sort of the backlash of our somewhat conservative community [in Southern Alberta]. (Provider 5)

These experiences highlight that, despite the importance of social support in promoting 'good grief' experiences, there is a distinct lack of social supports available for those navigating loss and grief related to MAiD. This may be particularly pertinent in rural Southern Alberta, where conservative values are dominant, and the risks of disclosure may intersect both personal and professional roles within one's community.

Thematic Summary

In all, the lack of accessible and appropriate support options for families and professionals involved in MAiD highlights the impact of stigma on experiences of related grief. Without safe spaces dedicated to the specific experience of MAiD bereavement, family members often navigate their experience in isolation, hesitant to seek out supports within their communities where MAiD remains a highly contentious issue. Similarly, healthcare professionals working within the MAiD program describe a lack for formal emotional supports and instead rely on their personal networks to process the emotional toll of their work.

Discussion

Within this section, I present a preliminary discussion of my findings and present recommendations for policy, practice, and further inquiry based on how these findings are situated within the current landscape of evidence. In the following chapter, I expand upon these points and provide additional details about recommendations before concluding this thesis with my reflections on the process.

Before I discuss the key findings of this study, I feel it is important to acknowledge the diversity in the political and religious affiliations of participants in this study. Previous research has suggested that high religiosity and conservative political values are associated with opposition to MAiD, both within Canada (Pennings & Reid, 2020) and globally (Inglehart et al., 2021). While personal values – including those aligning with religious teachings or political groups – can indeed influence an individual's receptivity to MAiD, these claims often lack nuance and risk oversimplifying the various factors that shape one's proclivity to assisted dying practices. Participants in my study frequently noted that the prevalence of politically conservative values and religiosity within rural Southern Alberta communities played a role in shaping their experience of MAiD-related grief. However, many participants – all of whom expressed some degree of acceptance and support for MAiD – self-described as spiritual or religious (45%) and/or politically conservative

(21%). This supports previous findings (Bloomer et al., 2024; Sedgwick et al., 2024) highlighting diversity in perceptions towards assisted dying, suggesting that the experiences of MAiD-related grief that have informed my findings were not shaped by these factors alone.

The three themes generated through my analysis contribute to the growing literature on the MAiD-specific experiences of grief. My findings suggest that while MAiD may offer patients, their loved ones, and healthcare professionals the opportunity to avoid or reduce experiences of a ‘bad death,’ bureaucratic policies and processes can introduce barriers and reduce accessibility, while secrecy driven by pervasive stigma around MAiD can complicate the emotional processing and grief journey for those impacted. Further, the geographic isolation from major population centres, tight-knit communities, and a heightened presence of religiosity and conservativism within the rural communities of Southern Alberta can magnify the impact of these challenges, further exacerbating limitations in accessing appropriate end-of-life options and relevant emotional supports. This study provides additional nuance to findings of previous research examining the role of assisted dying in experiences of grief. Findings from my study challenge, confirm, and expand upon existing evidence, contributing to our growing understanding of MAiD-related grief and the factors influencing it within the Canadian context.

Consistent with previous research (La Brooy et al., 2024; Martin et al., 2023), participants frequently described their experience with MAiD as peaceful and well-aligned with patients’ wishes, reinforcing the role of assisted dying in preventing experiences associated with a ‘bad death’ (Wilson & Hewitt, 2017). However, my findings also emphasize the bureaucratic hurdles that can disrupt this process and related experiences of grief. Specifically, the final consent requirement contributed significant distress to the end-of-life experience, and participants feared that a patient would lose cognitive capacity before receiving MAiD, ultimately rendering them ineligible. This supports and expands upon the findings of previous studies which have highlighted the emotional toll of balancing patient autonomy with legislative safeguards among family members (Thangarasa et al., 2022) and healthcare providers (Variath et al., 2022a); my findings suggest that patients too experience this challenge. While the introduction of the Waiver of Final Consent has helped to alleviate this burden in some cases, this study highlights the need for further refinement to appropriately balance patient autonomy, equitable access, and ethical considerations particularly for vulnerable groups.

Another significant challenge highlighted within my findings was the forced relocation of patients from private, faith-based healthcare facilities due to institutional policies prohibiting the provision of MAiD on-site. Participants described these transfers as physically and emotionally distressing, echoing previous findings that suggest that relocation can disrupt the dying process and have profound negative impacts on the grief experiences of patients' loved ones (Wiebe et al., 2022; Yan et al., 2022). Beyond the logistical difficulties associated with moving a patient nearing end-of-life – particularly within rural settings, where alternative facilities may not exist within close proximity – witnessing a patient endure unnecessary suffering during a transfer can exacerbate distress for family members and healthcare professionals, which can have lasting impacts on the grieving process.

Stigma surrounding MAiD also played a key role in shaping the grief experience among patients, loved ones, and healthcare professionals within my study. Many participants expressed hesitation around disclosing their involvement with MAiD due to fears of judgment or social rejection. In turn, this limited their ability to seek support from loved ones, community members, colleagues, and professionals, which may have lasting implications on their ability to navigate their grief. This finding supports and expands upon previous research by Crumley et al. (2023) who found that secrecy, judgment, and guilt are common yet hidden experiences among individuals involved in or impacted by MAiD. While the authors described these experiences as largely independent, my findings highlight their interconnection, suggesting that awareness of stigma surrounding MAiD may motivate secrecy, which inadvertently reinforces the very stigma that motivated it. This aligns with previous findings that demonstrate the role of secrecy in experiences of disenfranchised grief, where individuals feel unable to openly mourn or seek validation for their loss (Andriessen et al., 2020; Crumley et al., 2023; Yan et al., 2022) . Finally, findings from my study suggest that the impact of stigma may be particularly profound within rural areas like Southern Alberta, where tight-knit communities and a relatively high prevalence of conservative values amplify participants' concerns around judgment and social repercussions due to involvement in MAiD (Brassolotto, Manduca-Barone, & Sedgwick, 2023; Sedgwick et al., 2024).

Overall, this study contributes to the growing body of literature on MAiD-related grief, emphasizing the interplay between policy, institutional practices, and social attitudes within a rural Canadian context. While MAiD can indeed facilitate a 'good death' for many, key legislative and systemic barriers, alongside stigma-driven secrecy, can complicate the both the experience of assisted death and the grief that accompanies it. Addressing these challenges will require a multi-faceted approach that balances the importance of regulatory safeguards with policies that prioritize patient autonomy, equitable access to healthcare services, and appropriate bereavement supports. Below, I have summarized some key recommendations for policy, practice, and future inquiry, which I expand upon in greater detail in the following chapter.

Recommendations

Policy and Legislation

Findings from this study have highlighted opportunities for refinement to current policies and practices of MAiD program in Alberta. Specifically, the final consent requirement creates substantial distress among patients and their loved ones and can contribute to complications in healthcare providers' grief when they are unable to provide MAiD following a patient's cognitive incapacitation. Thus, I suggest (a) expanding eligibility for the Waiver of Final Consent to all MAiD-approved patients, or (b) introducing advanced requests for MAiD.

Policies held by faith-based healthcare institutions prohibiting the provision of MAiD within their facilities have subjected patients to painful transfers, which not only impact their own end-of-life experience, but the grieving process of their loved ones. Further, these transfers pose an additional burden on an already strained healthcare system. To address these concerns, I recommend that all publicly funded healthcare facilities, regardless of religious affiliation, be mandated to (a) permit MAiD provisions on-site, or (b) dedicate space within their building to be under the jurisdiction of provincial or territorial health authorities that would allow for MAiD provisions without requiring the resources, funds, or personnel from the faith-based institution.

Practice and Accessibility

Controversy and stigma surrounding MAiD constitute a significant barrier to accessing both formal and informal social supports for individuals considering, anticipating, providing, or grieving MAiD. To address the stigma at a societal level, public awareness and educational campaigns, modelled after those for similarly contentious topics (e.g., substance use and addiction, mental illness), should be implemented to foster open discussion around end-of-life options, MAiD among them. This may be particularly important in rural areas where limitations to privacy may amplify the impact of stigma.

Given the often-persistent nature of stigma, it is important that individuals impacted by MAiD have access to safe, dedicated support systems where they can openly discuss their experiences without the fear of social repercussions. Thus, I suggest the development of (a) peer-support groups for loved ones bereaved by or anticipating bereavement from MAiD, (b) structured support networks for healthcare providers involved in MAiD-related care, and (c) family-oriented counselling and mediation services integrated into the MAiD program to address and alleviate interpersonal conflicts throughout the MAiD process. Beyond providing otherwise-isolated individuals with resources and skills to support their grieving process, these supports may also be useful in fostering open discourse around end-of-life and contribute to increasing awareness and combatting stigma.

Future Research

Despite a growing body of literature on experiences of assisted dying, there are many aspects that have yet to be thoroughly explored. Further research on the experiences and perspectives of individuals from various ideological backgrounds is warranted to uncover nuance in how personal values may impact the experience of grief. Findings from such work may be helpful in informing the development of inclusive supports for MAiD-related grief and interpersonal conflict and potentially contribute to combatting persistent stigma. To this end, the development and evaluation of online or distance-delivered educational initiatives and bereavement support programs are needed to understand the feasibility, acceptability, and impact on grief-related outcomes, particularly for individuals who may face geographic and/or social isolation.

Additionally, much of the previous work exploring MAiD-related grief has relied on cross-sectional and qualitative designs. While these studies have been instrumental in generating knowledge within this relatively young field, longitudinal studies assessing the short- and long-term impacts of MAiD policies across various jurisdictions on grief-related outcomes are needed to inform ongoing policy development and adaptation. Finally, with upcoming legislative changes allowing MAiD for individuals suffering solely from mental illness expected to come into effect in the next two years, future research should prioritize the involvement of individuals with expertise and/or lived experience of life-limiting mental illness. These perspectives will be crucial in maintaining a balance between patient autonomy and regulatory safeguards and ensuring equitable access to appropriate care through end-of-life.

Conclusion

This study highlights the experiences of MAiD-related grief within the context of rural Southern Alberta, demonstrating how stigma, resource scarcity, and professional isolation shape the experiences of individuals navigating emotional complexities and grief related to MAiD death. While findings confirm and expand on existing literature on MAiD-related grief within broader national and international contexts, this study provides key insights into the rural-specific barriers that warrant further attention. Expanding grief supports for bereaved families, integrating formal debrief and support processes for providers, and fostering community-level awareness and acceptance around MAiD may contribute to improved experiences of MAiD-related grief, particularly within rural settings. Future research should explore the experiences of rural patients, family members, and providers involved in MAiD with an explicit focus on their experiences with grief and assess the feasibility and acceptance of implementing targeted supports and awareness initiatives, particularly outside of major population centres. These avenues may provide additional insight into self-identified factors contributing to grief and lay the foundation for improving the experiences of those impacted by MAiD.

CHAPTER 3:

INTEGRATIVE DISCUSSION, RECOMMENDATIONS, AND REFLECTIONS

Introduction

Through a secondary reflexive thematic analysis, I designed this thesis to explore experiences and influencing factors of grief related to MAiD among patients, loved ones, and healthcare professionals in rural Southern Alberta. In Chapter 1, I provided a review of the extant literature on MAiD, grief, and rural health- and end-of-life care, established my positionality and orientation towards this analysis, and described the steps I took throughout the analytic process. In Chapter 2, I presented the themes I generated through this analysis, which highlight the role of MAiD in allowing for a 'good death' experience, distinct challenges related to MAiD policy and processes, and the impact of stigma on individuals' experiences of MAiD-related grief. In this final chapter, I discuss the contribution of my findings to existing literature, describe the key implications of these findings, and provide recommendations for policy, practice, public discourse, and future research on MAiD and related grief experiences. Finally, I conclude this thesis with a critical reflection on my journey in completing this project in which I discuss the unanticipated challenges, successes, and learnings that extend beyond the topic of my research objectives.

Summary of Thesis Findings

Participants in this study represented a range of political and religious backgrounds yet shared a common understanding of a 'good death' as one characterized by autonomy, control, comfort, and connection. MAiD deaths were often described as peaceful or beautiful experiences, highlighting its role in the 'good death' experience. However, many participants identified key legislative and societal barriers that complicated their experiences. These included the requirement for final consent before receiving MAiD, which introduced significant anxiety and stress that the patient would lose capacity before their provision and be unable to receive the procedure. Additionally, the prevalence of religiously affiliated healthcare facilities within rural Southern Alberta that prohibit MAiD provisions from occurring on-site often necessitated patient transfers. These were often physically and emotionally distressing for the patient, their loved ones, and the professionals involved in their care. In some cases, patients required sedation to minimize their suffering during relocation, which diminished their decision-making capacity, rendering them ineligible for MAiD. Beyond these obstacles, the societal stigma surrounding MAiD was also implicated in shaping the grief experiences of family members and healthcare professionals, who often felt pressured to conceal their involvement in the program. This stigma, along with the final consent requirement and institutional policies prohibiting MAiD at certain facilities, influenced how participants navigated experiences of MAiD, loss, and grief.

Comparisons and Contributions

Building on the previous work of others, the themes borne from this investigation contribute nuance to our understanding of how MAiD-related grief is experienced and the factors that influence such experiences. In what follows, I discuss how my findings may confirm, extend, refine, or challenge those of previous investigations, and the potential implications on our understanding of grief experiences surrounding MAiD.

Characteristics of MAiD Supporters

Participants in my study represented a wide variety of political and religious affiliations but were all generally in favour of and willingly engaged in the MAiD process.

This challenges previous work suggesting that religious beliefs and alignment with conservative political parties decrease acceptance of and willingness to engage in MAiD-related practices (Bator et al., 2017; Beuthin et al., 2018; Hawrelak et al., 2022; McCarthy & Seal, 2019; Pennings & Reid, 2020; Pesut, Thorne, Storch, et al., 2020). While differences in acceptance and willingness to participate in assisted dying programs indeed may vary across political and religious affiliations, such broad claims may contribute to secrecy and isolation among proponents of MAiD who find belonging in religious and/or politically right-leaning communities. Similar to religiosity and political affiliation, perspectives about MAiD exist along a spectrum, rarely fitting neatly within the extremes of 'total support' or 'total opposition' (Sedgwick et al., 2024). Future research exploring experiences of MAiD-related grief among individuals with various perspectives is warranted to understand how support needs may vary across this spectrum.

MAiD as a Good Death

Key Factors of a 'Good Death'

While broader literature suggests that avoidance of pain is a key factor in ensuring a 'good death' (Rainsford et al., 2016; Wilson et al., 2009; Wilson & Hewitt, 2017), MAiD patients, healthcare providers, and MAiD-bereaved family members in my study placed more value on the aspects of control, autonomy, and connection through the end-of-life. This partially aligns with previous work exploring the perspectives of MAiD-engaged groups on factors of a 'good death'. For instance, in a scoping review of the literature, Martin and colleagues (2023) found that individuals accessing MAiD associated a 'good death' with maintaining autonomy and control through end-of-life, but also with avoiding pain and suffering in the dying process.

Recent work by La Brooy et al. (2024) reported similar findings from a sample of family caregivers of patients who had accessed the Australian version of MAiD.[1] Specifically, the authors noted the importance of ensuring dignity, autonomy, and control through the end-of-life phase as key factors in facilitating a 'good death', while physical suffering, emotional pain, and loss of control characterized a 'bad death' (La Brooy et al., 2024). Participants from my study and La Brooy et al.'s (2024) spoke about their experience with MAiD in contrast to previous 'bad death' experiences that they had witnessed; MAiD commonly provided patients and their loved ones with reassurance that allowed for peace and patient dignity through the dying experience in a way that 'natural' deaths often did not. Thus, while my study participants appeared to more strongly value the opportunity to control, autonomy, and connection offered by MAiD over the prevention of pain and suffering, this remains an important attribute of the 'good death' experience within MAiD-seeking, -providing, and -supporting groups.

There are a few possible explanations for the limited emphasis on avoiding pain within my findings. First, the rural context of my study may play a role in explaining this discrepancy. Although rural residents do value the avoidance of pain and suffering as part of a 'good unassisted death' (Rainsford et al., 2016; D. M. Wilson et al., 2009), the opportunity to access MAiD may decrease rural residents' focus on the potential for end-of-life suffering, thereby reducing their emphasis on its prevention as a factor of a 'good assisted death'. More likely, however, it may be that my participants' desire for control is

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[1] Australian legislation uses the term 'Voluntary Assisted Dying' (VAD), defined as "the assistance provided by a health practitioner to a person with a terminal illness, disease or medical condition to end their life." Like MAiD in Canada, VAD laws vary by jurisdiction. For more on assistance in dying in Australia, see Waller et al. (2023).

in fact a desire to *control the degree of suffering* rather than a general sense of control over their end-of-life experience. While this was less emphasized by participants than the importance of a general sense of control, some did speak about MAiD as an opportunity to control symptoms, pain, and suffering through MAiD (Patient 1, Patient 3, Family Member 7, Provider 8, Other Professional 2). In this way, the avoidance of pain identified within literature on the factors associated with a 'good death' may in fact be intrinsically related to the importance of control.

'Good Grief' for a 'Good Death'

There is ample evidence to suggest that MAiD offers an opportunity for a 'good death'. Regardless of the specific factors one may associate with a 'good death,' alignment between them and the actual death experience may play a role in predicting 'good grief' (Tenzek & Depner, 2017; Wakenshaw & Sillence, 2018; D. M. Wilson et al., 2016, 2019). For example, Wakenshaw and Sillence (2018) suggest that the absence of aspects associated with a 'good death' can contribute to a more challenging grief experience for the bereaved. La Brooy et al. (2024) suggest that this extends to bereavement following assisted death experiences as well. In their study of the experience of grief among Australian family members bereaved by MAiD, La Brooy and colleagues (2024) note that the alignment of the assisted death experience with their loved one's wishes and values provided family caregivers with support through their bereavement. Findings from my study support this claim, further suggesting that this extends beyond bereaved family members to healthcare providers as well. Like patients and their loved ones, healthcare professionals in my study felt that MAiD deaths often aligned with patients' values and end-of-life wishes. These participants spoke about a heightened sense of fulfilment related to their role in facilitating patients' value-aligned deaths and often described MAiD deaths as more positive experiences than other deaths they experienced in their roles.

Overall, for those who value autonomy, dignity, and control at end-of-life, assistance in dying can provide an opportunity for a ‘good death’ experience, which may offer some protection from challenging or complicated experiences of grief. However, my findings also highlight key factors that complicated the MAiD experience for participants and contributed negatively to their experience of death and grief.

Bureaucratic Challenges with MAiD

Two of the factors that contributed challenges to participants’ MAiD and grief experiences were related to policies and processes of the Canadian MAiD program: (a) the final consent requirement, and (b) institutional policies necessitating the transfer of patients out of certain facilities to receive MAiD. Bureaucratic challenges related to assisted dying legislation and their impact on the experience of grief are not unique to Canada. For instance, La Brooy et al. (2024) reported that challenges in timely access to medication used to hasten death in Australia complicated family members’ grieving process; in Switzerland, challenges during the mandatory forensic investigation following an assisted death contributed to post-traumatic stress among patients’ loved ones (Wagner et al., 2011). Though difficulties with bureaucratic policies and processes may contribute to challenges in the experience of grief following MAiD, they often play a vital role in protecting the rights and autonomy of vulnerable groups. The tension between these safeguards and the emotional well-being of MAiD patients, family members, and care providers highlights the need for policies that balance the need for regulatory oversight with accessible and compassionate end-of-life care.

Final Consent Requirement

Legislative context. As described in Chapter 1, MAiD has procedural safeguards in place to ensure that patients' choice to access assistance in dying is fully informed, freely given without undue pressure or external influence, and able to be withdrawn at any point before provision (Department of Justice Canada, 2024). One such safeguard is the requirement for a patient to provide final consent immediately before receiving MAiD, which Track 1 patients can now waive due to amendments made following the passage of Bill C-7 in March 2021 (Alberta Health Services, 2021a; CAMAP, 2024b; Department of Justice Canada, 2021, 2024). Data used within my analysis were collected shortly after the amendment was passed and include experiences of MAiD deaths that occurred before the amendment, as well as those that took place afterwards. Among the latter, participants' experiences involved patients who a) were ineligible for the waiver (i.e., patients whose deaths were *not* reasonably foreseeable), b) were eligible but did not use a waiver, and c) waived the final consent requirement.

My findings reinforce existing literature on the challenges of the final consent requirement, which suggest that it can contribute to stress, anxiety, and uncertainty for MAiD patients, their loved ones, and care professionals due to the potential for the patient's loss of cognitive capacity and subsequent loss of access to MAiD. In addition, these findings offer insight into how waivers of final consent may shape experiences of MAiD-related grief, an unanticipated finding that contributes to a relatively underexplored area within the broader discourse on MAiD and associated grief. In what follows, I first discuss participants' experiences with the final consent requirement, its impact on their experiences of grief, and how these findings align with existing literature. I then explore the perceived benefits and drawbacks of the final consent waiver, comparing my participants' perspectives with previous research on healthcare professionals' perceptions of the waiver, and integrating broader literature on themes such as anticipatory grief and the experience of a 'countdown' to death.

MAiD without a Waiver of Final Consent. Participants whose experiences did not involve a waiver of final consent consistently described concerns about whether the dying person would be able to maintain cognitive capacity to provide final consent. In many cases, this introduced or exacerbated anxiety and fear during the end-of-life phase as they attempted to balance the importance of a 'good death' with the risk of patients' loss of capacity and consequent ineligibility for MAiD. Thangarasa et al. (2022) recently described the experience of navigating this balance as a 'race to the end' and found that the uncertainty around a loved one's ability to maintain cognitive capacity through their MAiD provision contributed to fear, anxiety, and concern among caregivers. This analogy aligns with my findings, capturing the sense of urgency, anxiety, and fear expressed by participants within my study. While Thangarasa et al.'s (2022) work focused on the experiences of family members anticipating or bereaved by a MAiD death, my findings suggest that this analogy extends to MAiD care professionals and patients as well, and the associated uncertainty and anxiety has implications on the experience of grief, regardless of whether a patient lost their cognitive capacity before their provision ('losing the race') or was ultimately able to receive MAiD ('winning the race').

MAiD care professionals in my study described challenges with both the *potential* and *actual* experience of losing the race. The prospect of a patient's loss of capacity created a persistent sense of unease and providers feared being unable to honour their patient's clearly expressed end-of-life wishes; when capacity loss did occur, care professionals described feeling helpless and regretful that they could not provide a ‘good death’ experience for their patient. These findings complement those recently reported by Variath and colleagues (2022a) who described some key challenges healthcare providers faced during this ‘race to the end’ (Thangarasa et al., 2022). Specifically, challenges included: delays due to patients lacking relevant information about their prognosis or the availability of MAiD; difficulty in determining patients’ risk for capacity loss; balancing effective symptom management with protecting patients’ cognitive capacity; and moral distress when expediting provisions to avoid capacity loss (Variath et al., 2022a). Together, findings from my study alongside those presented by Variath et al. (2022a) provide nuanced insight into the factors affecting healthcare professionals’ experiences of grief related to the final consent requirement.

Finally, my findings present novel insights into patients’ first-hand concerns about their potential loss of capacity before MAiD. Though the sample of patient participants was small, patients’ fear that they would become ineligible to access MAiD and consequently lose control over their dying experience was clear. In all, findings from this thesis suggest that the requirement for final consent immediately before MAiD provision may negatively impact the experience of death and related grief among patients, family members, and care professionals alike.

MAiD with a Waiver of Final Consent. As noted earlier, I was surprised to find that multiple participants described challenges associated with the waiver of final consent and that the waiver – not just the final consent requirement – may play a role in the experience of MAiD-related grief. Specifically, my findings offer insight into the benefits and drawbacks of the waiver perceived by healthcare professionals, and the perceived impact it can have on patients and their loved ones. While healthcare professionals experienced feelings of helplessness and disappointment when unable to provide MAiD due to a loss of capacity, they also described discomfort with providing MAiD to patients who are not cognitively present. According to Variath et al. (2022b), MAiD providers can find comfort and closure in the opportunity to share final moments and words with patients before death. There is a wide range of factors that may contribute to a patient's loss of capacity to consent, some of which may also inhibit their ability to engage in meaningful conversations (e.g., terminal delirium, comatose; Soroka et al., 2022; Wiebe et al., 2021). My findings support this, with a few care professionals describing the unease of providing MAiD to patients who have lost their cognitive capacity to engage, and others who expressed aversion to participating in such provisions. In these cases, healthcare professionals may face more challenging experiences of grief. On one hand, providers may mourn losing the opportunity to form meaningful connections with patients prior to their passing, which can hinder their ability to find closure. Further, care professionals' grief may be complicated by lingering doubts about whether the patient would have consented had they maintained their cognitive capacity, and/or cognitive dissonance related to their role in providing the patient with a 'good death' while also valuing the important ethical and legal role of the final consent requirement.

The potential impacts of the waiver of final consent on patients' and loved ones' experiences of MAiD and associated grief have yet to be explored in the existing literature. Findings from this study suggest that selecting a date for provision may be challenging for patients and their loved ones. In selecting the date that their life will end, patients and loved ones are likely confronted with the reality of the coming death and potentially evoke a feeling of a ‘countdown’ (Beuthin et al., 2022; Young et al., 2024) or ‘parade of lasts’ (Beuthin et al., 2022; Yan et al., 2022). The concept of a ‘countdown’ after a patient selects their date of death has been described in existing literature as being beneficial to some participants and challenging for others. For example, Beuthin et al. (2022) investigated the experiences of grief and bereavement among family members and friends of people who had died by MAiD (prior to the amendment allowing the final consent requirement to be waived) and found that for some, the ‘countdown’ to a loved one’s death provided a distinct timeframe for them to take time off work and/or travel to spend time with their loved one, while others felt that knowing the date that their loved one would die felt disorienting and intensified anxiety and anticipatory grief for their impending loss (Beuthin et al., 2022). While findings from my study suggest a similar trend, participants were not asked directly about whether their MAiD experience involved a waiver of final consent. Thus, future investigations focused on family members' and friends’ experiences with the use of a final consent waiver are warranted.

Relocation for MAiD Provision

Legislative context. As described in greater detail in Chapter 1, healthcare in Alberta is primarily delivered by Alberta Health Services (AHS) which contracts Covenant Health to manage some hospitals, continuing care, and end-of-life care facilities as part of the integrated health system (Alberta Health Services, n.d.-a; Church & Smith, 2022; Covenant Health, n.d.). While Covenant Health has recently permitted MAiD assessments and other preparatory care activities to occur on-site, it prohibits the provision of MAiD due to Catholic teachings (Covenant Health, 2022). As a result, patients residing or receiving in-patient care at Covenant Health facilities who wish to receive MAiD must be transferred to another location to receive the service.

My findings suggest that transferring end-of-life patients from faith-based facilities may complicate the dying and grief experience of patients, loved ones, and healthcare professionals. Patients and their loved ones are prone to significant emotional strain during transfers, as the process can often be painful for patients and distressing to witness for their loved ones. Further, the logistical uncertainties about where the death will take place can detract from the 'good death' experience that MAiD was intended to offer. Additionally, this can impose added administrative burdens for healthcare providers faced with arranging and facilitating patient transfers to a new provision location which may complicate their experience. Each of these aspects – both independently and in conjunction with one another – can complicate the feelings surrounding these deaths.

My findings complement those of Close, Jeannerete, et al. (2023) who described similar emotional and logistical challenges faced by families and healthcare professionals in other Canadian provinces. Similar to my findings, the authors described a painful transfer process, logistical barriers, constrained agency over one's place of death, and obstructed access to MAiD as factors negatively impacting the experience and contributing to distress throughout the process (Close, Jeanneret, et al., 2023). Notably, Close, Jeannerete, et al. (2023) also described variability in the scope of objection across institutions; while some facilities may permit preparatory activities including MAiD assessments, others abstain entirely from all MAiD-related care tasks. Although my participants did not describe any first-hand experiences with complete abstention within a facility, some did express gratitude that their loved one could be assessed and prepared for MAiD prior to being transferred for provision. Some degree of institutional flexibility in permitting MAiD-related care tasks may help in facilitating a 'good death' experience despite the need for relocation. However, the lack of consistent, transparent policies around on-site MAiD provisions across institutions may also contribute to uncertainty and confusion, as patients and loved ones may assume that a facility that allows on-site assessments would also allow provisions, resulting in unanticipated changes to their end-of-life expectations (Close, Jeanneret, et al., 2023). In some cases, this lack of transparency may delay facilitating a patient's transfer until they have decompensated to a point where they would require comfort sedation for transfer, which may detract from their ability to provide final consent after being relocated, ultimately obstructing their ability to receive MAiD and complicating both the end-of-life and grieving experience.

Beyond the impact of patient transfers, institutional objection to MAiD presents an interesting and important ethical dilemma in weighing patient agency against Charter Rights to freedom of conscience and religion (Department of Justice Canada, 1982). While nearly all Canadian provinces and territories continue to allow private institutions to abstain from providing MAiD (Abortion Rights Coalition of Canada, 2022), the province of Québec amended their Act Respecting End-of-Life Care in 2023 to mandate that all publicly funded healthcare institutions must offer MAiD as part of their services (Act Respecting End-of-Life Care, CQLR c S-32.0001, 2023). This amendment was recently upheld by a Superior Court judge who ruled that patients' right to access legal forms of healthcare outweighs institutions' right to freedom of conscience and religion (Charitable Works of the Roman Catholic Archbishop of Montreal v. Attorney General of Quebec, 2024; Serebrin, 2024). This case emphasizes the tension between institutional values and patient agency in health and end-of-life care decisions within a publicly funded system and sets a legal precedent that may influence the implementation of similar mandates across healthcare jurisdictions in Canada.

The ethical dilemma regarding institutional objection is also discussed internationally. In Australia, Kerridge and colleagues (2023) critically examined this issue through an ethico-legal lens, providing arguments both for and against respecting institutional objections in the context of Australian legislation. Notably, the authors argue that institutions, unlike individual healthcare practitioners, do not have consciences and therefore cannot truly exercise conscientious objection (Kerridge et al., 2023). While I wholeheartedly agree with this position, the Québec Superior Court case described above complicates the issue. In light of the court's decision to deny the faith-based institution's request for exemption from the mandate to offer MAiD, the archbishop, a significant funder of the plaintiff and other faith-based institutions, expressed a reluctance to continue this financial support (Serebrin, 2024). This highlights the complexity of this dilemma; while mandating MAiD at all publicly funded institutions may enhance access to MAiD specifically, it could also inadvertently limit access to health and end-of-life care more broadly by discouraging religious leaders from providing financial support, potentially resulting in reduced capacity within the healthcare system. Acknowledging such risks, Kerridge and colleagues (2023) propose a 'compromise' position, in which objecting institutions may abstain from providing MAiD only when the patient can reasonably access the service without significant harm or loss of eligibility, in which case they must allow the procedure to occur on-site (Kerridge et al., 2023, p. 820). In the Recommendations section of this chapter, I incorporate this proposal into my own recommendations for MAiD policy and legislation in Alberta (see pages 106-109).

In summary, the relocation of patients from objecting institutions to receive MAiD constitutes significant emotional and logistical burdens which can complicate the end-of-life and grieving experience for patients, their loved ones, and healthcare professionals.

While some jurisdictions, such as Québec, have attempted to address this issue by mandating MAiD availability in all publicly funded institutions, the potential loss of funding from religious organizations may inadvertently reduce, rather than enhance, access to care.

MAiD-Related Stigma Contributes to Secrecy, Limiting Open Discussion and Access to Support

Stigma plays a significant role in how patients, family members, and care providers experience death, dying, and grief, particularly within the context of MAiD. In this study, participants varied in their willingness to disclose their involvement with the program. While some shared their experiences selectively, others spoke openly with relatives, friends, or members of their broader communities. Those who disclosed their involvement were prone to encountering judgment or backlash; in some cases, this contributed to feelings of shame, guilt, or regret, which negatively impacted their experience of grief. In contrast, nearly all participants who concealed their involvement did so to protect themselves and/or the patient from becoming the target of that judgment. This aligns with previous research indicating that family members bereaved by MAiD frequently experience guilt, judgment, and secrecy (Crumley et al., 2023). However, while Crumley et al. (2023) describe feelings of guilt, judgment, and secrecy as independent experiences, my findings suggest that they are highly interconnected. Specifically, the anticipation of stigma often led participants to keep their involvement secret, which inadvertently reinforced the perception that MAiD is something to be hidden, ultimately perpetuating the stigma. Thus, while secrecy around one's MAiD involvement may protect against the negative impacts of stigma on grief at a micro level, it may negatively impact the grief experience in the long term and enable stigma at the macro level.

Impacts of Stigma and Secrecy on MAiD-Related Grief

One way in which stigma-driven secrecy may negatively impact the experience of grief related to MAiD is by limiting access to appropriate social supports. The degree of social support perceived throughout bereavement plays an important role in protecting against intense or complicated grief experiences (Bonanno et al., 2002; Mason et al., 2020; M. Stroebe et al., 2013). Secrecy around experiences of loss may decrease the level of social support perceived by bereaved individuals, resulting in feelings of isolation and disconnection in navigating one's grief (Marek & Oexle, 2024). In this case, participants in the current study described that individuals bereaved by MAiD often found general grief support groups unhelpful as they felt the need to censor their experiences or risk facing opposition or rejection from others in the group. Instead, participants were often led to process their grief with support only from those aware of MAiD's role in the process. This finding highlights an opportunity to develop social support resources targeted towards individuals bereaved by stigmatized or otherwise disenfranchised losses to better promote connection and support amongst individuals often grieving in isolation.

The impact of secrecy may also negatively impact the grief experience by limiting access to a 'good death' via MAiD. The stigma around MAiD may manifest in patient hesitancy to discuss their interest in the procedure with their healthcare provider, fearing judgment or potential harm to their patient-provider relationship. Similarly, healthcare professionals may keep their involvement in MAiD discreet, fearing backlash from their communities and potential harm to their relationship with patients. As a result, while MAiD may be *available* within a community, its *accessibility* may be hindered by secrecy. Subsequently, patients opting to forego inquiring about MAiD may be less likely to have a death experience that aligns with their perception of a ‘good death’. This may amplify experiences of anticipatory grief among patients, who may mourn the death experience they had hoped for, and/or the anticipated impact their non-MAiD death will have on their loved ones.

Before concluding, I feel it important to acknowledge that this discussion is based on findings from participants living and/or working in rural Southern Alberta, where close-knit communities may amplify the effects of stigma and secrecy on MAiD-related grief. In rural settings, healthcare professionals and patients often have relationships that intersect both professional and personal roles (Brassolotto et al., 2021; Brassolotto, Manduca-Barone, & Sedgwick, 2023; Sedgwick et al., 2024). This may manifest in exacerbated fears of judgment between care professionals and patients who risk damaging both their professional and personal relationships. This concern may be amplified by the limited availability of alternative health and end-of-life care services, as any strain in the relationship between patients and their sole healthcare provider can significantly hinder access to care. As such, I suggest that rurality should be considered when developing programs designed to combat stigma and support individuals and communities through grief.

Recommendations

My findings highlight several systemic and procedural challenges that impact the experience of MAiD-related grief for patients, loved ones, and healthcare professionals in rural Southern Alberta. These challenges stem primarily from legislative policies, barriers to accessibility, and gaps in appropriate and accessible grief-support services. To address these concerns and improve the experience of those involved in MAiD, I propose the following recommendations for policy and legislation, practice and accessibility, and future research. In addition to these recommendations, which I have based on the findings of my thesis and previous work on MAiD in Canada, I support continued efforts to enhance the quality and accessibility of healthcare and social services to support the quality of life *and* death for all Canadians.

Recommendations for Policy and Legislation

Legislative policies surrounding final consent requirements and facility-based restrictions on MAiD provision present significant emotional and logistical challenges for patients, family members, and care providers. Addressing these barriers is crucial to ensuring accessible, compassionate, and equitable end-of-life experiences and supporting individuals through the grieving process.

1. Recommendations related to the Final Consent Requirement.

The current requirement for patients to provide final consent immediately before receiving MAiD is an important safeguard within the program to protect vulnerable individuals and ensure that MAiD is always entirely voluntary. However, it can also contribute to significant distress and anxiety through end-of-life, impacting the associated experience of grief. While the implementation of the Waiver of Final Consent has helped to alleviate some of this burden, my findings highlight that it has not fully addressed this issue. To improve patient autonomy and reduce uncertainty at end-of-life, the following legislative changes should be considered:

(a) **Expand eligibility for Waiver of Final Consent** to include all patients approved for MAiD, regardless of whether their death is deemed ‘reasonably foreseeable’. This may alleviate stress and anxiety during the dying process, facilitating a death experience that more closely aligns with patient wishes and the experience of a 'good death'.

OR

(b) **Introduce advanced requests for MAiD**, allowing patients to formally document their decision to receive MAiD at a future point when they may no longer have decision-making capacity. The province of Québec has recently taken steps in this direction in amendments made to its Act Respecting End-of-Life Care (Bill 11, 2023; Act Respecting End-of-Life Care, 2023, c. 15, s. 15). Nation-wide expansion of this option would provide greater autonomy for individuals facing progressive and degenerative conditions, reducing anxiety and stress through the end-of-life experience.

These recommendations are made under the current legislative framework, under which individuals whose sole underlying medical condition is a mental disorder (MD-SUMC) are ineligible for MAiD under a temporary exclusion introduced in Bill C-7 (Department of Justice Canada, 2021). This exclusion was introduced to allow adequate preparation of safeguards, protocols, and capacity within the healthcare system (Department of Justice Canada, 2021). Recently, the exclusion was extended until March 2027, following which individuals with MD-SUMC are expected to become eligible to receive MAiD. Concerns about characteristics of suicidality, including impulsivity and ambivalence, often underpin arguments against MAiD for MD-SUMC (Council of Canadian Academics, 2018). However, as illustrated in my findings, the MAiD process is not a 'quick fix' – instead, the process requires ongoing reflection, engagement with healthcare providers, self-advocacy, and adherence to procedural safeguards and protocols (e.g., completing two independent assessments). As such, I argue that individuals with MD-SUMC who have satisfied eligibility criteria and met relevant safeguards should be granted the same degree of agency in their end-of-life decisions as those with a physiological SUMC, including access to final consent waivers and/or advance requests.

Another aspect to consider in interpreting these recommendations is the ethical debate around whether advance MAiD requests may be used against individuals living with or anticipating the development of stigmatized disabilities, emphasizing an ableist perspective that it is “better to be dead than disabled” (Peters, 2024, p. 1). To be clear, this is not a view that I endorse. There have been numerous documented instances of systemic discrimination and abandonment of individuals living with disabilities within the Canadian healthcare system that absolutely warrant substantial consideration in the development and implementation of MAiD policies and protocols (Grant, 2023). In addition, disability rights advocacy groups have argued that allowing advance requests for MAiD may compromise rather than protect patient agency by favouring their past decision (to request MAiD) over their current desires (Vachon, 2025). Specifically, Vachon (2025) notes that stigma surrounding progressively disabling conditions, such as dementia, can negatively influence individuals’ perceptions of their future quality of life, prompting them to enter advance requests for MAiD out of fear of suffering. This fear may be rooted in the belief that their future will be marked by unbearable suffering, which may not play out in reality. Vachon further emphasizes that such advance requests made by the ‘current non-disabled self’ could override the agency of the ‘future disabled self’, setting a dangerous precedent for individuals living with disabilities (2025).

While clinical best-practice guidelines for MAiD practitioners emphasize that individuals retain the right to *withdraw* consent at any time before administration, even if they have lost the capacity to *provide* consent (CAMAP, 2024a, 2024b), the historical context of discrimination against individuals with disabilities means that concerns about coercion and loss of agency must be considered in the development and implementation of MAiD policies and protocols. Thus, I present the following caveats: to mitigate these risks, standardized training protocols for MAiD practitioners should be developed, in collaboration with individuals with lived and living experience of disability, to ensure care professionals have a comprehensive understanding of ableism and its potential impact. Additionally, practitioners should be trained to identify verbal and non-verbal signs of resistance from patients and to halt the provision of MAiD in such instances, even when an advance request or final consent waiver is in place. As an added layer of protection and accountability, I recommend the mandatory presence of an additional practitioner who has undergone these trainings during provisions involving final consent waivers or advance requests. This individual would serve as a secondary observer for signs of refusal from the patient and be responsible for documenting the process to enhance accountability and adherence to these practice standards. Ideally this individual would attend the provision in-person which may present challenges particularly in rural communities. As such, attendance via video-call should be permitted when the circumstances require it. To avoid unnecessary surprises at the end-of-life, these patients submitting advance requests or final consent waivers should be informed about the required attendance of the additional provider at the time of their request.

2. Recommendations related to forced patient relocation for MAiD provision.

In 2023, nearly 9% of all patients who received MAiD had been transferred to a different location for provision, necessitated by institutional policies prohibiting MAiD within the patient's original facility (Health Canada, 2024a). These transfers can be excruciating for patients, at times requiring the use of anaesthetic medications which can reduce a patient’s ability to consent, potentially resulting in an inability to receive MAiD entirely (Manzhura, 2021). Further, the transfer process can contribute to heightened anxiety and stress for the patient’s loved ones (Serota, Buchman, et al., 2023; Wiebe et al., 2022), while also creating tension and increasing the workload among care providers, particularly those in rural areas (Close, Downie, et al., 2023). As described earlier, the province of Québec has attempted to address these harms by mandating that all publicly funded healthcare facilities offer MAiD within their scope of services, which has prompted the archbishop to reconsider their conscientious ability to financially support these facilities (Charitable Works of the Roman Catholic Archbishop of Montreal v. Attorney General of Quebec, 2024). Thus, to minimize harm to patients and family members while respecting organizations’ rights to conscience and religion, I recommend that the following policy change be considered:

(a) Mandate that all publicly funded healthcare facilities**,** including faith-based institutions, either:

  i. Permit MAiD provisions on-site, or
  ii. Incorporate, within the same building, an easily accessible space funded and operated by provincial or territorial health authorities (without utilizing the funding or resources from the objecting organizations), that permits MAiD provision to ease the process of patient transfers.

OR

(b) Allow institutional objection to providing MAiD, so long as:

  i. Preparatory care activities, such as assessments, may occur on-site to minimize patient transfers ahead of provision,

ii. Patients requesting MAiD are efficiently and effectively referred to a practitioner or team to arrange an alternate location and facilitate the transfer, and

iii. The patient's condition allows for the safe and (within reason) comfortable transfer to an appropriate off-site location to receive MAiD.

If these criteria *cannot* be met, the objecting institution **must** either:

- i. Allow a non-objecting staff physician or nurse practitioner to administer MAiD within the facility, or
- ii. Grant external MAiD practitioner(s) privileges to administer MAiD within the objecting facility, alleviating the institution from direct involvement in practices that contradict its guiding principles.

In their review of Canadian media articles and grey literature discussing institutional objections to MAiD, Knox and Wagg (2023) suggest factors involved in the ongoing debate around this topic, including differences in perceptions of the relationship between institutions and the practitioners associated with them, and a lack of harmony between the rights of conscientious objectors and patients pursuing MAiD. In developing these recommendations, I aimed to balance patients' right to a 'good death' with the recognition that these institutions strive to provide patients with a good quality of life and death, despite differences in moral values and beliefs. Further, many institutions that object to MAiD already allow and engage in passive forms of euthanasia through cessation of life-sustaining treatments and interventions as part of a compassionate care framework

(Covenant Health, 2016). Given the common goal of alleviating patient suffering through end-of-life, these recommendations should be interpreted as an effort to prevent patient suffering and complications to loved ones' and care providers' grief while allowing faith-based facilities to continue to provide compassionate care according to their ethical frameworks. By offering flexibility in these recommendations, I aim to strike a fair balance between accommodating patients' right to a dignified, comfortable, and value-aligned end-of-life experience and respect for the wide variety of perspectives and acceptance towards MAiD among those providing care to individuals at end-of-life.

Recommendations for Practice and Accessibility

Beyond legislative changes, there is a pressing need to improve bereavement support, professional training, and public awareness around MAiD. Addressing the stigma and ensuring care providers, patients, and families are adequately prepared and supported may help reduce the experience of distress and isolation throughout the grieving process. With this in mind, I propose the following:

1. **Integrate communication about existing MAiD-specific grief-support resources within the MAiD process:** Traditional grief support groups may not be appropriate to support the unique experiences of individuals bereaved by MAiD due to residual stigma related to assisted dying practices. Non-profit groups including Bridge C-14, the MAiD Family Support Society, and Dying With Dignity Canada have developed resources for individuals considering or pursuing MAiD, loved ones of MAiD patients, and professionals involved in MAiD care (Bridge C-14, n.d.; Dying With Dignity Canada & MAiD Family Support Society, n.d.; MAiD Family Support Society, n.d.). These resources are

available online; among others, they include live information and grief-support Zoom sessions, educational resources, interactive support networks via social media, and links to certified social workers, counsellors, and psychotherapists who specialize in helping clients navigate the MAiD journey and experiences of grief (Bridge C-14, n.d.; MAiD Family Support Society, n.d.). Professionals who work in the MAiD program should be aware of these resources and share them with patients and their loved ones early in the MAiD process to encourage access among individuals who may benefit from such support.

2. **Introduce family-centred mediation and pre-MAiD counselling services:** While many MAiD patients are supported by loved ones, some family members struggle with the decision, which can result in interpersonal tensions, emotional strain, and potential complications in the grieving process. Without adequate guidance, these conflicts may contribute to prolonged or complicated bereavement experiences. Services designed to address and navigate conflicting beliefs and perspectives between loved ones should be integrated within provincial and territorial MAiD programs and be offered once a patient has been approved to receive MAiD, while individual bereavement and grief counselling services should be available to loved ones both before and after MAiD provisions. Specifically, this may involve AHS funding to cover up to ten individual or family sessions for family members of patients approved for, approaching, or recently deceased by MAiD with a licensed care provider (e.g., social worker, counsellors, therapists, etc.) trained in navigating aspects of MAiD-related grief, and could also involve clinical ethicists who are trained in navigating value-based conflict. Addressing these tensions may reduce post-

death regret, guilt, or relational breakdowns among the bereaved, facilitating greater social support and positive grief experiences.

3. **Develop public health campaigns to enhance MAiD awareness and combat stigma**: While stigma was identified as a significant factor shaping grief experiences, it is not only an individual or interpersonal issue but a systemic public health concern. Secrecy and judgment surrounding MAiD can limit open discussion, restrict access to crucial grief and bereavement support services, and contribute to feelings of guilt and disenfranchisement among the bereaved. To address this concern, we should prioritize the development of educational outreach initiatives to increase public understanding of MAiD, particularly in rural areas where the impact of stigma is more expansive due to dual roles and limited alternative care options (Brassolotto, Manduca-Barone, & Sedgwick, 2023). These campaigns may be modeled after those targeting mental health and substance use stigma and include personal narratives, education on the legal and ethical foundations of MAiD, and engagement with communities (including objectors) to encourage open discourse and respect for differing opinions.
4. **Implement formalized supports for MAiD providers and assessors:** Healthcare professionals involved in MAiD-related care often experience emotional challenges related to their role, including distress over bureaucratic barriers, loss of patient capacity resulting in ineligibility, interpersonal tensions with colleagues and leaders in the workplace, and grief over the deaths of their patients. These experiences can contribute to provider burnout, moral injury, and workforce attrition, impacting not only the care providers themselves but the accessibility of healthcare services as a whole. Healthcare facilities in which

MAiD occurs (e.g., hospitals, nursing homes, hospices, and others) should integrate formalized support services into existing operational structures. Some professionals—though not all—in my study reported having post-provision debriefing sessions with their teams. However, they shared that these were often focused on discussing logistical challenges or areas for practical improvement rather than on the potentially difficult emotions that may arise during the process. I recommend that in addition to debriefing on the logistical aspects of MAiD provisions, AHS should develop and embed emotional support for care professionals into the MAiD program. For example:

a. Practitioners involved in MAiD assessments and/or provisions should be allotted a minimum of 30 minutes within two days, plus one hour within one month of MAiD assessment or provision (as per recommendations from Center to Advance Palliative Care; Nicol & Tiedemann, 2018) as dedicated time to connect and debrief the experience with other MAiD-engaged professionals. To facilitate effective and worthwhile discussion during these sessions, AHS should develop and circulate guidance on topics that may be beneficial to discuss, including both logistical and emotional aspects of the experience. In cases where MAiD care is provided by a sole practitioner (i.e., without colleagues present) who is not well-connected to other professionals in the field, it may be beneficial to develop an optional and confidential registry of other assessors and providers who consent to be contacted for the purpose of debriefing MAiD-related care experiences.
b. Leaning into the concept of the 'secret society' described by participants

within my study, it may be beneficial to implement a confidential, virtual network or directory of MAiD-engaged practitioners across Alberta. Professionals who wish to connect with others in the field could opt-in to having their name and contact information listed within a confidential database managed by Alberta's centralized MAiD Care Coordination team (Alberta Health Services, 2016). This may facilitate a greater sense of connection among professionals who, as described in my findings, may be prone to feelings of isolation in their role while also providing opportunities to discuss challenging situations and learn from others across the province.

c. Finally, AHS should consider developing a distributed network of counselling professionals contracted to provide emotional and mental health support to MAiD-engaged practitioners through the centralized MAiD Care Coordination Service. This network could utilize social workers, counsellors, and therapists across the province to deliver virtual, trauma-informed support on an as-needed basis. This service should be positioned as a formal component of the MAiD program and, ideally, funded through existing federal allocations for MAiD-related programming and support.

While I acknowledge that implementing these recommendations may be time- and resource-intensive in the short-term, they may contribute to a healthier grieving experience, reductions in healthcare provider burnout and attrition, and encourage community cohesion rather than divisiveness. Further, the incorporation of mediation and counselling services within the MAiD program may expand job opportunities for counsellors and psychologists, leveraging a greater diversity of educational and experiential perspectives and expertise.

Recommendation for Further Research

To further explore the complexities of MAiD-related grief and the structural, social, political, and emotional factors that influence bereavement experiences, future research in the following areas is warranted:

1. **MAiD perspectives and support needs across political and religious affiliations:** My findings suggest that political and religious affiliation does not necessarily determine the degree to which one accepts or supports MAiD. However, the secrecy and isolation experienced by MAiD proponents in religious and conservative communities remain underexplored. Thus, mixed-methods investigations on how individuals with various religious and political ideologies perceive, engage with, and/or grieve MAiD losses. Findings may inform the development of targeted support interventions for those across the political, religious, and MAiD perception spectrums, enhancing the availability of support for all. Additionally, perspectives from those who fall towards to 'total objection' end of the MAiD perception spectrum may be useful in understanding key concerns that feed stigma (Sedgwick et al., 2024).
2. **Longitudinal investigations on the short- and long-term impacts of various policies and practices across international jurisdictions:** There is significant variation in the legislative frameworks for assisted dying programs across jurisdictions which likely influence the accessibility and experience for patients, loved ones, and care providers. Longitudinal studies on outcomes related to grief and well-being among individuals involved in and/or bereaved by MAiD

death may be useful in understanding the impact of various legislative items and informing the implementation of policies to best support a healthy grief experience alongside patient dignity.

3. **Developing and evaluating online or distance-delivered educational initiatives and bereavement supports for rural and remote communities:** Residents of rural and remote communities face disproportionate obstacles in access to healthcare, including end-of-life and emotional support services (Cai & Lalani, 2022; Organisation for Economic Co-operation and Development, 2020; Wilson et al., 2020). Leveraging technology, researchers should prioritize designing and evaluating online or other distance-delivered interventions focused on (a) enhancing awareness and understanding of MAiD to combat stigma, and (b) providing social support and a sense of connection for individuals affected by MAiD loss in rural and remote areas of the country.
4. **Exploring experiences of grief among persons affected by MAiD for MD-SUMC:** The topic of MAiD for MD-SUMC has been explored through various lenses within the existing literature. However, with upcoming changes to Canadian legislation that will allow for severe mental illness as the SUMC when requesting MAID, ongoing investigation of this issue will be crucial in implementing these changes smoothly within the Canadian healthcare system. Building on this thesis work, studies investigating the grief experiences associated with MAiD for MD-SUMC in jurisdictions where it is already permitted, such as the Netherlands and Belgium (Snijdewind et al., 2022), alongside comparative analyses of legislative and cultural similarities and differences may provide valuable insight to predict potential challenges in

Canadian implementation. Additionally, clinical research should explore how suicidality as a symptom of mental illness may be distinguished from a sustained, rational desire for MAiD in the context of unbearable suffering to aid in the assessment of individuals seeking MAiD for MD-SUMC.

The recommendations I have outlined above reflect the need for changes in policy, practice, and research to better support those accessing, providing, and/or grieving deaths by MAiD. By addressing factors complicating the experience such as accessibility barriers, stigma, and relational conflict within these recommendations, they may contribute to reductions in anxiety, distress, and conflict throughout end-of-life and bereavement experiences for individuals and communities at the highest risk. While the implementation of these recommendations will require time and resources, they constitute an important step in the process towards improving patient autonomy, reducing negative outcomes associated with complicated and chronic grief, and fostering more open conversations about end-of-life care.

Researcher Reflections

The completion of this thesis marks the end of a long and challenging journey, marked by many instances that contributed to my own experiences of what I now understand as complicated grief. At the outset of my graduate studies, I intended to complete a quantitative thesis project investigating the impact of childhood trauma on addictive behaviour and substance use patterns; a topic that I was passionate about and familiar with through previous research projects I had worked on. Throughout my studies, I, like many others, encountered several challenges that inevitably shaped my experience as a researcher. Balancing my academic responsibilities alongside significant life events –

including the COVID-19 pandemic, multiple losses within my family and social circle, and a period of caregiving following a family medical emergency – added layers of complexity to this process. The impact of these events and the challenges I faced in navigating the emotions and grief that accompanied them ultimately impacted the progression of my thesis work, necessitating a change in supervisory support and transitioning to a new research topic and methodology. While I was not aware of it at the time, I now recognize that this shift was marked by a different form of grief; this time, grief related to my perception of lost time, opportunity, and self-confidence in my ability as a researcher. Although the hurdles throughout my graduate studies often felt insurmountable, I believe that they have been instrumental in solidifying my understanding of myself as an adaptive, persistent, and capable researcher and human being.

Before beginning work on what has culminated as this thesis, my experience in research was exclusively quantitative, and I had very little theoretical understanding of qualitative methods beyond introductory courses at the graduate level. The process of learning how to select and employ appropriate qualitative methods while simultaneously exploring a topic area I had no previous experience with was daunting. I frequently found myself reverting to practices common across quantitative methods but that do not align with those of qualitative approaches. For example, I distinctly recall struggling with moving my analysis beyond the categorization of experiences into themes and accepting that my findings would continue to evolve through the writing phase. My previous experience with quantitative research often felt limiting throughout this process as I struggled to let go of the drive for objectivity and allow myself to subjectively interact with my data. Over time, through frequent reviews of resources for conducting reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2021, 2022) and substantial support from my supervisory committee members, Dr. Brassolotto, Dr. Sedgwick, and Mr. Solowoniuk, I became comfortable integrating practices and perspectives I had acquired across quantitative and qualitative disciplines. The ability to incorporate practices and knowledge from various methodologies has been incredibly useful not only in my thesis work but also in my work in program evaluation consulting, as I feel well-prepared to manage and assess various types of data to reach conclusions and identify areas for continued improvement.

Beyond the learnings I have accumulated about MAiD, grief, and the Alberta healthcare system throughout this project, my unique experience through this degree program has taught me four valuable lessons about the research process and my place within it. First, I have come to appreciate the importance of flexibility in research, both in adapting to unexpected methodological shifts, and in recognizing that the research process itself is, more often than not, non-linear. Secondly, I have learned that discomfort and uncertainty are integral to growth; stepping outside of my methodological and content-area comfort zone ultimately strengthened my ability to think critically and approach my research with greater reflexivity. Another key lesson has been in accepting the value of collaboration and mentorship throughout the research process. Having the support and guidance of my supervisory committee has been instrumental in helping me navigate and overcome the various hurdles I have encountered throughout this degree. Finally, and perhaps most importantly, I have developed a deeper understanding and appreciation for the role of the researcher in generating knowledge. This has contributed to rebuilding and enhancing my self-worth within the research process, allowing me to integrate my perspectives, experiences, and emotions into the knowledge I have generated through this work. I feel incredibly fortunate to have had the privilege of learning about the experience of MAiD-related grief from the first-hand perspectives of our study participants. In conjunction with my own experiences of grief throughout my graduate career, and the support of my committee members, friends, and family, this work has inspired a renewed confidence in my abilities to adapt and overcome future challenges, and the opportunity those challenges provide for learning.

Conclusion

Through this thesis, I have explored the complexities of MAiD-related grief within rural communities in Southern Alberta, shedding light on the systemic, procedural, and social factors that shape the experiences for patients, their loved ones, and healthcare professionals. My findings highlight that while MAiD may often facilitate a ‘good death,’ it does not always lead to ‘good grief’. Challenges related to the policies and processes of the MAiD program, such as the final consent requirement, and forced patient relocation due to institutional restrictions on MAiD provision, have profound emotional and logistical consequences, amplifying anxiety and stress during end-of-life for patients, family members, and care providers.

Further, the experience of grieving MAiD is often influenced by a cycle of secrecy motivated by stigma and a lack of appropriate and accessible grief supports for those bereaved by MAiD. Together, these factors make it difficult for individuals to openly discuss their experiences and navigate their grief with the support of others. The need for enhanced support services both before and after MAiD provisions is crucial to support patients, family members, and care providers to navigate their grief. This is particularly pressing within rural communities where access to healthcare and bereavement supports is often limited. These findings emphasize not only the need for policy and legislative changes to ease the MAiD process but highlight the importance of developing targeted bereavement support services, enhanced professional training, and public education initiatives to reduce stigma and promote understanding. My hope is that these findings will contribute to ongoing legislative and practical developments, and inspire continued discussions about death, dying, and the impact of grief as a universal experience that connects rather than divides us.

Ultimately, my findings suggest that while MAiD can help to mitigate many of the factors associated with a 'bad death', it does not inherently ensure a 'good death', nor does it guarantee a 'good grief' experience for those left behind. The availability of MAiD is only one part of a much broader health- and end-of-life care system that has historically, and in many cases continues to, disproportionately fail to meet the needs of structurally disadvantaged groups. Death and grief outcomes are shaped not only by access to MAiD, but also by bureaucratic policies, institutional restrictions, and pervasive stigma surrounding the practice of assisted dying. This research has highlighted that even when death occurs on one's own terms, grief may still be complicated by factors both within and beyond the MAiD program itself. In conclusion, MAiD represents *one* path towards a 'better death' experience but is not a panacea for the complex and deeply human experience of loss. Continued efforts are needed to ensure that conditions surrounding death and grief are as supportive, equitable, and humane as possible.

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