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# MAiD (Medical Assistance in Dying) and Meaning: An Exploration of the Experience and Ability to Make Meaning through Involvement in a MAiD-Specific Bereavement Group, the Synergistic potential of COVID-19 and MAiD, and the Impact of Healthcare Providers Relationships from the Perspective of Relational Ethics on the Legacy of MAiD-Involved Families into their Bereavement

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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## Abstract

MAiD became legally accessible to Canadians with a grievous and irremediable illness in June of 2016. As I write in 2023, MAiD has been expanded to include patients who do not have a foreseeable death, with anticipated inclusion of those with mental illness as a sole underlying medical condition (MI-SUMC) in 2024. As MAiD now accounts for over 3% of all deaths annually in Canada, there is a growing impetus to explore ways by which MAiD practice can be improved and care can be extended to the family members following the death of a patient.

A hospital in southwestern Ontario created a curriculum for a MAiD specific bereavement group, to support this unique community of loss and further the Canadian initiative for excellence in palliative care (2019) – which extends to the entire network of those involved in supporting a dying patient. It was imperative that this be evaluated to determine if the promises made to this inaugural bereavement group were upheld, and how MAiD practice can be improved to meet this important initiative. In this process, three groups of findings emerged pertaining to:

1. Assessing and determining the impact and efficacy of the MAiD bereavement group using a mixed methods approach
2. The synergistic impact of COVID-19 public health measures on those bereaved by MAiD during the pandemic
3. The relationship between healthcare providers and MAiD-involved families, and the impacts of this relationship into their bereavement through a relational ethics framework

Findings suggest that a bereavement group can support families and help generate communities with shared experiences. Additionally, through secondary analysis, findings suggest that COVID-19 adversely impacted this group through additional isolation, most particularly for those who were already experiencing social isolation and stigma due to the nature of their significant person's death which was further supported by their involvement in a bereavement group. Finally, the relationship between the health care provider and the MAiD family can have a positive or negative impact on their bereavement narrative, depending on their level of engagement, support of the family before and after the death, and facilitation of access for the patient to MAiD.

**Keywords:** MAiD, Bereavement, Family experience, COVID-19, Grief, Support, Ethics, Euthanasia

## Summary for Lay Audience

MAiD (Medical Assistance in Dying) has been accessible to Canadians since 2016. As the practice undergoes ongoing changes and as an increasing number of Canadians access MAiD, it is important that we understand the needs of family members' needs during and after this process. This research demonstrates that a bereavement group helps create community for those bereaved by MAiD who may experience challenges disclosing this type of death of a loved one. This research also indicates that COVID-19 regulations impacted group members' ability to create community, discuss their loss, and begin to create new identities after the death of a significant person. Finally, this research suggests that the way a healthcare provider approaches MAiD in discussions with patients and family members can have a lasting impact on family members' bereavement, including how they talk about the experience of losing their loved one. This research provides recommendations to health care providers in an effort to guide and support their practice around MAiD and MAiD-involved families.

# Co-Authorship Statement

## **Primary Authorship**

Allyson van Kessel (Oliphant) was the primary author of the manuscripts that constitute this integrated article-style thesis. This work is predominantly her own and reflects her interpretation of quantitative and thematic data.

## **Senior Authorship**

Senior authorship for this work is granted to Dr. Elysée Nouvet, who contributed significant time, guidance, intellectual material, and feedback in the formulation of these manuscripts.

## **Supporting Authorship and Committee Members**

Dr. Kenneth Kirkwood, Dr. Carrie Arnold, and Dr. Maxwell Smith provided comments, feedback, and expertise in their areas with respect to the content and considerations in each manuscript.

## **External Authorship**

Dr. Andrea Frolic and Ms. C. E. Dougherty provided feedback and their expertise with respect to the manuscripts in which they are listed as co-authors.

## **Intellectual Property**

All authors contributed intellectual property to all manuscripts in which their authorship is listed .

## **Research, Data Collection, and Analysis**

The data collection, analysis, and synthesis for the purposes of manuscript generation was conducted by the primary author. All authors provided feedback, intellectual material, and expertise in the generation of this work and supported the primary author in publication.

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Dedicated in loving memory of my Papa John and Grandma Barb.

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*“Grief is not a disorder, a disease or sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.”*

- Dr. Earl A. Grollman

# 1 Introduction

## 1.1 A Brief Canadian History of MAiD

Medical Assistance in Dying (MAiD) became a legally accessible option for Canadians in June of 2016 (Sommerville & Chan 2016). However, the beginning of Canadian engagement in the conversation about the permissibility of euthanasia began in the early 1990s. In September of 1993, Sue Rodriguez, who had Amyotrophic Lateral Sclerosis (ALS), appealed to the British Columbia (B.C.) Supreme Court to receive medical assistance in ending her life (Rodriguez v. British Columbia, 1993). Rodriguez was the first to bring forth a federal Supreme Court appeal for access to euthanasia in Canada (Beaudoin & Marshal, 2006). Narrowly, the Supreme Court decided that this practice was incongruent with current medical and social values, and Ms. Rodriguez was refused (Butler et al., 2013). Having lost her appeal, Rodriguez ultimately ended her life with the assistance of an unnamed physician in 1994 (Brenna, 2021).

Over the next two decades, criminal homicide cases, such as those of Dr. Maurice Genereux (Butler et al., 2013), Robert Latimer (Koch, 2007), and Dr. Nancy Morrison (Robb, 1998) emerged across Canada. These cases tested the law and generated debate around normative and practical ethics concerning the tolerability and practical elements of MAiD, while prompting explorations of the cultural permissibility of MAiD in this country. However, none of these cases were levied as a challenge for euthanasia permissibility until *Carter v. Canada*.

In the 2015 British Columbia Supreme Court decision in *Carter v. Canada*, it was found that the conditions of *Rodriguez v. Canada* did not apply in the same way to *Carter v. Canada* (Chan & Somerville, 2016). Chan and Somerville (2016, p. 146) state that Justice Lynn Smith “reasoned that she could legitimately revisit *Rodriguez* primarily based on social and legal developments since that judgment was handed down in 1993.” This global shift is significant, and the change in permissibility in other jurisdictions is key in the determination of permissibility in the *Carter* decision.

## 1.2 Carter v. Canada and Bill C-14

In 2015, the family of Kay Carter, joined by Gloria Taylor and assisted by the British Columbia (B.C.) Civil Liberties Association, advocated on behalf of Kay Carter to the B.C. Supreme Court for the right to access MAiD (Chan & Somerville, 2016). Kay Carter had spinal stenosis and was suffering without a foreseeable end. Carter had decided to access an assisted death through Dignitas in Switzerland and left Canada to travel for this service (Somerville & Chan 2016). Gloria Taylor had ALS and was in a state of irreversible decline and suffering.

Global changes in the permissibility of euthanasia would support and inform the Supreme Court decision in the case of *Carter v. Canada* (2015). Active euthanasia refers to either a prescription given or an action taken to cause a patient’s death (positive action), rather than a withdrawal or withholding of care which would constitute passive euthanasia (negative action). Both terms denote the role of the clinician or another person in the patient death (Gutierrez Castillo & Gutierrez Castillo, 2018). When the *Carter v. Canada* case landed in the B.C. Supreme Court, several jurisdictions worldwide had begun to allow active euthanasia (Roehr, 2021). Switzerland was host to permissible assisted death, with

precedents dating back to approximately 1937 (Roehr, 2021), pending this be a non-physician assisted suicide deemed to not be for selfish reasons (Hurst, 2003). In North America, the state of Oregon began allowing for the self-administration of prescribed oral medications to hasten death in 1997 (Emanuel, 2001). The Netherlands followed suit in 2000 (Sheldon, 2001), though they had been practicing euthanasia for more than a decade prior to codification in law (Emanuel, 2001). Luxembourg and Belgium joined countries with legalized assisted suicide in 2002 and 2009 respectively (Nys, 2017). Growing public debate combined with these changes in legal options in several jurisdictions made it possible for a trial judge to revisit the judgment in *Rodriguez*. The following excerpt from *Carter v. Canada* (2015) describes this decision:

The trial judge [Justice Lynn Smith] was entitled to revisit this Court's decision in *Rodriguez*. Trial courts may reconsider settled rulings of higher courts in two situations: (1) where a new legal issue is raised; and (2) where there is a change in the circumstances or evidence that fundamentally shifts the parameters of the debate. Here, both conditions were met. The argument before the trial judge involved a different legal conception of [s.7](#) than that prevailing when *Rodriguez* was decided. In particular, the law relating to the principles of overbreadth and gross disproportionality had materially advanced since *Rodriguez*. The matrix of legislative and social facts in this case also differed from the evidence before the Court in *Rodriguez*. (published online)

In 2015, the Supreme Court of Canada upheld the judgment of Justice Smith in the B.C. Supreme Court (Chan & Somerville, 2016), thus determining that Canadians should have a right to decide the circumstances of their death when faced with an illness causing enduring suffering and without foreseeable improvement. Subsequently, the Supreme Court gave the federal government a stay of a single year to produce legislature that would govern MAiD in Canada. In June 2016, Bill C-14 (Government of Canada, 2016) was given royal assent and amended the criminal code of Canada, providing the legal requirements and framework through which MAiD could be performed.



Bill C-14 stipulates several necessary criteria by which a person can be approved for access to MAiD in Canada. These are outlined in Section 241.1 and include:

- (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

(Bill C-14, 2016)

Section 241.2 further describes the necessary criteria for determining what illnesses constitute grievous and irremediable. It states that the applicant for MAiD must meet the following criteria:

- (a) they have a serious and incurable illness, disease, or disability;
- (b) they are in an advanced state of irreversible decline in capability;
- (c) that illness, disease, or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

(Bill C-14, 2016)

Bill C-14 further establishes that a patient must undergo two independent eligibility assessments by either a physician or nurse practitioner and be found eligible in both assessments in order to proceed with MAiD. For the patients with reasonably foreseeable natural deaths (RFND, or Track 1) as described above, and before Bill C-7, patients needed to be able to provide final informed consent prior to medication administration for MAiD (Bill C-14, 2016)

### 1.3 MAiD in Canada: Then, Now, and Beyond

Two cases would emerge following the passage of Bill C-14 that sought to alter the legislated requirements established in this bill. More specifically, they sought amendments to the requirements for the foreseeability of death and the requirement to be in an advanced state of irreversible decline to access MAiD (Okninski, 2021; Senate of Canada, 2021). These cases, referred to as *Lamb v. Canada* (BCCLA, 2016), and *Truchon v. Attorney General of Canada* (CanLII, 2019), sought to have these criteria re-evaluated and MAiD access opened to those whose conditions caused enduring suffering but did not necessarily carry a terminal diagnosis (Senate of Canada, 2021). Upon the decision of the Superior Court of Quebec and Justice Beaudoin in *Truchon*, it was found that previous language was in violation of Section 7 and Section 15 Charter Rights and was given a six-month stay to be amended in the form of Bill C-7 (Library of Parliament, 2020). This resulted in the 2-track system, wherein MAiD patients are now classified as having a Reasonably Foreseeable Death (RFND, Track 1) or Non-Reasonably Foreseeable Death (N-RFND, Track 2). In the passage of Bill C-7, we would also see an amendment that would come to be colloquially called “Audrey’s Amendment” (Dying with Dignity, 2022). The amendment allows for a waiver of final consent to RFND patients (Bill C-7, 2021) and is

named after Audrey Parker, a Nova Scotia woman with terminal cancer who advocated for a waiver of final consent so that a person need not access MAiD earlier than planned out of fear of losing capacity (Dying with Dignity, 2022). Bill C-7 (Government of Canada, 2021) came into effect in March 2021 (Pesut et al., 2021).

The conditions of Bill C-7 open the floor for the inclusion of unique populations, with access anticipated for patients with Mental Illness as a Sole Underlying Condition (MI-SUMC). An expert panel has provided advice regarding safeguards that have now been published (Health Canada, 2022), and it is anticipated that patients with MI-SUMC will have access to MAiD as of March of 2024 following an extension (CAMH, 2023). Another provision to Bill C-7 involves a review for including mature minors in the population that can access MAiD (Government of Canada, 2016). While guidance and a timeline have not yet been provided on the topic of mature minors, Bill C-7 does mandate a review of this material (Morrison, 2021).

As I write in 2023, a third annual report on the status of MAiD in Canada has been released by the government, detailing the nature of MAiD deaths across the country. By the most recent measure, MAiD now accounts for 3.3% of all Canadian deaths (Government of Canada, 2022). The majority of requests for MAiD are for those who have cancer as an underlying condition (65.6%; Government of Canada, 2022). Though cancer is the most common underlying condition, oncologists only make up 1.3% of MAiD assessors and providers, with the majority of assessors and providers identifying as family doctors (68.2%; Government of Canada, 2022). Patients who have a RFND make up a majority of cases with only 2.2% being N-RFND cases (Government of Canada, 2022).

Reporting on data for use of the waiver of final consent is expected in the 2022-2023 report (Government of Canada, 2022).

## 1.4 MAiD-Involved Families

While the Third Federal Annual Report on Medical Assistance in Dying published in 2022 does provide data on physicians and patients involved with MAiD, there is a paucity of data detailing the role and experience of family in assisted dying across the country. Some data in the Third Report alludes to the involvement and impact of family on the patient experience. For example, the report includes the following statistics:

1. Family undertaking advocacy roles (61.4% of clinicians assessed patient voluntariness concerning their request for MAiD determined through consultation with family members or friends [Government of Canada, 2022]);
2. Family undertaking care provider roles (35.7% of MAiD patients described suffering as they perceived themselves to be a burden on family, friends, or caregivers 35.7% [Government of Canada, 2022]) and;
3. Family constitutes important relationships influencing patient decisions (7.4% of patients who withdrew their request did so because their family did not approve of MAiD.

(Government of Canada, 2022)

These data highlight the importance of family in MAiD experiences, but do not provide any detail on how families navigate their roles within the MAiD process and following their loved one's death. A handful of Canadian studies have begun to explore the experience of families during the MAiD process from a quality assurance, pragmatic, and practical perspective (Hales et al. 2019; Oczkowski et al., 2021; Weibe et al 2018). A small number of additional studies have documented family accounts of MAiD through an experiential perspective (Beuthin et al. 2021; Frolic et al., 2021; Goldberg et al., 2019;

Hashemi et al., 2021). A topic that remains understudied is the experiences of bereavement of MAiD-involved family. This has consequences for the ability of Canadian healthcare jurisdictions and services to anticipate and develop evidence-based supports for these key MAiD stakeholders.

Within the limited research that does exist, there are indications that MAiD-involved families may have unique bereavement experiences and needs, compared to non-MAiD-involved families in Canada. One study, for example, notes an expressed desire by those who experienced the death of a significant person by MAiD for bereavement support specific to their type or loss (Frolic et al., 2021). Another study reports that healthcare providers note a potential need for bereavement supports tailored to this community but do not have the resources to do so (Troutin et al., 2020). A statistic presented at the Canadian Association of MAiD Assessors and Providers (CAMAP) meeting in 2018 suggested that “only 55 percent of families feel able to speak openly about MAiD as the manner of death” (Ditchfield, 2018, published online). Given the relative novelty of this type of death in Canada, it is important to build understanding of MAiD family bereavement. Doing so can ensure that any responses to requests or needs particular to this population are informed by available evidence and subject to quality improvement.

## 1.5 The Family Experience of Assisted Death in a Global Context

Globally, there have been some studies on the impacts of assisted death on families following the death of a significant person (Ganzini et al., 2009; Pronk et al., 2021; Swarte et al., 2003; Wagner et al., 2010). While the relevance of studies outside Canada cannot be assumed, it is worth briefly synthesizing key findings from this existing global research.

Doing so underlines a lack of conclusive findings on if and how assisted death impacts families' grief and bereavement, and thus the importance of further research on this subject.

In Switzerland, Wagner et al. (2010) explored the rates of post-traumatic stress and depression amongst loved ones of people who died by assisted suicide. They did find a slightly higher prevalence of depression amongst their study population (Wagner et al., 2010). Specifically, Wagner and colleagues (2010) found that:

Twenty-two percent of the respondents in our study were found to have clinically relevant impairments in physical health and 16% were diagnosed with depression. In the Zurich Older Age Study, the prevalence rate was 2.3% for major depressive disorder and 9.3% for subsyndromal depression. Therefore, participants in this assisted suicide study showed a higher prevalence rate of depression than did a comparable sample. (p. 546)

It is unclear and not expressly addressed in this research to what extent, if any, the method of assisted death in Switzerland – assisted suicide rather than euthanasia (Hurst, 2003) – may impact this outcome compared to other jurisdictions.

The Netherlands operates a system for euthanasia that more closely resembles Canada's. As euthanasia has been accessible for a longer period (since 2001), there have been amendments within their system that have opened access to MAiD for MI-SUMC and mature minors (Sheldon, 2001). While MAiD for MI-SUMC was never expressly restricted in law, an increase in psychiatric patients seeking MAiD led to significant revisions in the Physician Assisted Dying (PAD) guideline for psychiatric patients in 2018 (van Veen et al., 2022). This departs from Canadian Bill C-7, which established a sunset clause on the exclusion of MI-SUMC patients of initially 24 months (Health Canada, 2022). In an early

exploration of grief following a death by euthanasia prior to these amendments, Swarte et al. (2003) found that:

the bereaved families and friends of cancer patients who died by euthanasia had less grief symptoms and post-traumatic stress reactions than the families and friends of comparable cancer patients who died in a natural way. (p. 3)

At least one later study conducted in the Netherlands (Pronk et al., 2021) following the aforementioned amendments in the Netherlands reported a sense of “ambivalence” amidst family members as they describe the experience of their loss as it relates to euthanasia for those with MI-SUMC. This ambivalence was explained by the authors as connected to family members’ understanding of their significant persons suffering, while still experiencing challenges accepting the choice to die.

Several states in the United States of America have access to self-administered euthanasia through the use of a prescribed substance. The states that currently offer legal access to assisted death are Oregon, Washington, Montana, Vermont, and California (Emanuel et al., 2016) and most recently, New Jersey (The Office of the Chief State Medical Examiner, 2019). Self-administration of oral medication is the only current method of assisted death in the United States (Emanuel et al., 2016). With reference to the euthanasia statistics of 2021, the 2022 government of California End of Life Option Act (EOLA) report states that “87.0 percent informed their family of their decision to participate in EOLA.” Ganzini et al. (2009) in their study of American euthanasian shared similar findings to Swarte et al. (2003) in terms of the risks of more challenging post-death outcomes for the family. While the findings of these studies may not necessarily correlate

to the experience of Canadians, it is important to note that there is a growing interest in the family experience of MAiD.

It is unclear at this time if there exist additional studies of the bereavement experiences for euthanasia-involved family in the non-English-speaking literature. Yan et al. (2022) noted this as a shortcoming in their scoping review of MAiD bereavement globally. Yan et al. (2022, P. 13) state that “this review had exclusion criteria for articles that were not in English. Therefore, there are experiences that may be expressed in other languages and cultures regarding grief and bereavement around MAiD that are not captured.”

## 1.6 A non-pathologized approach to grief

[G]rief is not a disorder, a disease or sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve. (Grollman, 1993, p.6)

My approach in this thesis follows Grollman (1993) and others (Doka, 2017; Stroebe et al., 2017), in taking the position that grief is a normal, expected, necessary part of the human experience following the death of a significant person. Grief and bereavement scholar Wilkinson (2000) proposes six statements that might guide those aiming to uphold a non-pathologizing approach to grief. Informing my approach throughout my research, these are:

1. Grief is a normal response to loss.
2. Grief is positively healthy, since failing to grieve (when appropriate) is unhealthy.



3. Grief involves cognitive good.
4. Grief is a rational response to loss.
5. Grief ought not be treated or “medicalized.”
6. Grief has a distinct, sustaining cause.

(Wilkinson, 2000, p. 291-292)

Taking a non-pathologizing approach to grief in death and dying research is more important than ever at this historic juncture. This is because there is evidence that grief is being increasingly pathologized in North America through the removal of bereavement as an exclusion in the diagnosis for major depression in the DSM-5 (Pies, 2014). Failure to acknowledge that major depression may be normal following a loss within the DSM-5 falls in line with the concept of loosening the boundaries of where a normal behaviour ends and a mental disorder begins – referred to as concept creep (Haslam, 2015). It is unclear whose interests are served through such concept creep.

How one frames grief has real impacts that are both ethically and pragmatically important for healthcare providers and society to consider. Any push towards pathologizing grief, particularly when the observed grief appears to deviate from what a layperson may consider “normal”, has the potential to result in harm or greater burdens for the person who is bereaved. For example, as Wilkinson (2000) notes, the pathologizing of grief can lead to the marginalization of the requests of the griever rather than rising to meet their expressed needs. Treatment of grief as a disease may not consider if the response is in fact, fulfilling a purpose for the bereaved person (Lutz et al., 2022). This is not to say that grief cannot

become complex; however, it is identified that complex grief is relatively uncommon and affects a minority of people (Stroebe et al., 2017).

Additionally, pathologizing grief may subject the bereaved individual to increased responsibilities and expectations with respect to “fixing” themselves (Granek, 2014). Recent literature addresses the problematic elements of grief pathologization and the push towards “working through” a grief experience, with McLean et al. (2022) stating:

Endorsement of the need to “work through” grief could lead to pressure for some level of social conformity such that individuals attempt to align their grief experience with that of the in-group expectations (i.e., grief work). However, this response can have negative consequences as research has found that “forcing” or feeling pressure to grieve a certain way results in increased maladjustment. (p. 1415)

Such expectations perpetuate limiting and normative assumptions of how an individual might, can, or should respond in the face of loss. These assumptions can be ethnocentric or enact epistemic violence in their casting of responses that might be considered normal in some cultures as universally unhealthy and undesirable. Such narrow views are also empirically untenable. Several works in the study of death and bereavement (thanatology) have stressed and demonstrated with examples that the experience of grief is diverse, culturally bound, and expressed with a high degree of variability within cultural contexts (Granek, 2013; Grollman, 2014; Peña-Vargas et al., 2021).

## 1.7 Objective and Purpose of this Research

With an exponentially growing population of MAiD patients annually, and MAiD becoming increasingly accessible for more diverse patient populations, it is reasonable to expect that a growing number of families will be bereaved by a MAiD death in Canada. A

feature of MAiD that will remain certain is that a majority of those who have experienced the death of a significant person by MAiD will grieve.

This research provides an in-depth exploration of the experiences of MAiD-involved families during their bereavement within the context of the winter of 2020-2021. It explores how a bereavement support group may offer benefit to families who self-enroll following the death of a significant person in their lives by MAiD. The bereavement support group curriculum was developed through the expertise of the facilitators and bereavement group supervisor, who had also consulted with Bereaved Families of Ontario (BFO) around the development of their peer-facilitated bereavement group curriculum. The bereavement group team was situated within a hospital organization in Southwestern Ontario.

This research aims to inform and support the iterative and ever-developing practical elements of MAiD from a whole-person and relational perspective that is inclusive of the under-considered needs and experiences of the grieving family. The manuscripts contained in this thesis in three discrete chapters address several key considerations. The first manuscript explores formal structured support for bereavement and the impacts of offering resources such as this to MAiD-involved families. It also considers whether this model of group support that is free of charge, professionally facilitated, and offered virtually is meaningful to the participants (*Making Meaning from MAiD: A Mixed Methods Evaluation of the Experience of a Medical Assistance in Dying (MAiD) Bereavement Group*). The second manuscript considers the unique impacts on bereavement during the COVID-19 pandemic in conjunction with the experience of grief following a MAiD death, and how some of these impacts can be offset by offering communities of support virtually

(Love, Limitations, and Loss: The Unique Experience of MAiD Grief in the Time of COVID-19 from the Perspective of Directly Involved Family). The third and final manuscript addresses family experience and interactions with the healthcare system and healthcare providers. It explores how these experiences are then carried into the bereavement narrative and the practical implications from a relational ethics perspective. This manuscript was generated based on the expressed wishes of participants to discuss their experiences with healthcare providers and how these experiences impacted them (Don't Shy Away: A Relational Ethics Approach to Understanding the MAiD Legacy and Experience with Health Care Providers through Narrative Analysis of Bereaved Family).

Each of these chapters independently advances the understanding of the family experience through and following a death by MAiD. It describes opportunities to augment and inform policy and practice as it relates to how organizations and clinicians engage and support families following the death of a significant person by MAiD. When read together, these chapters offer a storied and detailed narrative of the bereavement experience, and the many influences, challenges, joys, and opportunities that punctuate the experience of grief following the death of a significant person by MAiD between 2020 and 2021. This body of research demonstrates how these particularities can be considered, resourced, and supported in the interests of better bereavement support for families. This serves an ethical function, as by creating infrastructures such as this bereavement group, we ensure that families have access to needed support and are not indirectly harmed by the predominant structure of siloed healthcare.

## 1.8 Reflections

My engagement in this research began through a request to support the evaluation of a bereavement group, hosted through a Southwestern Ontario Hospital system. I had been working with this system for years as a research assistant and intern, and this program of research was a natural continuation of the work I had been previously involved in.

My research interests were not originally in MAiD but in end-of-life care access in Northern Ontario. My grandparents lived and died there, and I have always wondered what palliative care access meant for them as they progressed through their respective experiences with advanced cancer. While this was my plan in my earliest research days, these things have a way of changing focus. I started my master's degree in 2015 and my internship in 2016 when MAiD first became accessible to Canadians. Under the supervision of a medical anthropologist at McMaster, I was offered the opportunity to conduct my master's research on the narratives of MAiD providers during this pivotal moment in history. This would prove to be a decision that would alter my professional and academic trajectory. I would continue to focus on and support MAiD research in the coming years through this same organization. As the research evolved, so did the questions around MAiD service provision and how a hospital system provides high-quality care continuously throughout the MAiD process from the first initiation of conversations about MAiD to support of those who accompany a patient who died by MAiD into their bereavement.

### 1.8.1 Methodological reflections, challenges, and considerations

This research expanded my methodological understanding and provided important experience and insights into how research can contribute to the quality improvement and sustainability of practice in healthcare. I began this journey with limited familiarity with the use of mixed methods for intervention assessments, and while I still maintain my primary interests and competency in qualitative research, the importance of quantitative data from the perspective of knowledge translation and demonstration of results for the purposes of quality improvement for an organization was of consideration in the structure of this research. These data can provide an accessible and readily demonstratable result of an intervention but must be coupled with qualitative findings that explain the nature of the data itself.

Quantitative results are valuable in health research as healthcare stakeholders may feel that:

accessing quantifiable information and data is relatively simple compared to qualitative research. This latter methodology requires time and considerable effort in the field, allocating resources to a relatively small sample of participants. Therefore, when looking at a broad and diverse field such as general human services, perhaps statistics can deliver more valid data in order to ascertain present and future trends. (McCusker & Günaydin, 2015, p. 539)

Citing Coyle (2000), McCusker and Günaydin (2015) further state that:

Another aspect of this research method relates to the ability for organizations to act on the findings and formulate valid policy based on generalized statistical evidence. Arguably, a valid objective from research is by investigating existing problems and future trends, such as in the field of general human services, thereby, influencing the establishment of 'informed' policy by human services organizations' decision-

makers. Supporting this argument, a study into both research methodologies suggests that “in the right circumstances, quantified models can be valuable tools for policy analysis” [Coyle, 2000, p.225]. (p. 541)

While this normative preference for quantitative data is present in medical practice, made evident by a preference for evidence-based medicine (EBM) predominantly constituting quantitative studies, the pandemic appears to have necessitated a shift towards EBM+, which is becoming more inclusive of qualitative works (Greenhalgh et al., 2022). This is not to say there are no valid critiques for qualitative research, with Stroebe et al. (2003) stating,

One of the main disadvantages, however, is that the descriptive orientation limits the extent to which they can provide causal explanations for grief phenomena, assess the efficacy of grief interventions, or identify correlates of complicated grief. Furthermore, reliability and validity of the measures used in qualitative assessment remain a major concern. (p. 238)

The inability of qualitative research to determine a causal relationship is rather contentious (Ruffa & Evangelista, 2021). This quote is also important to underlining the pragmatism of integrating quantitative approaches when one’s research aims to support quality improvement in healthcare. In many parts of the world, and certainly in Canada, there is a dominant and normative expectation that if research is to guide healthcare decision-making and the allocation of resources, that research should demonstrate quantifiable impacts.

The decision to use a mixed methods approach was intentional and with precedent. Margaret and Wolfgang Stroebe, as well as Henk Schut, are experts in the field of grief and bereavement and have made significant contributions to the body of literature on the

experience and research of grief. These include, but not limited to, the dual-process model of bereavement – a core theoretical framework in the second manuscript in this dissertation (Stroebe & Schut, 1999). Stroebe et al. (2003) emphasis a mixed methods approach in bereavement research, and state that:

Quantitative and qualitative research complement each other in the bereavement field. There are good reasons to argue for methodological pluralism. In our view, there is a lot to be said for quantitative evaluation to be preceded by qualitative, in-depth assessment. In this way, the advantages of each approach can be realized, and the disadvantages to some extent overcome. (p. 238)

Upon the determination that mixed methods may offer a more fulsome picture of the grief experience (Stroebe et al., 2003), I undertook a scoping study of grief psychometric tools for my comprehensive exam. As I am not a physician, nor were any members of the bereavement team, it was determined to be inappropriate to seek out a tool that offered any form of diagnosis as that would be well outside our professional scopes. Some core exclusionary criteria for psychometric tools included tools that offered a pathology or diagnosis for the grief experience, involved anticipatory grief, focused on suicide (as I took the position that suicide loss and MAiD loss do not share core similarities), and cannot be created to be completed by anyone but the participant themselves. Inclusion criteria included that tests include consideration of social, spiritual, or cultural aspects within bereavement; exist in English; and were accessible (i.e., could be completed by an assisting person if the participant was unable to read or write to complete the test themselves).



Overall, 22 tools were identified that met these criteria. In reviewing these 22 potentially useful tools, further attention was paid to the ways in which the tools were developed and approached grief. Specifically, tools were assessed for demographic inclusion, the demographic of participants that formed the study population in the development of the test, limitations of the test, and inclusion of cultural considerations. In this process, it was determined that significant features to consider when deciding on an appropriate psychometric test included context; environment (social and physical); and the unique social features, cultural relativity, and social constructs within the grieving process.

It was determined that most psychometric tests were lacking consideration for attachment style, socioeconomic status, access to support, and test-taking accessibility. Though imperfect, the Grief and Meaning Reconstruction Inventory (GMRI) appeared to be the least pathologizing, addressed individual experiences of loss, and considered important features such as continuing bonds and meaning-making following a significant loss.

There is no perfect or entirely accurate way to determine the breadth and depth of the grief experience. Such a method does not currently exist, and the experience of grief simply remains too individual, storied, and complex. Stroebe et al. (2003, p. 237) affirm this core challenge in their work, stating that “it is difficult either to conceptualize or to measure even the most fundamental aspects surrounding grief, for it is a complex emotional syndrome.” Rather, it is an ongoing navigation of tensions between qualitative and quantitative, and the pragmatic intention of the research and the population it serves that ought to be considered.

### 1.8.2 Pandemic challenges and limitations

While this research expanded and tested my methodological competencies, so did the pandemic. I learned that research could pivot in its original intended focus and become incorporative of novel and unique data, such as how the pandemic experience can impact the bereavement experience of those experiencing non-pandemic related death. This was certainly a unique time to be conducting research on this topic, completing a fellowship at a healthcare organization, and concurrently completing a doctorate predominantly online. One of the particular challenges posed by the pandemic from the perspective of acquiring rich qualitative data was the absence of in-person observation. My research of a bereavement group was conducted online. Comforting gestures such as touches or hugs, or informal gestures denoting connection such as observing people moving closer together were infeasible in this virtual setting. While the pandemic brought about unique qualitative data, it also limited certain types of qualitative data that may have further strengthened this research. In particular and as noted in previous publications of mine on this topic, non-participant observation limited direct engagement with participants naturalistically (Oliphant, 2022).

## 1.9 Reflexive Considerations and Disclosures

Reflexivity is an important tool in the consideration of bias, data interpretation, and the context in mixed methods and qualitative research and has been considered to be of value in the conduct of qualitative research for the past 30 years (Mauthner & Doucet, 2003). This practice contributes to the interpretation and significance of qualitative research, as it allows the reader insight into the researcher, and thus, the interpretation of their findings (Dodgson, 2019). In exploring the necessary features of reflexivity,

Mauthner & Doucet, (2003) consider four key areas: social location and emotional responses to respondents, academic and personal biographies, institutional and interpersonal contexts, and ontological and epistemological conceptions of subjects and subjectivities (Mauthner & Doucet, 2003). Concerning social location and emotional responses to respondents (Mauthner & Doucet, 2003), a core challenge of this research was the development of trust, as the content and nature of this research involved emotional vulnerability, disclosure, and revealing of deeply held personal truths from the participants.

Trust was attained through the explicit description of my role (a learner, a student, a non-clinician), and the goal of the research itself. Attempts were made to distribute power more evenly by affirming that location of knowledge on this topic resided with participants, and I maintained my role as a learner. This is not to say that their narrative did not have an emotional impact on me. As I was planning my own wedding at the time, I saw a glimpse of a potential future loss that was at times rather heartbreaking. As such, I wanted to ensure that the desires expressed by this group were conveyed to the best of my ability through this work.

In considering academic and personal biographies (Mauthner & Doucet, 2003), I had been connected with the hospital system conducting this bereavement group for 5 years before engaging in this research. I was familiar with the facilitator and supervisory team and had collaborated with them in the past on other MAiD research and they had acted in mentorship roles throughout my learning. I have a professional history as an ethics intern and fellow within this same hospital system, and as a doctoral candidate at a Canadian University. From a personal perspective, I identify as white, heterosexual, middle-class,

and in a stable partnership. The population at the heart of this research shares similar demographics with me.

When considering the institutional and interpersonal contexts (Mauthner & Doucet, 2003) in which this research took place, I had a pre-existing affiliation with the SWO hospital organization that conducted the bereavement program. I had been involved in various programs of MAiD research at this organization since MAiD became accessible to Canadians in 2016. My previous research pertains to the experiences of MAiD assessors and providers, which offered insight into the processes of MAiD and the experiential elements of MAiD practice from the provider's perspective.

Finally, from the perspective of ontological and epistemological conceptions of subjects and subjectivities (Mauthner & Doucet, 2003), I specifically sought to be a means by which the participants could tell their stories. While this approach may be construed as idealistic, the focus groups that involved the majority of “face-to-face” interaction with me occurred after the bereavement groups, where group cohesion had occurred and an opportunity for trust building and integration had already occurred. This lessened a potential imbalance of power between the researcher and the “researched.”

## 1.10 Research Scope and Limitations

This research is a study of a small, unique group of individuals in an eight-week, single-weekly session bereavement program that is the first of its kind in a hospital context to the awareness of the authors. The bereavement group has yet to be offered a second time as of Fall, 2022. The study participants were selected purposively and screened for

appropriateness by a facilitator with experience in grief and bereavement, and psychotherapeutic approaches in healthcare.

There is exceptionalism throughout this study that created a very narrow and specific scope. Primarily the single eight-week bereavement group offering, as at the time there was a one-time source of funding for the operating costs of the bereavement group provided by CAMAP. Next, the specific screening criteria established by an external professional (i.e., not the researcher) for whom would be considered appropriate to participate based on their current mental state, the experience of a significant person's death by MAiD, and the ability to participate effectively in a group of this structure. This created a specific participant population, based on the facilitator's professional determination of eligibility. Finally, limitations imposed by the COVID-19 pandemic reduced the opportunities for in-person observation or an informal conversation regarding the group in an offline setting. This restricted the observation of more naturalistic interpersonal engagement.

This research contributes to our currently limited understanding of the bereavement needs, infrastructure efficacy, and experience of MAiD death from the family perspective. It provides preliminary evidence for quality improvement and best-practice development for this unique population.

## 2 Making Meaning from MAiD: A Mixed Methods Evaluation of the Experience of a Medical Assistance in Dying (MAiD) Bereavement Group

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### Statements and Declarations

**Authorship:** AO conducted, analyzed and reported data and developed the structure of this manuscript. All authors provided intellectual guidance, suggestions and feedback on multiple drafts. The primary author contributed a minimum of 85% of materials and efforts.

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## 2.1 Introduction

Medical Assistance in Dying (MAiD) became available to seriously ill Canadians in 2016 when the Federal Government passed Bill C-14, which decriminalized assisted death. MAiD is a clinical practice that involves a physician or nurse practitioner providing a patient with a substance to end that patient's life. It is a controversial medical practice across the globe and has complex ethical, philosophical, and clinical implications (Wagner et al., 2012). As we write in 2023, MAiD accounts for a minimum of three percent of annual deaths in Canada (Government of Canada, 2022) and as a result, many Canadians have supported family members and loved ones through this new practice and means of dying.

Emerging literature in Canada indicates that MAiD-involved families report a desire for readily accessible grief and bereavement supports (Frolic et al., 2020; Hales et al., 2019). Participants in studies conducted to date have made statements such as, "It might help just knowing that there is, to talk to somebody who is, you know, outside of the family and you sort of lean on," and, "You need someone to talk to after MAiD, whether a support group or therapist out in the area we live" (Hales et al., 2019, p. 593).

To better understand the needs of MAiD-involved families, one hospital system in Southwestern Ontario (SWO) established a practice of placing bereavement phone calls to MAiD-involved families. These phone calls made evident a demand for the hospital to

offer MAiD-specific bereavement services and support systems for those coping with this specific type of loss. These requests persisted despite the existence of other MAiD bereavement services, including peer-support or volunteer operated groups (e.g., Virtual Hospice, Bridge C-14, Bereaved Families of Ontario [BFO]). To meet this need, the SWO Hospital created a virtual MAiD-specific bereavement support group that was professionally facilitated and free of cost. The group was offered through a clinical center for those who had experienced a loss by MAiD in Ontario, Canada.

To help ensure that this program was delivering on its promises of high-quality grief support, the first two authors conducted a study examining the outcomes of involvement in this group. More specifically, our study assessed 1) whether the bereavement group supported participants' ability to create meaning following loss, and 2) whether it fostered a sense of community among participants. Due to the morally contentious nature of MAiD, participants were likely to be subject to isolation and disenfranchisement following the death of their family member. In this study, we define meaning-making as the process through which a person reconstructs and re-affirms meaning in their life following a death (Neimeyer and Thompson, 2014). This process has recognized benefits for those experiencing grief (Lichtenthal & Breitbart, 2015).

The bereavement support program evaluation study was conducted online from November 2020 to February 2021. To the authors' awareness, no other studies within the context of Canadian MAiD research have yet been produced exploring the relationship between meaning-making and bereavement group involvement. As such, this research constitutes a novel contribution to the growing body of literature about MAiD in Canada.



## 2.2 Background

### 2.2.1 The MAiD grief & bereavement knowledge gap

MAiD deaths have been rising in Canada since the practice was legalized in 2016. In 2019, grief supports tailored to MAiD-involved families – such as Bridge C-14, BFO Groups, and MAiD House – began to emerge across the country. These supports were established based on the understanding that MAiD deaths are historically unique and socially contentious, and therefore may pose particular challenges for families. These support groups can aid family members on the front lines of this new form of dying in Canada by creating a space to share their grief experiences where they feel safe and supported. With participants' consent, such groups can also provide important opportunities to build evidence-based understandings of whether and how MAiD generates unique bereavement-associated challenges in the Canadian context.

Research that advances the recognition that humans experience grief in diverse ways is necessary to ensure equitable access to grief and bereavement support. Previous studies demonstrate that grieving following a significant loss has a range of health impacts (Stroebe & Stroebe, 1987; van der Houwen 2010). As stated by van der Houwen et al. (2010, p. 195), “[e]xtensive research has shown that bereavement is associated with excess risk of mortality and with decrements in both physical and mental health.” Families, friends, communities health equity advocates, as well as healthcare systems at large may be formally or informally committed to providing support to those suffering the death of a

loved one. However, to ensure adequate provision of support, it is crucial to understand how different losses may generate different experiences of grief.

The backdrop to – and indeed a key justification for – the first author’s research is that it is unclear if and how MAiD losses result in unique experiences of grief within the Canadian context. One *potential* difference is that MAiD deaths may present a higher risk of disenfranchised grief. Doka (1989) first used the term disenfranchised grief to denote circumstances under which an individual’s grief may be blocked from social validation or expression. He argues that people can experience disenfranchised grief when

the circumstances of the death create such shame and embarrassment that even those in recognised roles (such as spouse, child or parent) may be reluctant to avail themselves of social support or may feel a sense of social reproach over the circumstances of death. (Doka, 1999, p. 38)

Doka (1989, 2002) outlines five factors associated with disenfranchised grief:

1. The loss is not recognized (e.g., miscarriage).
2. The death is stigmatized (e.g., suicide or homicide).
3. The relationship is not recognized (e.g., extramarital affair).
4. The griever is not recognized (e.g., children, elderly, those with intellectual disabilities).
5. The manner in which a person grieves (e.g., too emotional or too stoic).

Previous research outside Canada suggests that people may experience disenfranchised grief related to a MAiD loss in contexts where the practice is not morally approved by all members of society. Wagner et al.’s (2012, p. 384) work in Switzerland found that MAiD-involved persons were more likely to develop complicated grief and

Post-Traumatic Stress Disorder (PTSD) when they experienced “perceived disapproval in the social environment.” In their assessment, “these findings suggest that coping with death by assisted suicide can be complicated by the feeling that society will disapprove of the decision” (Wagner et al., 2012, p. 384). While we do not seek to generalize Wagner et al.’s findings to Canada, we argue it is feasible that some Canadians may feel unable to share details of their MAiD experiences and associated grief. Indeed, in 2018, a prominent MAiD advocate speaking to the Canadian Association of MAiD Assessors and Providers (CAMAP) stated that “only 55 percent of families feel able to speak openly about MAiD as the manner of death” (Ditchfield, 2018, published online).

### 2.2.2 A Non-Pathologizing Approach

This research takes the position that grief and bereavement constitute natural experiences and should not be pathologized. Recent literature from and about the grief and bereavement support community conceptualizes grief as human, necessary, and diverse (Granek, 2013; Grollman, 2014; Peña-Vargas et al., 2021). According to Dr. Earl Grollman (1993, p. 6), “grief is not a disorder, a disease or sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.” This non-pathologizing approach recognizes that it is unhelpful to treat grief as a clinical problem and to expect all responses to loss to look and feel the same when griever and circumstances of loss are diverse (Conklin, 2001; Kleinman & Good 1985; Palgi & Abromovich 1984; Rosaldo, 1989).

Grief pathologizing is relatively commonplace in Western medical systems. For example, the DSM-5 does not understand depression following a significant loss as an

exclusionary criterion for depressive disorders. This was a relatively recent (2014) and controversial change. Writing on the topic of this change, Dr. Ronal Pies (2014) states:

The removal of the bereavement exclusion in the diagnosis of major depression was perhaps the most controversial change from *DSM-IV* to *DSM-5*. Critics have argued that the removal of the bereavement exclusion will “medicalize” ordinary grief and encourage the over-prescription of antidepressants. Supporters of the *DSM-5*’s decision argue that there is no clinical or scientific basis for “excluding” patients from a diagnosis of major depression simply because the condition occurs shortly after the death of a loved one (bereavement). (p. 19)

How one performs sadness, loneliness, and mourning following a death is both culturally specific and deeply individual. Expressions and experiences of grieving are neither linear nor uniform. Research demonstrates that they can vary based on innumerable factors, including: social and cultural norms and customs for the expression and recognition of grief, dominant social ideas and values that frame certain losses as more tragic than others, biographical experiences that may impact an individual’s ability or willingness to grieve publicly, and biographical experiences that impact what a loss means to surviving loved ones (Becker et al., 2007; Hussein & Oyebode, 2009; Klass, 2013, 2014; Marshall & Sutherland, 2008).

The inclusion of grief and grieving behaviours in the *DSM-5* demonstrates an increased pathologization of grief rather than a normalization of grieving behaviours. Haslam (2016) refers to this phenomenon as a “concept creep.” While it is natural for psychological concepts to expand over time, Haslam (2016) specifically identifies the concept creep as occurring when psychological phenomena that were once considered “normal” become categorized as “mental disorders.” He argues that “recent editions of *DSM* sometimes loosen the criteria for determining where normality ends and mental

disorder begins. This quantitative easing allows milder, less disabling psychological phenomena to qualify as disordered” (Haslam, 2015, p. 8). This is evident in the medicalization and pathologization of grief, as the International Classification of Disease – 11<sup>th</sup> version (ICD-11), followed suit from the DSM-5 and incorporated prolonged grief disorder into its lexicon (Lutz et al., 2022). Lutz et al. (2022, p. 611) identify that despite this preoccupation with grief as a disease, the ICD-11 “does not consider whether the grief reaction fulfills its purpose in that individual.” Granek (2014) argues that pathologizing grief is inherently problematic because it frames grief as a problem that requires intervention and places the burden of management on the shoulders of the bereaved. They identify that:

In western industrialized societies, grief is considered to be a psychological condition and process that has a starting point, a middle point, and an end point. The task of the griever is to do their “grief work” and get back to the job of living full, productive lives as soon as possible. If the griever is not able to “move on” fast enough or “well enough,” it is their responsibility to seek professional help which often takes the shape of a therapist or a prescription for medication. (Granek, 2014, p. 62)

This pathologization of grief then creates economic, political and social burdens for the bereaved in addition to their experience of grief. These additional burdens are harmful to bereaved people.

In the field of medical ethics, this form of harm is called iatrogenesis, or iatrogenic harm. Sampath (2022, p. 735) defines iatrogenesis as “harm experienced by patients resulting from medical care.” The limited social tolerance for negative emotions imposes significant burden on the bereaved to “fix themselves.” Granek (2014) argues that societal norms create a “duty” to be happy, which in turn builds a narrative that a person is

“unwell,” “broken,” or somehow wrong if they experience grief. Granek (2014, p. 62) states that “the ‘right’ to be happy, as Gorer (1967) wisely noted, has turned into an obligation that has no tolerance for the time and space required of mourning and the emotional intensity that grief entails.”

### 2.2.3 Program Structure and Curriculum

The bereavement program at the core of this study was co-designed by the SWO Hospital System and private practice professionals with expertise in grief and bereavement, and psychotherapy. The lead facilitator was experienced in online bereavement support and has been involved in the care of the bereaved for many years. Support groups were co-facilitated by credentialed personnel with decades of experience in grief support, grief and bereavement psycho-education, and social support for those experiencing a loss. Due to public health limitations on in-person meetings related to the COVID-19 pandemic, the SWO MAiD bereavement support group was offered virtually. The virtual format enabled participation of group members from regions outside of the hospital’s immediate area. However, participation was limited to Ontario residents because group facilitators are registered to practice in this province. The program was approved by and operated in accordance with the SWO Hospital System’s privacy office and was operated at no cost for participants. To our awareness, this is the only professionally facilitated MAiD-specific bereavement support group offered to date in the province. Throughout this paper, we refer to the bereavement group as “the program,” and to its collective participants as “the group.”

The professional facilitation aspect of this bereavement group sets it apart from existing programs, most of which are conducted by peer (mutual) facilitation. We consider

the professional facilitation to be critical to the program's efficacy. According to Neimeyer and Sands (2006),

a common challenge confronted in mutual support groups bereaved by the violent death of a loved one is the 'uncontained' telling of the stories of such loss, complete with traumatic sensory details of the circumstances of the death and scene of dying. Immersion in such accounts frequently can be overwhelming for both the narrator and other group members. (p. 306)

While we certainly do not equate a MAiD death with violent death, we wish to acknowledge that individuals may experience emotional and psychological challenges following *any* death of a significant person. Any experience of death has the potential to provoke a substantive stress response, which can cause a bereaved person to become overwhelmed when retelling and reliving their experience. A professional facilitator offers an evidence-informed and structured container for these retellings so that participants may process, express, and explore emotions with reduced risk of harming themselves or other group members.

The bereavement group was broken into eight virtual, synchronous sessions conducted through the SWO Hospital System secured Zoom platform. Sessions occurred weekly and were held in the evenings to accommodate participants' schedules. Facilitators designed initial sessions to build group cohesion and trust as their experience and expertise suggests it can be difficult for individuals to speak openly about their loss. All sessions involved an hour of psychoeducation focusing on a range of topics, including grief

normalization, how to create continuing bonds<sup>1</sup> with the deceased, natural emotional responses, and the non-linear nature of grieving. Sessions frequently concluded with a group discussion during which participants talked about their loss and how they were implementing the program's education in their lives. Programming for several weeks focused specifically on MAiD, covering topics such as the experience of the MAiD process, the day of the loss itself, the experience of stigma associated with MAiD, the overall impact of this particular kind of loss, and how to normalize specific grief concepts such as continuing bonds. Additionally, a professional from the MAiD team at the SWO Hospital System was available to respond to inquiries from the group before two of the regularly scheduled sessions began. Each session ended with a formal "check out" that included a discussion of the myth of closure. Facilitators encouraged the group to continue to connect with one another outside the program and we understand that some members continue to meet informally.

Social connection and the creation of a community of loss (i.e., a group that has experienced similar deaths of significant persons) have been identified as important indicators of positive bereavement outcomes (Logan et al., 2018). Logan et al. (2018) state that:

Although social support is consistently reported to be one of the most significant predictors of psychological outcomes following bereavement (Burke & Neimeyer,

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<sup>1</sup> Continuing bonds are a means by which an individual can continue and preserve connection with the deceased. Examples of continuing bonds include continued practice of ritual or activities living party once shared with the deceased, or interactions with the deceased that reinforce the idea that a death does not conclude a relationship (Klass et al., 1996).



2013), studies have found that bereaved persons often do not receive sufficient or timely informal support to moderate their grief experience. (p. 471)

With social support being such a meaningful indicator of positive bereavement outcomes, it is unclear how bereavement experiences and supports were adapted to and interacted with the realities of COVID-19 and its restrictions on in-person interactions.

## 2.3 Methodology

This study's overarching goals were to assess the program's ability to facilitate meaning-making and foster sense of community for participants. To assess the program, the authors developed a mixed methods approach that combined results from a psychometric tool called the Grief and Meaning Reconstruction Inventory (GMRI) with focus group data.

### 2.3.1 Study design rationale

#### 2.3.1.1 Rationale for Mixed Methods

This research constitutes a mixed methods study through the use of both the GMRI and qualitative focus group data. Following Caruth's (2013) recommendations for "primary empirical study level" mixed methods research (MMR), these quantitative and qualitative data were gathered independently from one another, but analyzed in tandem to strengthen the quality of findings (Caruth, 2013).

The decision to use the GMRI as an assessment tool for group outcomes was informed by several considerations. Experts within the field of grief and bereavement indicate that a mixed methods approach is the most comprehensive means to explore the

grief experience (Stroebe et al., 2003). Stroebe et al. (2003, p. 238) specifically identify that “quantitative investigation of grief reactions involves the use of self-report rating scales focusing specifically on personal reactions to bereavement.” Most importantly, Stroebe et al. (2003, p. 238) assert the value of grief measurement tools because they “enable a tracking of grief symptoms over time or following intervention.” This point was particularly salient to the present study because of the study’s focus on exploring of grief over time and following engagement in bereavement support.

A mixed methods approach also facilitates translating results into recommendations for hospital stakeholders. Previous research documents that health stakeholders expect quantitative results and are more likely to integrate recommendations based on quantitative research (McCusker & Günaydin, 2015). Readily accessible quantitative data will assist in the effective translation of the value of this bereavement group, as described by its participants. Quantitative data can also potentially describe a level of a causal relationship between the group structure and the participant-reported outcomes and can thereby support the sustainability of similar groups, some which may have limited resources. Though the inability to provide causal insights is contentious and debated in qualitative research (Ruffa & Evangelista, 2021), there is significant merit to their inclusion as a means of offering an explanation for the quantitative findings.

The authors acknowledge critiques of a quantitative approach (Knaapen, 2014; Little, 2003) – such as “truth” as a plastic concept and the shortcomings of “one-size-fits all” models (Little, 2003) – but could not dismiss the advantages of quantitative measures. Qualitative methods were therefore also employed as a means of offering an explanation for the quantitative findings and to develop a more fulsome description of the bereavement

experience (Stroebe et al., 2003). This approach is supported by Verhoef and Casabeer (1997, p. 65), who state that “by combining quantitative and qualitative methods, a degree of comprehensiveness may be achieved that neither approach, if used alone, can achieve.” In this study, we employ qualitative methods to contextualize primary quantitative data, which enables us to expand our understanding of the experience of a bereavement group.

This study approaches mixed-methods using a sequential explanatory design. Referencing Creswell (2003), Ivankova et al. (2006) state that:

The mixed-methods sequential explanatory design consists of two distinct phases: quantitative followed by qualitative (Creswell et al. 2003). In this design, a researcher first collects and analyzes the quantitative (numeric) data. The qualitative (text) data are collected and analyzed second in the sequence and help explain, or elaborate on, the quantitative results obtained in the first phase. (p. 5)

Ivankova et al. (2006) also describe data prioritization, explaining that in a typical sequential explanatory study design, the quantitative data constitutes the prioritized dataset.

They state that:

In the sequential explanatory design, priority, typically, is given to the quantitative approach because the quantitative data collection comes first in the sequence and often represents the major aspect of the mixed-methods data collection process. The smaller qualitative component follows in the second phase of the research. (Ivankova et al., 2006, p. 9)

The present study also prioritized quantitative findings because of our study goals. The study’s purpose was to determine if and how participation in the bereavement group changed participants’ capacity for meaning-making after the death of a significant person through MAiD. Thus, this research prioritized the analysis and description of the GMRI findings and employed focus group data to augment GMRI data.

### 2.3.1.2 Evaluation Research Study (ERS)

An additional goal of this research was to determine whether the bereavement program met the needs of participants, and the study is therefore also an Evaluation Research Study (ERS). An ERS is a deductive summative evaluation of an intervention, wherein the end results dictate the success of the project (Scriven, 1991). It is a form of applied social research that is “designed to find out whether a program ... is effective” (Newman & Robson, 2012, p. 11). While an ERS does not differ significantly from other social research in terms of technique, a key “difference lies in the fact that decision-makers, who may not be researchers themselves, narrowly define the scope and purpose of the research with the objective of using results in a practical situation” (Newman & Robson, 2012, p. 11). This holds true of this research, as the intent from the outset was to use the data for the purposes of continuous improvement, quality assurance, and determination of delivering upon the espoused goals of the grief and bereavement group in its future iterations. For this study, we employ the final GMRI scores as the end results that offer insight to the success of the program.

### 2.3.1.3 Pragmatic Inquiry

Lincoln and Guba (1986, p. 7) state that “the eternal questions are best answered ... by putting queries directly to nature and letting nature answer.” This study aligns itself with pragmatic inquiry because it considers the natural, lived experiences of individuals to be a source of truth and validity in research.

Pragmatic Inquiry is a method of research inquiry that dates to the early 20<sup>th</sup> century (Morgan, 2007). Key theorists such as Dewey, James, Pierce, and Mead approached this form of inquiry as:

antithetical to heartless expediency and mindless abstractionism. To appreciate pragmatism is to appreciate man's mercurial essence, the transformative power of human nature itself. The root metaphor of pragmatism is not "systematized knowledge," an airtight epistemology, conceptually or empirically based, but living inquiry. (Rochberg-Halton, 1986, p. 4)

In describing Dewey's approach, Morgan (2007, p. 69) states that "it is not the abstract pursuit of knowledge through 'inquiry' that is central to a pragmatic approach, but rather the attempt to gain knowledge in the pursuit of desired ends." Morgan (2007) further states that,

A pragmatic approach reminds us that our values and our politics are always a part of who we are and how we act. In the end, these aspects of our worldviews are at least as important as our beliefs about metaphysical issues, and a pragmatic approach would redirect our attention to investigating the factors that have the most impact on what we choose to study and how we choose to do so. (p. 70)

Pragmatism as a paradigm of inquiry that is well-suited for studies of individual understanding of experience because it validates the "truth" of individual worldviews. The approach is useful for research that explores an individual's values and meaning systems, and how people carry these through their experiences, including bereavement. Finally, pragmatism is useful for anthropologists and ethicists (of which the primary author is both). These fields require heightened attention to reflexivity, which challenges researchers to understand their observations partially as reflections of their own worldviews and to integrate this understanding with their interpretation of data.

There are three key features of the pragmatic approach that are closely linked to mixed methods research: abduction, intersubjectivity, and transferability (Morgan 2007). Abduction is a form of "reasoning that moves back and forth between induction and deduction—first converting observations into theories and then assessing those theories

through action (Morgan, 2007, p. 71). This form of thinking is similar to how researchers often collect and analyze data in mixed methods studies. The authors employed an abductive to the present study by conducting primary analysis of GMRI data, and then integrating qualitative focus group data to further parse those findings. Intersubjectivity comprises the recognition “that there is a single ‘real world’ and that all individuals have their own unique interpretations of that world” (Morgan, 2007, p. 72). This is captured in the present research because it treats bereavement group members’ narratives and perspectives as truth within their system of values, experiences, and beliefs. Finally, transferability is an approach to presenting research that enables the reader to see its application in different contexts (Lincoln & Guba, 1985). Morgan (2007) furthers this concept by stating that,

we cannot simply assume that our methods and our research approach make our results either context-bound or generalizable; instead, we need to investigate the factors that affect whether the knowledge we gain can be transferred to other settings. The classic example is assessing whether the results from one particular program evaluation have implications for the use of similar programs in other contexts. (p. 72)

In this context, a pragmatic approach is distinctly well-suited to ERS research. This research evaluates the bereavement program and explores of the use and practicality of the GMRI. Researchers assessing bereavement groups (both in and outside MAiD contexts) and/or working to determine a rigorous GMRI-based methodology that can further the tool’s applications can consider the present study’s strengths and limitations.

## 2.3.2 Data collection tools and methods

### 2.3.2.1 Selection and administration of the Grief and Meaning Reconstruction Inventory (GMRI)

The quantitative psychometric tool that was used in this research is the Grief and Meaning Reconstruction Inventory (GMRI). At the outset of this project, the bereavement group team sought to establish a mixed methods approach based on recommendations in the literature. The primary author completed a literature review to evaluate tools employed to measure the experience of bereavement. The team selected the GMRI as its quantitative data collection tool because it aligned best with the team's research goals and conceptualizations of grief. It comprises 29 questions that address five key factors: continuing bonds, personal growth, sense of peace, emptiness, meaninglessness, and valuing life (Appendix 1, GMRI). These factors are social and they centre an individual's experience rather than assign a diagnosis. The GMRI does not provide a psychiatric diagnosis of any sort. Given the previously noted problematic tendency to pathologize grief (Granek, 2014; Lutz et al., 2022; Pies, 2014), it was imperative that this study did not subject participants to any diagnostic processes. The GMRI was selected as a promising data collection tool because it supports a non-pathologizing approach to the documentation and analysis of bereavement experiences. Strengths and limitations of the GMRI and of the focus groups are addressed in the discussion.

Demographics of participants in this study were similar to those of the GMRI validation population. Participants in both groups predominantly experienced a loss resulting from anticipated death, and most were white and women (Gillies et al., 2014). However, the GMRI validation population has a median age of 27 (Gillies et al., 2014),

indicating participants were notably younger than those in our study. Our study administered the GMRI twice; once before the program began to determine a baseline for participants, and once after its conclusion to determine in what areas the program may have affected participants' capacity for meaning-making.

To account for experiences particular to MAiD, we added three additional questions to our version of the GMRI. These questions assessed whether participants were able to connect with others and disclose the nature of their loss openly despite the particularities of a MAiD loss. The overarching aims of these questions were to determine the presence or absence of disenfranchisement, and evaluate whether participant attendance to the program affected the experience of disenfranchisement. These three questions are discussed further in the Disenfranchisement section of Findings.

### 2.3.2.2 Qualitative data

Following the conclusion of the bereavement group, two focus groups were held in mid-February 2021 in order to collect qualitative data. Each focus group comprised seven participants, with all 14 bereavement group members participating in one session. They were conducted on Zoom, and consisted of a semi-structured group interview to ascertain the impact and efficacy of the bereavement group, as well as potential areas for program improvement. Focus groups were recorded and manually transcribed verbatim. These data were then analyzed inductively and iteratively, and used to augment and support the findings of the GMRI.



### 2.3.3 Participant Sample and Recruitment

Program participants were recruited by hospital staff conducting bereavement support calls to MAiD patient family members. These phone calls were a pre-existing standard element of practice in the hospital's assisted dying program. During calls, staff provided information about how to connect with a bereavement group facilitator for screening. A facilitator also distributed a recruitment poster through their professional and social networks within Ontario, which resulted in the referral of at least one potential participant. This study employed purposive and convenience sampling in participant recruitment.

The bereavement group was only open to family members who had offered support to the patient throughout their illness and during the MAiD process, and who had been present for the MAiD death. In this study, the term "family member" is used interchangeably with friend, partner, spouse, child, and more. At the determination of the program facilitator, participation was limited to one member per family. This format offered the greatest amount of support to as many people as possible. There was no specific requirement pertaining to passed time since the death because readiness to engage in this type of support is best left to the discretion of the participant. This method is supported by Aoun et al. (2012), who state that:

it is clear that offering professional support to all bereaved people is unlikely to be effective, let alone affordable, and that it can be counter-productive for those not in the high-need group. For instance, unnecessary intervention may disrupt the natural course of grieving and the presence of interventions could trigger a loss of social support if friends and family withdraw from the bereaved as a result of their receipt of professional services. (p. 15)

To maintain professional standards of practice, one program facilitator screened participants to determine whether they were appropriate for the program. Screening was also conducted to ensure that any persons expressing suicidal ideation, presenting significant emotional dysregulation, or at imminent risk of self-harm were not accepted in this program. Facilitators would instead refer such individuals to appropriate care. Screening also assessed whether potential participants had experiences that could add complexity to their bereavement experience and that may be better addressed in a one-on-one therapeutic context rather than a group setting.

### 2.3.4 Data Analysis

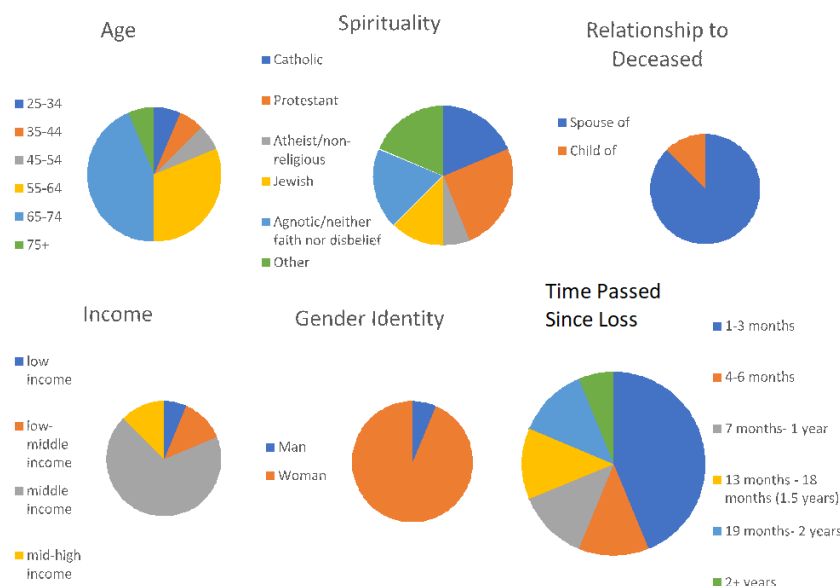
GMRI data was collected and aggregated to represent the sentiments of the group as a whole rather than as individuals. The efficacy of this program was determined based on changes in mean scores across the GMRI's five categories. In four categories (Continuing Bonds, Personal Growth, Sense of Peace, Valuing Life), an overall increase in mean score would indicate program success. In the fifth category (Emptiness and Meaninglessness) program efficacy would be associated with a decrease in mean score. Finally, an increase in the overall score of the additional questions about disenfranchisement may indicate improvement for group members in this area. Within the literature, there is a paucity of data about the meaning in the changes GMRI scores. Our data is therefore observational and posits possible (rather than definitive) explanations for the increases and decreases in overall scores. This research does not seek to make firm assertions about the numerical value of the differences in pre- and post-program GMRI scores.

Focus group data were analyzed using NVIVO software and coded using the five factors of the GMRI. The purpose of this approach was to augment the GMRI data and provide explanatory data for the increases and decreases in the pre- and post-program GMRI scores. This research implemented a deductive thematic approach to analysis. This research was deductive because we used GMRI factors to form the basis for the codes that categorized the qualitative focus group data.

### 2.3.5 Ethics Approval

This study was approved by two research ethics boards (Appendix 2). The Western Research Ethics Board (WREB) approved this study on October 16, 2020 and the Hamilton Integrated Research Ethics Board (HiREB) approved this study on November 10, 2020.

## 2.4 Results



**Figure 1**

*Participant Demographics*

Overall, 14 individuals enrolled in the bereavement group and maintained their enrollment throughout the eight week course of the program. Two individuals who had been approved

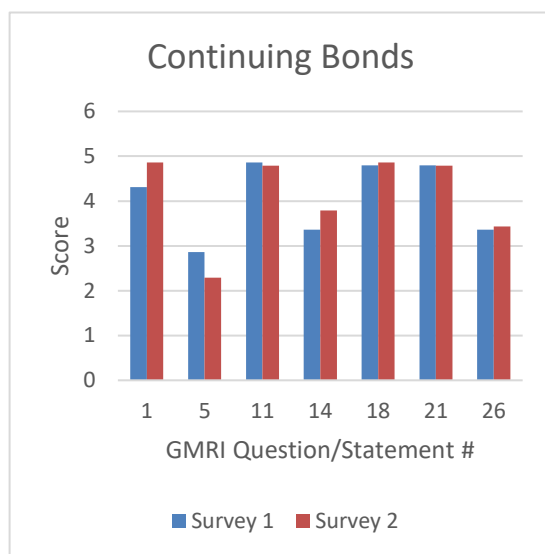
through the screening process left prior to the first session, but remained in the participant nomenclature (i.e., Participants are named as participant 1-16, even though only 14 members participated). All members attended every session and there was no attrition amongst members who attended the first session. All 14 members completed the first GMRI before the first session, and the second GMRI after the final bereavement group session but before participating in a focus group. All group members attended a focus group; seven members attended the first, and seven attended the second. The first focus group was held one week after the completion of the program and the second was held two weeks after the completion of the program.

All participants identified that they were present at their family member's bedside at the time that MAiD was administered, and that they witnessed their family member die. While a majority of participants were the spouse of the deceased, two participants identified themselves as the child of the deceased. All participants self-identified as white, and many identified as middle income and over the age of 65. Thirteen participants identified themselves as women, and one participant identified themselves as a man. This sample had relatively equal representation from Catholics, Protestants, atheists, and agnostic/neither belief nor disbelief. A minority identified themselves as Jewish or "other," elaborating that this meant spiritual but non-religious. Most participants indicated that they were between one and three months bereaved at the time of the first GMRI

The findings described below draw from both GMRI and focus group data, with focus group data mapped onto GMRI categories using codes described above. Focus group quotes support the quantitative findings of the GMRI data and provide augmentative explanation for data from the pre- and post-program tests. We interweave GMRI and the

focus group data to offer a view of the “lived experience” of meaning-making throughout a MAiD bereavement program.

### 2.4.1 Continuing Bonds



**Figure 2**

#### *Continuing Bonds Aggregated Data*

Continuing Bonds refers to how an individual continues to connect and create legacy in relation to their loved one. Exploration of this factor in the GMRI appears in Statements 1, 5, 11, 14, 18, 21, and 26 in the GMRI (Appendix 1). Individual items aimed at measuring this factor include Statement 1 (The time I spent with my loved one was a blessing) and Statement 21 (I cherish the memories of my loved one). Across all relevant items measuring for Continuing Bonds, the first and second GMRI both yielded an overall mean score of 4.27. This suggests that this factor remained consistent across the course of the program. Scores for certain statements (e.g., Statements 1 and 14, Memories of my loved one bring me a sense of peace) increased marginally, while others decreased (eg. Statement 5, I will see my loved one again).

During the program, a facilitator told participants that “grief lasts as long as love lasts.” Several group members indicated that this statement resonated with them. One participant reflected upon this quote, and stated that:

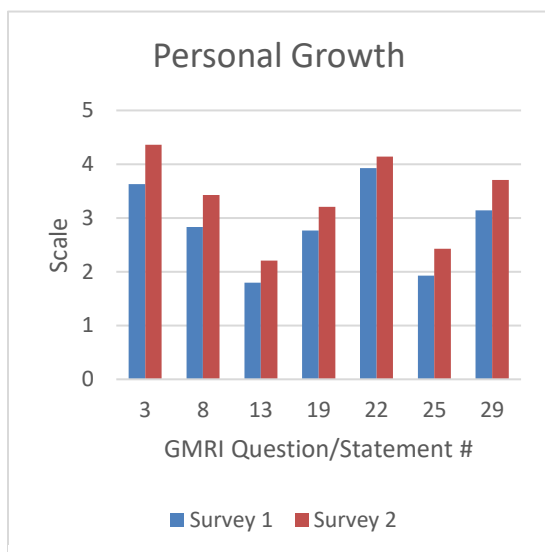
I thought that was a really great thing to learn, because I thought you were just supposed to kinda forget. Like, huh? \*laughs\* so it was nice to hear that and then

the continuous bonds concept, that's nice that people do that, and that's normal, very normal! And to help you process and keep those bonds going, it's quite normal to do things to remember or honour or cherish a person. And I didn't know what to do with grief, right? Because I thought you were just kinda supposed to forget... and keep going on with your life. They only give you three days off of work for bereavement. You're just supposed to forget. So it's nice to hear you aren't supposed to forget, you do move on, but you can take that person with you by doing the continuous bonds and it never goes away because the love I had for [parents] doesn't do go? Away. It didn't just disappear, right? – *Participant 3*

Participants shared similar sentiments throughout the course of the program. This suggests that learning that grief does not simply end and a loved one does not simply become forgotten was significant because it helped them understand their grief and their attachment to their loved one. These statements also help contextualize the decrease in the score associated with Statement 5. While participants may no longer feel attached to the idea of having their family member return to them, they may be becoming more accustomed to the concept of connecting with these memories across the course of their life. In other words, they may be normalizing maintaining an ongoing connection to their loved-one rather than awaiting a reconnection in death.

#### 2.4.2 Personal Growth

In the context of the GMRI, Personal Growth refers to an individual's capacity to be introspective and self-reflective, and to grow psycho-emotionally independently of their



**Figure 4**

*Personal Growth Aggregated Data*

**Figure 5**

*Sense of Peace Aggregated Data*

*Personal Growth Aggregated Data*

relationship. Personal Growth demonstrated higher scores in every area in the post-program GMRI, with scores increasing across program participants. The overall mean score for Personal Growth in the pre-program GMRI was 2.94. The second GMRI yielded a mean score of 3.35. Statements 3, 8, 13, 19, 22, 25 and 29 were linked to Personal Growth.

Scores for Statements 3 (Since this loss, I am more self-reflective), 8 (Since this loss, I am a stronger person) and 29 (Since this loss, I have pursued new avenues of learning) demonstrated the highest increase between the pre- and post-program GMRI. Reflecting on the impact of learning about grief through the

psycho-education components of the program, one participant and stated that:

It was very informative and very validating, I didn't know... I mean, obviously I didn't know exactly what to expect going in to it? But the first, I think three, sessions were basically little lessons on grief... and like, I don't know. A lot of things we went over were answers to questions I didn't even really know I had. Figuring out like, oh, what I've been experiencing is a grief burst, or like, you know... or, like, I don't know. Like, there's a name for the kind of grief I am feeling! Like, it was just really... it brings... and when you're that emotional, when you're that lost and like, that... any kind of validation or information is ... it's just so necessary. It was just really helpful. Very validating, very informative. Which kind of soothed the grief. – *Participant 12*

In both focus groups, several participants reflected on the impacts of learning and made statements similar to Participant 12. Participants reported that attributing language to their experience helped them understand and grow from the experience. It also encouraged them to pursue new knowledge related to grief and grief-normalization. Several participants expressed that they derived comfort from this learning and that they were eager to continue learning by participating in other grief support forums and reading literature. One participant identified that they had grown in their ability to share their experiences with other meaningful people in their life, which reflects Statement 22 (Since this loss I value friendship and social support more). They also indicated following the program; they were able to engage with fond memories of their significant person:

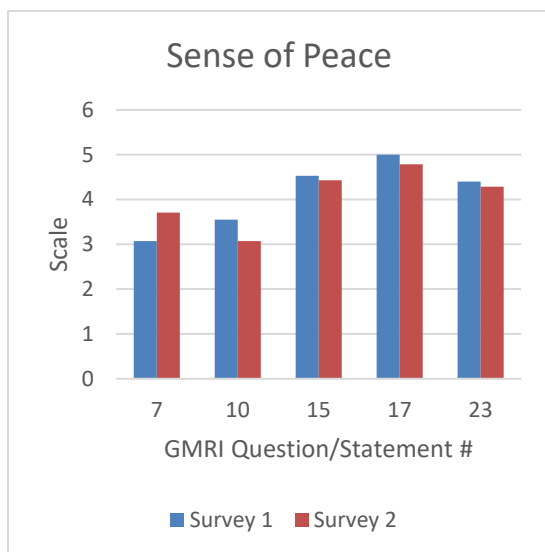
I am also able to share feelings, not so much the grieving feelings, but being able to remember the good times we had together as a couple and the stages we went together through life, and I think I share those with people. Not so much like, oh, you know, worries for me, but to reflect on the good times we had together. Like, we were really blessed, and I think you know, this group here helps you... you don't realize gratitude, and to be thankful for the things and the people you have and to say thank you in the proper way and for the things that... mean something to you –

*Participant 7*

### 2.4.3 Sense of Peace

Sense of Peace was a factor that declined across participants between the first and second GMRI. The overall mean value for this factor in the first GMRI was at 4.11, which suggests that some participants had found a way to make peace with their loss. However, the mean score in the second GMRI was 4.05. This is a decrease of 0.05, or  $\sigma$  0.65, and is





**Figure 7**

*Sense of Peace Aggregated Data*

**Figure 8**

*Emptiness and Meaninglessness*

*Aggregated Data*

*Sense of Peace Aggregated Data*

less than one standard deviation below the mean for the total dataset. Though this is a very modest decline, it could indicate that participants were experiencing marginally less peace in relation to their loss following the bereavement group. Sense of Peace included Statements 7, 10, 15, 17 and 23, which relate to perceptions of readiness for the loss itself as well as the family member's readiness to die. Though the overall score declined, the score for Statement 7 (I have been able to make sense of this loss) increased in the post-program GMRI.

A statement from Participant 1 provides potential insight as to why participants may have had a reduction in

overall sense of peace throughout the course of this group:

“I learned a lot. It was... it really helped me to be more mindful, understanding that it's... it's gonna be forever. And it's not something that is fixed. Grief is love and it's not going anywhere. And not to... punish myself when I have a STUG [sudden temporary uptick in grief]. And how... people do it differently because there are two of us in this house and we are both doing it differently. And having that knowledge that it's different makes me a little more, I'm hoping, understanding \*chuckles\*. So, it was huge... it was huge.” *-Participant 1*

Throughout the program, many participants developed an awareness of how unfamiliar they had been with grief and with how grief would feel. Participants defined themselves in retrospect as being “unprepared” for the experience and gravity of grief. Many also expressed a sense of being lost or numb initially following the loss because they did not have a sense of direction or capacity to revisit the experience of the death. Such feelings could contribute to the reduction in Sense of Peace, particularly in areas like Statement 10 (I was prepared for my loved one to die). Over time, participants may realize that perhaps they were not as prepared as they had initially thought and they desire more with their family member. One participant illustrates this concept in the following statement:

I was not prepared. And I spent a year caregiving, and I thought about a lot of deep stuff and talked about a lot of deep stuff and had conversations that we’ve all had that nobody wants to have, but I just felt. Gob smacked. – *Participant 1*

#### 2.4.4 Emptiness and Meaninglessness

Emptiness and  
Meaningfulness

##### Figure 10

*Emptiness and Meaninglessness*

*Aggregated Data*

##### Figure 11

*Valuing Life Aggregated Data*

*Emptiness and Meaninglessness*

*Aggregated Data*

Emptiness and Meaninglessness is a reverse-scored factor, meaning that a decrease in scores would indicate success in the program’s aims to supporting meaning-making and reduce the sense of emptiness following loss. This factor included Statements 2, 6, 9, 16, 20 and 27. The mean score for Emptiness and Meaninglessness in the first GMRI was 2.63. In the second, the mean score was 2.28. Scores declined in all

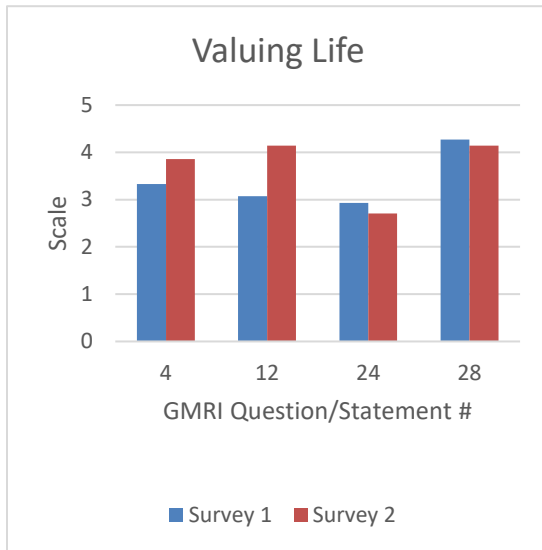
areas except Statement 2 (I do not see any good that has come from this loss). For Statement 2, respondents answered with higher agreement in the second GMRI.

Throughout this program, some participants experienced and processed information about their family. Some participants realised that there had been inconsistencies in the narrative of their spouse and were coming to terms with their partner's fallibility in addition to the experience of their death. Others simply experienced a necessary safe space to explore and address their grief. In grief, participants were not romanticizing the deceased but rather addressing their humanity and the challenges in the relationship. When participants were asked about seeking support prior to this program, a statement from one participant reflected the theme of emptiness:

Um... I couldn't look for anything at the time, I was just so sort of... completely floored. Completely. It wasn't... the only concern that we had before MAiD and before spouse died was to stop the pain. And MAiD was absolutely fantastic... I was just so, so glad that, you know, it was there and it stopped the pain. Because otherwise they were in agony. And I never gave a thought to living without them, but for some reason that just didn't cross my mind! It wasn't. And so, after they died, I was just completely floored. – *Participant 11*

It is possible that before the program, participants were more engaged in the daily management of overwhelming grief. Throughout the program, participants' awareness of their own emotions increased, as did their understanding that grief is a normal ongoing experience and achieving traditional "closure" may be unrealistic. It is reasonable that participants would experience a reduced sense that "good" has come from the death of their loved-one as their awareness of the points above increased.

### 2.4.5 Valuing Life



**Figure 13**

*Valuing Life Aggregated Data*

**Figure 14**

*Disenfranchisement and Isolation*

*Aggregated Data*

*Valuing Life Aggregated Data*

In this context, Valuing Life, refers to a person’s ability to live in the present, and to value their existence and the existence of those they hold dear. The overall mean score for Valuing Life in the first GMRI was 3.65, and was 3.71 in the second GMRI. This represents a quantitative increase in this area. This factor was represented in Statements 4, 12, 24 and 28. Statements 4 (I value family more) and 12 (I value and appreciate life more) saw the largest numerical increases in overall scores. Statements 24 (Whenever I can, I seize the day to the fullest) and 28 (I have come to understand that life is short and gives us no guarantees) declined overall.

This study was conducted during the second wave of COVID-19 in Ontario, and it is likely that this contributed to the decline in score for Statement 24. During this time, there were few opportunities to “seize the day.” One Participant stated:

I am assuming that if it was non-pandemic I would probably be visiting my siblings more often, and bringing my kids and we would be hanging out and talking and

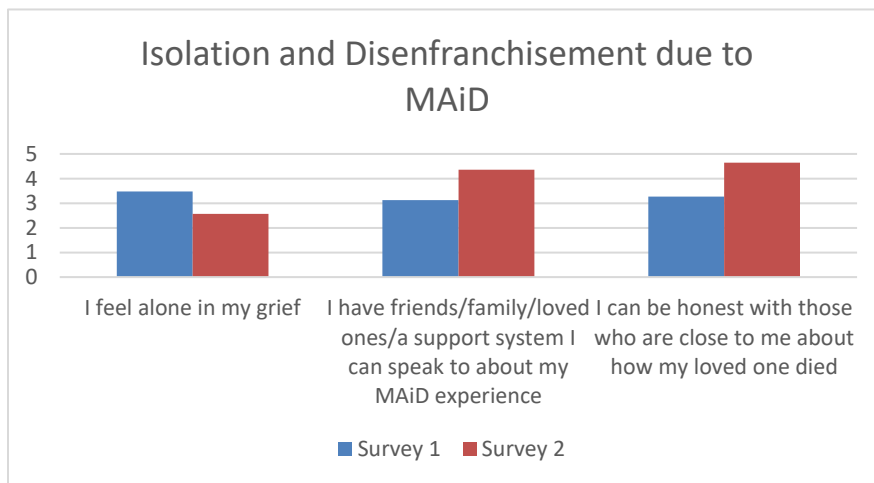
reminiscing or socializing... because it's been a little bit lonely? Right? -

**Participant 3**

This sentiment resonated with the group, with many indicating that they felt exhausted by the pandemic restrictions, including the inability to see family and friends or to be in public without assuming health or legal risks.

Finally, due to the age of many participants, their losses occurred at the end of relatively long lives and therefore constituted normative deaths (death that is reasonably expected and understood). Several participants expressed contentment over their perception of how their family member had lived. Most particularly, Participant 9 reflected on the adventurous life they had shared with their spouse. As a result it is perhaps to be expected that Statement 28 may not resonate in a group that has otherwise had relatively long lives.

**2.4.6 Disenfranchisement**



Following the GMRI, participants were asked to respond to three additional statements. These statements were also scored on Likert scale of 1 to

**Figure 16**

*Disenfranchisement and Isolation Aggregated Data*

5 in order to determine degree of agreement or disagreement with the statement. The purpose of these statements was to determine if MAiD had impacted participants' ability to form open and honest connections pertaining to the nature of their loss and whether they experienced disenfranchised grieving and isolation. As explained above, MAiD-involved families may be more likely to experience disenfranchised grief because of the contentious nature of their loss. One participant stated that:

I was very happy to join this group because it was specific to the MAiD process and I feel that I had a lot of... my grief issues where specific to having gone through that whole process. And it... there didn't seem to be any... it was a very specific thing to relate to other people about and there was no one really I could relate to about it. And also because of the confidentiality problem that I had because of my ethnic background, and so... I felt very alone and very isolated and really wanted badly to connect to a group that had gone through this. – *Participant 15*

Though not all participants experienced the desire to hide the nature of their loss to the same degree as Participant 15, several other participants also articulated their hesitance to disclose. Following the conclusion of the program, the score for Statement 1 declined. This suggests that the creation of community through this program reduced isolation related to this specific kind of loss. Creation of viable supports and support systems was recognized by Participant 8, who stated that:

I was so grateful, as I said, to have folks to talk to about it. Initially I was a bit apprehensive, though happy about a support group... I was apprehensive because I thought I would be the youngest one there \*voice breaks\* but I haven't... I haven't felt like, I haven't felt different than anybody. Because everybody has similar stories. It's been very helpful. – *Participant 8*

This further emphasizes the value and significance of MAiD-specific bereavement supports. This community can be subject to social risk through disclosure. In addition, due

to the relatively rare occurrence of MAiD, family members may not know others in their community who can relate to the unique nature of this type of death and resulting grief.

## 2.5 Discussion

### 2.5.1 The Significance of Making Meaning from Loss

Gillies et al. (2014) explore the value of meaning-making, defining it as a process of negotiation between who someone once was and who they are becoming. They state that “meaning is made, found, or reconstructed when the grieving individual makes progress in this process of negotiation by reaffirming or reformulating his or her prior system of meanings” (Gillies et al., 2014, p. 62). Meert et al. (2015) elaborate on this concept further in their exploration of work by Parks (2010). Meert et al. (2015) address the nature and impacts of meaning-making:

people possess orienting systems referred to as global meaning (e.g., beliefs, goals, sense of purpose) through which they interpret life experiences. When faced with a tragic event such as a child’s death, people assign meaning to the event, referred to as appraised meaning. The extent of discrepancy between global and appraised meaning determines the extent of distress a person experiences; this distress stimulates meaning making. Through meaning making, people attempt to bring global and appraised meaning into alignment, thereby restoring a sense that the world is meaningful and life is worthwhile. Also as described by Park’s (2010) model, for those who seek meaning, successful meaning making (i.e., meaning made) leads to better adjustment to the tragic event, whereas unsuccessful meaning making leads to continued discrepancy and distress and ongoing meaning-making attempts. (p. 454)

Meert et al. (2015) identified four key areas of meaning-making linked to the work of Gillies et al. (2014), who developed the GMRI. These areas are sense-making, benefit finding, continuing bonds, *and* identity reconstruction (Meert et al., 2015, p. 454). Sense-making, in this context, refers to “the bereaved person’s attempts to find a benign

explanation for the loss (e.g., why it happened) and is often framed in philosophical or spiritual terms” (Meert et al., 2015, p. 454). The MAiD bereavement program demonstrated that group members were able to understand and empathise with the decisions their family members made, while recognizing the humanity and reality of their family members’ experience. Benefit finding refers to “the bereaved person’s attempts to identify positive consequences of the loss (e.g., silver lining) such as a greater desire to help others, strengthened relationships, and reordered life priorities” (Meert et al., 2015, p. 454). While many group members remarked upon the ongoing hardships of grief and the myth of closure, many also concluded the program by discussing their travel plans and their developing senses of independence.

Continuing bonds (Klass et al., 1996) “refers to an ongoing attachment to the deceased person” (Meert et al., 2015, p. 454) and was a focus of the psychoeducation component of this program. Group members spoke about memorializing their loved-ones and about traditions that they will continue to honour the memory of their family member. At the conclusion of the program, they were able to look upon these memories with fondness. Finally, identity reconstruction refers to “a reorganization of one’s sense of self after the loss of a loved one” (Meert et al., 2015, p. 454). Though this program was only eight weeks in duration, by the program’s end, group members were beginning to see themselves in new identities (e.g., widow) that identified directly with their loss. They were also beginning to reconcile their identities. However, it is important to note that the pandemic and associated health measures and isolation inhibited participants’ capacity to generate or re-create social identities. Identity reconstruction therefore may not be as strongly reflected in this data compared to programs conducted in a non-pandemic context.



While meaning-making is a process that is consistent across all forms of loss, the data in this research is specific to those bereaved by a MAiD death. As such, it should not be used to make statements that are incorporative of other forms of loss.

### 2.5.2 Community, Social Support and MAiD

Social support, in this context, refers to a person's capacity to be supported by members of their social network or peer group. This can include individual friends, church leaders or spiritual mentors, immediate family, and more. Thus, attention to items such as religious or spiritual identity are relevant. Logan et al. (2018) state:

Although social support is consistently reported to be one of the most significant predictors of psychological outcomes following bereavement (Burke & Neimeyer, 2013), studies have found that bereaved persons often do not receive sufficient or timely informal support to moderate their grief experience. (p. 471)

The creation of this bereavement program and the subsequent community of loss offers social support to a group that does not always feel comfortable candidly and openly discussing the nature of their loss.

Furthermore, creating the group online during the COVID-19 pandemic, enabled participation in a community during an otherwise highly isolating time. Many members were recently bereaved and experiencing challenges like being unable to hold funerals in a way that they felt appropriate. This made participation in a community with an intimate understanding of their loss even more significant.

### 2.5.3 Significance of Professional Facilitation

Peer and professional facilitation have distinct advantages from one another. Peer facilitation has been found to create more robust informal support networks, while

professional facilitation has been found to create the greatest psychological functioning for participants (Toseland et al., 1989). In a study exploring caregiver burden and hardship, Toseland et al. (1989, p. 470) determined that “the professionally led groups improved caregivers’ psychological functioning slightly more than did the peer-led groups.” Furthermore, they found that professionally facilitated programs led to greater improvement in psycho-social challenges (Toseland et al., 1989). Though the results of the research by Toseland et al. (1989) do suggest that people experiencing psychological distress are best suited to a professionally facilitated program, there is a paucity of research about the impacts of a peer-facilitated programs and how they differ from professionally facilitated programs. Furthermore, research on this topic specific to MAiD in Canada does not currently appear to exist. As such, the professional-facilitated nature of this bereavement group contributes to the novelty of the present research and overall program.

There is significant variability across cultures in grief responses, rituals, and mourning, as well as in what is considered to be socially acceptable means of coping with a death (Conklin 2001; Kleinman & Good 1985; Palgi & Abromovich 1984; Rosaldo 1989). Several factors can contribute to these differences, including gender roles within individual cultures and subcultures, perceptions of death and the afterlife, cultural tolerance for emotional displays, and the role of spirituality and religion in response to grief. This concept was demonstrated in a study of post-death experiences and grieving experiences of African-Americans following a loss by homicide (Neimeyer & Burke, 2011). The authors found that negative religious coping (ex: blaming God) led to an increased likelihood of developing complicated grief. When exploring the grief and bereavement experience of MAiD-involved families it is important to consider that individual culture

may influence a person's bereavement trajectory. Such considerations should factor into the analysis of more diverse datasets. The population involved in this study was predominantly white, Catholic or Protestant, and middle-income, which limits the generalizability of our findings.

## 2.6 Strengths and Limitations

Though unique data was available through this study, the relative homogeneity of the sample makes results less generalizable. It is possible that this sample is reflective of the population that accesses MAiD services in Ontario. However, it is difficult to ascertain this with any certainty at this time due to a lack of adequate demographic data on MAiD patients (e.g., self-reported race, income, socio-economic conditions). The sample of participants in this data was both convenient and purposive. Despite limitations in terms of diverse data, this study is a valuable starting point in the consideration of the needs of MAiD-bereaved persons.

Of note, future research may benefit from exploring how participants interpret the categories described in the GMRI. This could determine whether participants have varying interpretations of these categories. This may also lead to a conversation wherein participants explore alternative language for the GMRI that better captures the intentions of each factor.

This study is first of its kind to explore a MAiD-specific bereavement program in Ontario that is free-of-cost, virtual, and professionally facilitated and therefore provides a novel contribution to the literature. This constitutes a core strength of this work. A key challenge encountered in this work was the COVID-19 pandemic. Health measures

necessitated an entirely online group, which made it difficult or impossible to observe body-language, touch, and post-session connections amongst group members.

Results are tempered by a lack of previous research using the GMRI as a pre- and post-program test. There is no current indication of what constitutes “success” with respect to differences between the pre- and post-program GMRI. Robert Neimeyer, one of the developers of the GMRI identifies potential challenges of employing quantitative measures to study of grief and emphasizes the need for greater qualitative considerations in such studies (Neimeyer & Hogan, 2001). However, the “snapshot” nature of the GMRI (i.e., It reflects how a participant is feeling in the moment) makes it challenging to determine what changes may constitute “significant” or “meaningful” improvements as a result of the bereavement group, and which may be simply attributed the passage of time. Additionally, though the GMRI as a tool has been validated by its developers, its validation may not consistently transfer to all populations that researchers may study. The GMRI’s use of linear Likert scales also poses inherent issues because grief is not a linear experience. Simply, the GMRI represents a singular moment in time where the experience is measured in the moment the participant responds, and may not be able to capture fluctuations over time.

Due to the challenges associated with quantitative measurements of experiences, interviews from the focus groups, which included positive feedback about the bereavement group, is necessary to evaluate the benefits of the program. The results of this research are tempered by the GMRI and by the paucity of GMRI-based studies that describe significance in terms of quantitative measures. Member checking to ensure congruence with participant experience could further contribute to the rigor of this research.

A core aim of this study was to provide preliminary evidence that may support the continuation of the bereavement group if some measure of benefit to the participants could be observed. In previous unpublished studies by the primary author, an assessment of validated grief measurement tools was conducted and it was determined that the GMRI was the least pathologizing because it considered social challenges following a death, the connections to the deceased that are social in nature, and did not seek to determine if depression or anxiety were present. It is felt that if this group could derive benefit, it would be ethically imperative to offer this group and create infrastructural sustainability in the future.

Future research might consider more diverse samples, more isolated populations both geographically and socially, and the impacts of peer versus professional facilitation within programs that are MAiD-focused. Furthermore, studies determining the sustainability and impact of hospital and health institution-based and funded bereavement support warrant further investigation. There is an impetus to have MAiD-specific bereavement programs that are not integrated into non-MAiD programs. Offering a safe space for disclosure and open conversation in a community of loss should be prioritized as it is more likely to offer benefits while reducing the risk of harm.

Furthermore, research that employs the GMRI to determine the impact of an intervention such as a bereavement program should consider the inclusion of a control group of individuals with similar backgrounds (e.g., death of a family member by MAiD). A control group will allow for the determination of the true impacts of the bereavement program when compared to the natural movement through grief without intervention. This would further facilitate our understanding of what constitutes a meaningful score increase

or decrease using the GMRI. The GMRI may best serve as an augmentative tool for qualitative data and observation, rather than a primary method of data collection. Mixed methods are still considered a more encompassing approach to grief research (Stroebe et al., 2003). However, the GMRI is potentially more effective as a secondary rather than a primary tool.

Finally, studies comparing the impacts and efficacy of peer facilitated compared to professionally facilitated MAiD bereavement support programs should be conducted to ensure that the highest quality of care support is being offered in an effective way to a community that carries the risk of disenfranchisement.

## 2.7 Conclusions

Overall, the structure, content and facilitation of this program emerged as quantitatively and qualitatively effective. The program delivered upon the promises of quality and efficacy for those experiencing a loss through MAiD. While many programs that offer MAiD bereavement rely on peer facilitation, the results of this study demonstrate the impact and efficacy of professional facilitation. A direct benefit of professional facilitation is the improved grief literacy provided through psychoeducation by a specialist in grief and loss, as well as the accuracy of grief knowledge translation to members of the public. As such, creating bereavement support programs and implementing measures to determine their efficacy and potential areas of improvement is important to the promises of quality care espoused by clinical centers.

This research demonstrates that an eight-week, professionally-facilitated virtual bereavement support program for those who are bereaved following a MAiD death is

impactful. The program supports those who are grieving in making sense of their experience and in accepting and making new meaning in their lives. Programs such as this one create communities where members can share experiences, which was of particular significance during COVID-19.

Finally, this program of research demonstrates that a bereavement program can be accessible and effective for populations experiencing a myriad of death-based losses, beyond MAiD. There exists opportunities for clinical centers to use their own internal resources to create and operate bereavement programs for areas where deaths are commonplace, such as oncology and palliative care. Services such as these ensure that not only are patients being cared for but their families as well. Thus, models of care such as this adhere to the whole-person model of end-of-life care that health organizations strive towards.

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### 3 Love, Limitations and Loss: The Unique Experience of MAiD Grief in the Time of COVID-19 from the Perspective of Directly Involved Family

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**Keywords:** Assisted Dying, MAiD, Euthanasia, COVID-19, Pandemic, Bereavement, Grief

#### **Statements and Declarations**

**Authorship:** AO conducted, analyzed and reported data and formed the structure of this manuscript. All authors provided intellectual material, guidance and support in the writing of this manuscript. The primary author contributed a minimum of 85% of materials and efforts.

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### 3.1 Introduction

In 2019, a novel coronavirus was identified in Wuhan, China. This virus quickly spread, leading to a global pandemic that affected every World Health Organization (WHO) region (WHO, 2020). In an attempt to slow the spread of the virus, countries around the world imposed such as mask mandates, social distancing, and the closing of services and business. This affected bereavement practices in Ontario by limiting the number of visitors allowed in hospitals and delaying funerals. Legal requirements for isolation and distancing between households affected people's ability to grieve together. These public health measures intended to prevent the spread of illness therefore also had the potential to adversely impact people's bereavement experiences and their capacity to access adequate psychosocial support. Stroebe and Schut (2020) conducted a scoping review of pandemic grief literature, and concluded that,

social isolation has brought with it the lack of physical support from family and friends or physically present spiritual support, reflecting sometimes severe societal disruptions in general. Such distancing can intensify feelings of loneliness that is part of any bereavement experience, even without isolation orders in place. (p. 502)

Following the acute traumatic phase of grief, some people experience an intermittent characterised by personal growth and resilience. This is called post-traumatic growth (PTG; Michael & Cooper, 2013). PTG can occur when the bereaved individual is provided with the right social supports, personal characteristics, and environment (Calhoun et al., 2010; Michael & Cooper, 2013). However, grief also has the potential to be profoundly distressing and to pose meaningful health risks (van der Houwen et al. 2010). Van der Houwen et al. (2010, p. 195) state that “[e]xtensive research has shown that bereavement is associated with excess risk of mortality and with decrements in both physical and mental health.” Contextual features, such as attachment style and level of access to social supports, can offer some degree of prediction with regards to psychological risk and likelihood of adverse psychosocial experiences during bereavement (Stroebe et al., 2010).

This paper aims to advance understanding of grief associated with Medical Assistance in Dying (MAiD) within the context of the first and second waves of the COVID-19 pandemic in Ontario. We draw on the qualitative analysis of narratives from 14 individuals who participated a MAiD bereavement group between November 2020 and February 2021. The study brings attention to the dimensions of loss and grief that are specific to MAiD and those specific to the global COVID-19 pandemic. It is proposed that these two unique forms of loss, operating synergistically and amplified grief experiences for families involved in MAiD deaths during the pandemic. At this time, no other research has considered the relationship between MAiD bereavement and COVID-19 regulations. This research therefore constitutes a novel contribution to the Canadian-focused MAiD and COVID-19 literature.

The impetus for the paper was informed by the desire participants shared to discuss their experiences both in the context of MAiD and during the pandemic, and it is participants' underlining the particularities of their grief during the pandemic that has brought the authors to examine COVID-19 and MAiD. This paper seeks to define the unique nature of MAiD loss and of loss during a global pandemic. It then examines the synergistic potential of these two forms of loss and how their co-occurrence affected people's grief experience.

## 3.2 Background

### 3.2.1 MAiD and Grief

For the purposes of this paper, grief is defined as the natural and expected response to loss. Grief is a typical adaptive response to the death of a significant person, and the authors do not seek to pathologize this response. That said, in certain circumstances, grief can become maladaptive. In this context, maladaptive grief refers to “the condition of delayed, distorted, and/or unending reactions to normal grief” (Reeves & Boersma, 1990, p. 283). Maladaptive grieving, often has roots in maladaptive dependency, can lead to grief prolongation (Denckla et al., 2011). This is characterized by “separation distress, intrusive thoughts, or intense distress related to reminders of the loss, as well as at least five grief-related PTSD symptoms (avoidance of thoughts, feelings, and talking about the loss, avoidance of people and places related to the loss, and feelings of detachment from others)” (Denckla et al., 2011, p. 5).

Four previous studies have employed quantitative methods to explore the relationship between the experience of witnessing a MAiD death and the development of

complex grieving patterns. The studies address that unique features of the MAiD experienced have potential to have lasting effects on bereavement, but they do not conclusively determine if the procedure itself has an effect (either positive or negative) on family members.

In the first of these studies, Swarte (2003) employed grief inventory scales to measure the impact and traumatic outcomes of witnessing a euthanasia in the in the Netherlands. They found that “the bereaved families and friends of cancer patients who died by euthanasia had less grief symptoms and post-traumatic stress reactions than the families and friends of comparable cancer patients who died in a natural way” (Swarte 2003, p. 3). Ganzini et al.’s (2009) research about the experience of grief amongst MAiD-involved loved ones in Oregon supports Swarte’s findings. In contrast, Wagner et al. (2010) conducted a study about rates of post-traumatic stress and depression in assisted suicide involved loved-ones in Switzerland and found a slightly higher prevalence of depression amongst their study population. At this time, there is no conclusive data indicating whether MAiD has positive or negative impacts on family members who involved in the care for a loved one and present at the time of their death.

An emerging topic of interest In the Canadian MAiD literature is the ways that the MAiD process impact the experiences of MAiD on involved family members (Beuthin et al., 2021; Hales et al., 2019; Oczkowski et al., 2021; Weibe et al., 2018). MAiD access and assessment often requires advocacy and direct care involvement from patient by family members. Little is known at this time about if and how MAiD grief differs in meaningful ways from grief related to loss by natural death. Emerging research does suggest some distinct features of MAiD loss may have lasting impacts on family members (Frolic et al.,



2020; Goldberg et al., 2019; Hashemi et al., 2021) but the unique attributes of bereavement remain under-described. To date, only one study has explored the specific elements of MAiD death and the legacy of the experience for surviving family members in Canada (Frolic et al., 2020). Frolic et al. (2020) found that MAiD-involved families experience disenfranchisement particular to MAiD because of the inability to openly disclose or discuss the nature of their significant person's death. A study in Switzerland also found that MAiD-involved families are more likely to experience disenfranchisement and the related adverse impacts on bereavement (Wagner et al., 2011). Wagner et al. (2011, p. 384) note that "many of the participants stated that they had not talked to friends, colleagues, priests or neighbours about the way their loved one had died." The authors further reflect that "the extent to which participants' experiences are denied or invalidated by their family or societal environment may have an important effect on their psychological adaptation to the traumatic stressor" (Wagner et al., 2011, p. 384).

### 3.2.2 COVID-19 and Grief

Grieving a loss in isolation is a distinct experience of the COVID-19 pandemic. In addressing this experience, Wallace et al. (2020) state that:

In response to the spread of the COVID-19 pandemic, communities have begun implementing large-scale "stay-at-home" orders, which in many cases are mandated by local or state leaders. Hospitals and other facilities are limiting or banning the physical presence of visitors. As deaths occur, the physical, mental, and social consequences of isolation of social distancing may impact the potential for complicated grief (CG). While clinicians should not assume that all patients or family members are experiencing CG now during the height of the COVID-19 pandemic, it is important to understand how current circumstances may set the stage for CG to occur after death. (p. 71)

During the COVID-19 pandemic, several restrictions were enacted across the world as disease burden in hospitals waxed and waned. These public health interventions and restrictions were necessary to stem the course of viral spread, but also posed significant social challenges globally. For example, a study in the United Kingdom found that clinician experienced challenges related to their capacity to support bereaved individuals through their grief (Pearce et al., 2021). The authors state that:

Regardless of cause of death, it was emphasised that the support provided was largely consistent, as all families had experienced similar restrictions prior to and after a death. Frequently reported were the impact of restrictions on funeral arrangements (61%), and reduced opportunities for in-person interaction also produced difficulties when identifying bereaved people who might need support (56%). (published online)

This speaks to the experience of grief during COVID-19 because bereaved individuals had to grieve in isolation and faced restrictions in how they could conduct ceremonies and rituals for their deceased loved ones (Aguilar et al., 2022; Selman et al., 2021). These experiences, combined with stress related to the pandemic itself, have the potential to worsen psychiatric wellbeing. Indeed, Mortazavi et al. (2020) discuss the potential for a potential “psychiatric pandemic” to emerge as a result. There is currently a paucity of literature that explores families’ experiences of grief related to non-COVID deaths that occurred during the pandemic. There is no such research from the perspective of Canadians.

COVID-19 restrictions also affected people’s ability to socialize, and as a result bereaved people faced the daunting task of making sense of their loss without access to social support. In this context, social support refers to a person’s capacity to connect with and receive support from members of their social network or peer group. Cacciatore et al.

(2021, published online) state that scholars have found “a relationship between loneliness and post-bereavement depressive symptoms, adding to the global burden of mental illness.”

Similarly, Logan et al. (2018) state:

Although social support is consistently reported to be one of the most significant predictors of psychological outcomes following bereavement [Burke & Neimeyer, 2013], studies have found that bereaved persons often do not receive sufficient or timely informal support to moderate their grief experience. (p. 471)

Prior to COVID-19, there was already a lack of social support for the bereaved in general. This only worsened during the pandemic. Wallace et al. (2020) theorize that this decreased access to social support may increase the likelihood that people will experience complicated grief and potential associated negative health outcomes.

Finally, the inability to plan a funeral, memorialization, or ceremony to celebrate a deceased person’s life can have negative impacts on the grief of those left behind. According to Weir (2020),

When people aren’t physically present to say goodbye and grieve with other mourners, they may be more likely to experience a sense of ambiguous loss... With an ambiguous loss, it’s very hard to get closure. There’s often a lot of frustration and helplessness because people feel disempowered. (published online)

This raises the important point that grief can be prolonged when people experience disenfranchised grief or grief related to an ambiguous death. However, Weir’s emphasis on closure implies that grief following the death of a loved one will end. This understanding of closure is a myth that does not serve to adequately support persons experiencing grief and loss (Boss & Carnes, 2012). This is not so say that acute grief cannot undergo prolongation as a result of limitations in the social processing of a death (Scheinfeld et al.,

2021). Prolongation of grief can have its own mental and physical complications. Zhai and Du (2020) state that:

as a result of unusual prolonged and disabling grief, more individuals are at greater risk of prolonged grief disorder (PGD) in this pandemic. PGD will imperil mental and physical wellbeing consequently because of the disturbance causing significant impairment in essential areas of functioning. (p. 80)

### 3.3 Methods

The current analysis is based on data collected in the course of a mixed methods study that aimed to determine the impact and efficacy of the first professionally facilitated, MAiD-specific bereavement group offered to individuals affected by MAiD in Ontario, Canada. Findings corresponding to the study's original objectives are presented elsewhere (Oliphant et al., in preparation). The present manuscript is based on a secondary analysis of the qualitative data (non-participant observation and focus groups) collected in the course of this study.

The MAiD-specific bereavement group at the centre of our team's research was conducted from November 2020 to February 2021 and coincided with a more severe wave of the COVID-19 pandemic in Ontario. As such, the group was conducted in a virtual environment to ensure participant safety. Participants were invited to have their cameras on in order to create a sense of community. Non-participant observation of the group occurred across the program's eight sessions and focus groups were conducted following its conclusion.

### 3.3.1 Recruitment and inclusion criteria

Participants in this study were recruited through phone calls with a group facilitator. The facilitator drew from their experience and professional expertise to determine potential members' appropriateness for enrollment (no suicidal ideation, willingness to participate, etc.) based on their experience and professional expertise. The facilitator also informed participants that this bereavement group was part of a program of research. Potential participants who were determined not to be appropriate for the program were referred to other supportive services. Group members consented to participation in both the bereavement group and the research program through a scripted informed consent process. This was administered over the phone as well as through a written consent form that participants signed and submitted by mail (Canada Post), or digitally (scanned copy or cell phone image) prior to the first session. All consent forms were stored in a secured SharePoint.

### 3.3.2 Data Collection and Analysis

The original study's goal was to explore the impact of the bereavement group rather than the impact of MAiD. However, in the course of reading and re-reading the focus group transcripts it became evident that there were features of both MAiD and the pandemic that warranted additional consideration. The initial study involved the use of a psychometric test (GMRI), non-participant observation, and focus groups to determine the impact and efficacy of a MAiD-specific bereavement group that operated virtually between November 2020 and February 2021. This paper presents findings from the observation and focus groups. This study specifically focuses on the narrative data collected from the focus

groups because it is descriptive in nature and addresses the lived experience of grieving a MAiD loss during COVID-19.

Analysis is based on a qualitative inductive approach, wherein the focus group transcripts were used to generate the initial coding structure. Transcripts were manually produced, then manually coded for initial code structure, and finally digitally coded in NVIVO. Similarly, descriptive notes were taken during each session that detailed observations such as body language, general agreements or consensus in the group, acknowledgements in the form of nods. These observations were then coded into the structure established in the focus group coding. This process of comparing and reviewing codes then growing theory based on this data constitutes a method of constant comparison (Glaser, 1965) and triangulation for coherence (Tracy, 2010). NVIVO (2019) software was used for data organization and analysis.

This research utilizes techniques from grounded theory for this secondary analysis, as the data directed the coding structure and ultimate findings of this research. Constant comparison is frequently implemented in the conduct of grounded research (Corbin & Strauss, 2014). This approach to research enables an inductive approach to data that is immersive for the researcher. Our study offers an interpretation of a nuanced, complex, and diverse series of unique experiences (Corbin & Strauss, 2014) with respect to concurrent MAiD and pandemic-related isolation. As such, grounded theory constitutes an appropriate theoretical framework for this research because it “is concerned with psychosocial processes of behavior and seeks to identify and explain how and why people behave in certain ways, in similar and different contexts” (Foley & Timonen, 2014, p. 1197). This lends itself well to the understanding of intersecting and unique phenomena,

such as the experience of living through a global pandemic while grieving a family member who died by MAiD.

### 3.3.3 Grounded theory techniques

Classic grounded theory is a “set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area” (Glasser 2004, no page). Furthermore, grounded theory “is concerned with psychosocial processes of behavior and seeks to identify and explain how and why people behave in certain ways, in similar and different contexts” (Foley & Timonen, 2014, p. 1197). This research implemented techniques from grounded theory methodology because the data form the foundation of the theory pertaining to the phenomena.

#### 3.3.3.1 A Constructivist Paradigm

According to Charmaz (2017), a constructivist approach to grounded theory

fosters asking probing questions about the data and scrutinizing the researcher and the research process. Unlike other versions of grounded theory, the constructivist version also locates the research process and product in historical, social, and situational conditions. (p. 34)

Charmaz further elaborates and states that “This methodological self-consciousness requires scrutinizing our positions, privileges, and priorities and assessing how they affect our steps during the research process and our relationships with research participants” (Charmaz, 2017, p. 35). The initial goal of this research was to work towards quality improvement by assessing the efficacy of the bereavement group through an Evaluation Research Study (ERS). As such, questions posed in the focus groups originally focused on this topic. However, participants indicated that there were aspects of their experience that were not captured in these questions and focus group topics expanded to offer participants

an opportunity to express these thoughts. These included core concepts such as the uniqueness of MAiD and the individual impacts of the pandemic.

### 3.3.4 Ethics Approval

This research required approval from two separate ethics boards because it was conducted through a Southwestern Ontario (SWO) academic hospital system that was not affiliated with the home institution of the primary author. Applications for ethics approval were submitted to both HIREB (Hamilton Integrated Research Ethics Board) and WREM (Western Research Ethics Board). WREM (Appendix 3.0) granted ethics approval on October 19<sup>th</sup>, 2020 and HIREB (Appendix 3.0) granted approval on November 10<sup>th</sup>, 2020. Both boards approved the research protocol as well as all instruments (Appendices 1.0 and 2.0) and communications.

## 3.4 Findings

### 3.4.1 Demographics and timing of loss

Overall, 14 participants joined the bereavement group and participated in all eight weekly sessions. All 14 participants engaged in the focus groups, with seven participants in each group. The majority of participants identified as white, between the ages of 65 and 74. Most were the spouses of the deceased. Most significant to this paper is the timing of their loss; the majority were one to three months bereaved as of the initial session on November 25, 2020. Lockdown measures began in March 2020, eight months prior to the first group session meaning that approximately two thirds of the group had experienced their loss during COVID-19. All participants were present at the bedside at the time of their loved one's death.



Analysis of the focus group and observational data brought to light the unique nature of MAiD loss during COVID-19. At the core of this uniqueness are the ways in which MAiD-specific and COVID-specific experiences of loss overlapped and, at times, exacerbated one another. In what follows, we present key qualities of loss in the context of MAiD and COVID as identified through thematic secondary analysis of the participants' narratives. We then offer a summary of participants' own reflections on how both COVID-19 isolation and their MAiD experiences interacted.

### 3.4.2 The experience of MAiD Grief

Several participants emphasized that MAiD neither made their grief worse nor better. Rather, it was simply different from their previous experiences. One participant had experienced a similar type of relational loss earlier in life. They emphasized that, though their second loss occurred through MAiD rather than by natural disease progression, it was “not easier. Just different” (*Participant 4*). Some of these crucial differences are: 1) the agency and control afforded by a MAiD death; 2) the ability to say goodbye; and 3) the particular experience of feeling unable to disclose the nature of the loss, which can lead to isolation.

#### 3.4.2.1 Agency and Control

Participants emphasized peace and control. The choice to die in such a specific way and under specific auspices offered some participants a sense of peace in their loss. At the same time, some participants expressed that the fact that this control was contingent on the capacity of the individual choosing to end their life with MAiD created additional stress.

All participants reflected that they took comfort from the fact that their loved one was able to choose how their life concluded and to die peacefully. This choice and control, though comforting at times, did also involve challenges that constitute unique features of the MAiD process. These features include:

1. When a patient is at risk of losing capacity and by extension lose their ability to access MAiD (prior to 2022 and the waiver of final consent), family often felt they were under pressure to support and facilitate access. When there were challenges in doing so, they experienced frustration, worry and disappointment.
2. When a participant felt they were at the mercy of someone else's decisions around their loved-one's planned death, they expressed a lack of control and the frustration and fear that ensues. Such instances occurred when physician felt the patient did not qualify for MAiD, or when physicians were unable or unwilling to provide information about MAiD.
3. The significance of the particular day of death impacted participants' experience of MAiD, as well as their subsequent experience of grief. Family experienced additional challenges when the patient requested MAiD sooner than anticipated. This left some with feelings of distress over the loss of time.

When reflecting on patient choice and capacity, and on the hope for a peaceful death, one participant stated that:

I had the opportunity to watch a young friend die of glioblastoma shortly after my spouse died. And because she had a brain tumor she of course could [not] opt for MAiD by the time things went south. It was far too late. SII... in the course of six months I saw someone die from MAiD and someone die naturally from cancer through the whole, sort of... progression. It was faster than we thought it would be but um... so I think with MAiD, you sort of, as 12 said, get to say goodbye to the

person you knew? You know? They are still talking to you, they are still aware and that kind of stuff which is hard because you don't want that to end, but watching somebody just fade away for weeks and weeks... is... –s pretty awful. - *Participant 2*

The statement above reflects underlying concerns that family members have about their loved ones losing capacity and becoming unable to access MAiD as planned. It also demonstrates the inherent challenges of knowing when a loss will occur and not wanting to lose a family member.

Participants expended a significant amount of energy as caretakers and to ensure that the wishes of their family member accessing MAiD were honoured, and these concerns were expressed across the bereavement group and focus groups. Particularly, participants expended significant energy to ensure that their loved one could access MAiD as per their (the patient's) plan. This placed caretakers in a position where they were not entirely in control of the situation or the decisions being made, while still understanding that they were about to experience a significant loss. This occurred in one case when a patient felt their condition was progressing intolerably and therefore decided to move up the date of their death:

I am harboring a little bit of resentment because mine happened before the actual date. And I feel I was cheated out of that one, solid week with my [spouse]. I mean, there were more things to say! SI. it's a different... it was a different kind of happening. Just, that morning, they [spouse] said call them [MAiD team], I can't stand it anymore, and it just... it all just transpired, it was out of my control. I guess that bothered me too. - *Participant 9*

Many participants explicitly or implicitly described the need they felt to stifle their emotions and personal desires to better support their loved one. However it is apparent that this absence of personal control did impact participants' bereavement. One participant

expressed a feeling of guilt for expressing their wishes for how the death would be choreographed, stating:

the planning you have to do...the... first of all having that discussion with your partner on... this something you want to do? Then... when do you want to do it? Then you have to think ok well, you have to tell family... and all the children... then I have to start asking questions like, how do you want to do it, where do you want to do it, who is going to be there... I... I had to kind of selfishly say please, could it just be you and I when it happens? You know? Luckily they said yes. Because I... we didn't really... oof... it was selfish. I didn't... wanna... have to worry about anyone else other than them in that moment... - *Participant 1*

Such accounts of distress – including feelings of guilt, shame, and blaming oneself for having their own needs during this time – were common. Participants did discuss the challenge of balancing their needs and desires for the remaining time with their loved ones. Some particularly difficult choices were those that excluded other options, such as patient time with their spouse vs. time with their children. These can may weigh heavily on participants following their loss.

One participant reflected on the challenges of connecting with their person and reflecting on their lives together prior to their MAiD date:

My person didn't really want to do that kind of stuff. They didn't really want to look at photos, they didn't really want to look at anything like that. I think that maybe that was just their personality? Not to show, I don't know, vulnerability or something. Just wanted to be tough the whole way but... yeah, they didn't seem interested in doing that. Like, we had gone on a family trip about 25 years ago, back home to [European country] and I had actually written a journal, every day that we were there I had written a little something about what we did. And I thought well, it might be fun, because I had sought some... I don't know if they were grief counsellors but a counselor, to help me help them process that they want to pass away, right? And what can we do to support my person during this process. And they suggested like, nice music that they like, watch a movie that they like, talk about old times, look at books or pictures, and [pronoun] wasn't... really interested?

So it was hard to connect with them that way. Because they didn't really want to. And when we wanted to plan their day, like whether they want a special meal or something they wanted to wear, they were really grumpy about that. They didn't really want to do that. Until we [kind of] had to, you know? And then I felt bad that we didn't do anything that special because they really weren't very interested in actually planning it. Like, on the actual day, I think I brought them some flowers, to put in the actual hospital room, and they were like "why did you do that?" and I think my sibling may have brought a picture from home and they were like—"why did you do that???" You're just going to have to bring it back.. - *Participant 3*

Such experiences of a person resisting requests or suggestions for symbolic final moments impacted the bereavement experience. Some participants expressed that they felt disconnection and a lack of peace when they were unable to engage in ritual or reflection with their person as this was not desired or meaningful to the patient despite the meaning it held for the participant.

### 3.4.2.2 A Proper Goodbye

Several participants expressed the advanced knowledge of the date and time of their MAiD loss provided them with opportunities to spend time with their person in meaningful ways and to say what needed to be said. This offered many individuals some comfort in their grief. As one participant noted,

I think what's really unique about MAiD is, it gives you, you know, you have the opportunity to see that person off? Whereas a lot of times when people pass away, you know, you aren't there, you get a phone call, like... an accident happened and you're not there basically and you're... well, you're never ready but you're not prepared and so it's a really unique kind of like, last final moment of intimacy you can have with your person.. - *Participant 12*

A sense of intimacy during a patient's final hours was prevalent across the group. Participants were able to create scenarios in which their person died "right," meaning the right people were present, they were wearing the right clothes, they were in the right place,

the right music was playing, and the right words were said. This helped them feel that they honoured the person they knew so well in their final moments. One participant stated that:

MAiD itself was absolutely fantastic, I would recommend it always, to anybody that was in that situation, um... it gave us the opportunity to say goodbye properly, not to be like, stuck in a hospital somewhere or I guess... even for us it was ok because they were in the hospital then they came home, and it gave us the opportunity to stay with them, to look through photos and to look at everything that we had done during our life, to see that they had had a very full life, and I think that was important before they died - *Participant 11*

MAiD offers a unique opportunity to plan the specifics of the day of death. This is especially true for participants who were in support of their loved one's choice to access MAiD. Participants who supported their person's choice to access MAiD, and who were able to have the right people present and to choreograph the death in a way that they felt did their person justice expressed a greater sense of peace with the loss and spoke highly of the process and practice itself.

### 3.4.2.3 Challenges in Disclosing the Nature of the Death

Not all participants necessarily supported their loved one's decision to access MAiD, but instead supported their loved one in their wishes. This complicated experiences of bereavement for some because their bereavement involved reconciliation within themselves with respect to their loved one's decision. Some participants felt unsupported by their communities or described facing family resistance to the decision to choose MAiD. One participant expressed relief at joining a MAiD specific bereavement group:

I was very happy to join this group because it was specific to the MAiD process and I feel that I had a lot of... my grief issues were specific to having gone through that whole process. And it... there didn't seem to be any... it was a very specific thing to relate to other people about and there was no one really I could relate to

about it. And also because of the confidentiality problem that I had because of my ethnic background, and so... I felt very alone and very isolated and really wanted badly to connect to a group that had gone through this. - *Participant 15*

Another participant had lost the support of their parents due to their spouse's decision to access MAiD, stating that, "[My] in-laws... having such a negative response from them... um... I mean, it has been... [spouse] passed away [date] and I have yet to hear from any of them..." (*Participant 8*).

Another participant reflected on the moment their spouse died by MAiD, and stated that,

it was just like... you know, it's like a weight is lifted off you but it's really not. You look down and your legs are crushed and you're just crushed, and where do you go? Where do you go to pick up things and go? And you know, it was difficult, we didn't tell a lot of people about the MAiD program or how they died, but they went through so much... it was unbelievable. - *Participant 7*

Another participant stated that,

I couldn't discuss it with anyone, except my children of course, it was very difficult. And I had a lot of people, some family members... who were very... who tried to talk my spouse out of it. Which was very difficult for me because it was their decision- *Participant 9*

Lack of community support led participants to feel like the cause of their grief could be adequately recognized or adequately. In some cases, experienced this lack of MAiD acknowledgement and acceptance from within the medical community as well. Some clinicians and staff made participants feel unsupported and put them in a position of caretaker and advocate, causing participants to expend significant energy in the process. One participant detailed the experience they had with a clinician while seeking information for their person:

the resident that we... oh, sorry they were a fellow... that we had assigned to us, an oncologist, was very standoffish about it. Who... the person who told us about MAiD was the psychiatrist at [hospital] and that is a brand new program, they have never had a psychiatrist in that hospital before. So, [the psychiatrist] was the one who mentioned it [MAiD] to us and when we brought it to the attention of the oncologist, they [the oncologist] just didn't want to... that was not something they wanted to talk about and again, um... on one phone call, [the oncologist] made reference 3 times to me about how difficult this was for them... - *Participant 8*

The frustration around rejection and barriers to care continued following the death and into the bereavement process, as some participants continued to feel anger and resentment. When attempting to speak to grief professionals, some were met with roadblocks. Some grief professionals assumed they would be less effective because a person's grief was "MAiD-specific." One participant discussed their experience seeking counselling, and stated:

I really did feel alone. Because I don't know anybody else who did... who has done the MAiD process... so, I mean, the counsellor I was with said to me "you know, it's different than regular grief" but that was it! That was all they told me! - *Participant 5*

The counsellor's unwillingness to discuss the details of MAiD left this individual feeling alone in their grief.

Overall, the procedural elements of MAiD create particular circumstances and experiences for family members, as opposed to a death by natural causes. These include:

- 1) The need to ensuring that their family member's wishes are honored, even if the participant feels uncertain, wishes for more time, or disagrees with their choice. This requires consistent effort and advocacy from the family member.
- 2) The opportunity to say a proper goodbye.



- 3) Isolation in their loss stemming in part from the inability to disclose the true nature of their loss to others in their communities.

There are unique opportunities in this kind of loss with respect to choreographing the “perfect” death and connecting intimately with their loved one at the end of their life. These elements can both adversely and positively impact the grieving process. However, the MAiD loss itself is not necessarily responsible for changes in grief behaviour.

### 3.4.3 The experience of loss during COVID-19

COVID-19 led to many changes in public health policy in Ontario as elsewhere. These included shutting down non-essential services, mask mandates, and mandatory social distancing. Restrictions also limited the mobility of individuals between regions. Several participants’ emphasized the particularity of grief experiences during the COVID-19 pandemic in their narratives. They addressed the social isolation, experience of secondary losses, challenges in redefining their identities following the loss, and risk-taking during pandemic restrictions.

#### 3.4.3.1 Social Isolation

COVID-19 necessitated the isolation of many within their own homes. For those experiencing loss, particularly spousal loss, this interrupted the coping mechanisms they had been using as means of distraction and displacement. Participants described that they could no longer use work, activities, and hobbies to sublimate their grief. While initially this was incredibly difficult, participants described isolation a time of significant learning in terms of how they managed and experienced their grief. One participant stated that,

because I had... bereavement before the pandemic and during the pandemic, and I think a lot of these people [other members in the group] are unfortunately all during the pandemic, I just found that before the pandemic I was into being busy busy busy! So every day had to have something on the calendar. You know? I had to have like, a walk with a friend or lunch with a friend or dinner with a friend or something. I had to see another human being every day or I would have a meltdown. And then when the pandemic hit \*comedically clears throat\* that became a whole lot less possible. And so.. I have had to learn to spend 24 hours with myself. Which at first was not possible, and now is possible. So whether that's... you know, I mean, I suppose that's a good thing to be able to get through a day without seeing another human being and not having a meltdown. - *Participant 2*

The majority of participants experienced their loss during the pandemic. However, there appear to be some notable differences in participant experiences between those whose loss occurred before March 2020 and those whose loss occurred after. Participants who experienced a loss after the onset of the pandemic expressed experiences of isolation in the early days of their bereavement that were not as prevalent in the accounts of those with pre-pandemic losses. Following the loss of a parent, one participant noted a growing distance between their siblings, and stated:

I am assuming that if it was non-pandemic I would probably be visiting my siblings more often, and bringing my kids and we would be hanging out and talking and reminiscing or socializing... because it's been a little bit lonely? Right? I do have my spouse and my [#] kids, but... you know, it's my siblings that know my parent the most like I do, right? Because I spent almost [many] years with them. It would... I think I miss that part? Because of the pandemic we didn't have that after time together to talk. And hang out, and reminisce.... I would imagine with the sibling I am a little closer to, I would probably have been visiting her with my kids and hanging out and stuff like that. And that would be helping. But we're not doing that. - *Participant 3*

The pandemic reduced opportunities to memorialise (e.g., have a funeral or a wake, attend ceremonies), to create continuing bonds (e.g., create new ritual around memorialisation with others, participate in activities that had once been shared with the deceased), and to discuss the legacy of a loved one. Many participants described these

processes as important, and it became apparent that their inability to practice them was impacting their grief. One participant stated:

We haven't had a celebration of life or funeral yet... and that in itself is another personal torture because um.. Nobody talks about them, and it feels like everyone has forgotten about them. And I know better but it hurts. It's... it's unkind and it's mean and I know funerals are for the living and stuff, and I've even tried um... like, one person said, "oh I had one person write down stories!" so on Christmas morning I had a whole bunch of pieces of paper I could read, all these stories about my loved one and I was like, that is brilliant. Tried to do it, and I got one story. I don't know... yeah... so lots of nastiness there with the pandemic. Multiple levels of not fair. - *Participant 1*

For this participant in particular, the pandemic led to a reduction in anticipated support. The reduction in social support in general was felt broadly across the group, and participants often discussed their frustration with social isolation during the weekly sessions.

### 3.4.3.2 Secondary Losses

Due to the pandemic, many participants experienced a phenomenon called secondary loss. These are non-death losses in addition to the death itself. In the case of MAiD, secondary losses can come before the death as restrictions severely limited opportunities to give the patient the final days or weeks they had hope for. One participant reflected on this period and on their inability to have a final trip with their spouse:

After [spouse] had their initial brain surgery, they pretty much couldn't read, they certainly weren't allowed to drive ever again, and they rode motorcycles their entire life and they couldn't ever do that again. Um... they couldn't even... because of covid, we couldn't even go anywhere. We couldn't even go to a beach. We couldn't go to the Caribbean or something. And between radiation sessions or whatever, and it was... it was cruel. So many losses. - *Participant 1*

Another participant reflected on the inability to bring their children to see their parent in the hospital, resulting in the patient being sent home and the participant having to shift their relational role from spouse to primary caregiver. They state that,

I felt so alone because they were in hospital... and then they got to a point where COVID was ramping up and they were only allowing me to go in. But then... they were missing the kids and they were dying, right? So... we wanted them discharged so they discharged them home and I was caring for them all by myself. - *Participant 8*

Secondary losses such as this have significant impact. In an effort to fulfill the needs of the patient and have as much time together as a family, this participant gave up their role as a spouse to assume the role of a medical caregiver.

Other participants reflected on the secondary loss of ceremonies such as funerals because many funerals were either postponed or modified to accommodate social distancing and mask mandates. One participant stated:

I mean, the funeral itself was... I don't know about anybody else's but it was sad. People had to call and you could stay 10 minutes and then the next people came in and nobody hugged each other... and it just wasn't right. It wasn't right. - *Participant 9*

Experiences such as this impacted participants' bereavement because they felt unfulfilled by their memorialisation practices.

### 3.4.3.3 Redefining Oneself

COVID-19 restricted in-person contact, which prevented people from connecting with individuals and groups that had experienced similar life events (including the loss of a spouse or parent). This emerged in participants' narratives as participants described how

this limited their ability to redefine themselves socially following the MAiD death of their loved one. According to Baddeley and Singer (2010):

When a family member dies, each surviving family member and the family as whole must inevitably confront the respective questions of “Who am I?” and “What is my family?” now that this critical member of their family is gone. Whatever previous narratives have served to answer each of these questions of self and collective definition, the loss poses an immediate challenge to their integrity. (p. 200)

This intertwined identity with a significant person, Depending on the degree and nature of someone’s attachment, the ways that their identity is intertwined with that of a significant person can have adverse impacts on a person when that attachment is lost through death.

Bellet et al. (2020) state:

Individuals whose goals and plans were closely intertwined with their relationship to the deceased and for whom the deceased was a primary attachment figure are most at risk for CG [complicated grief]. For individuals for whom this “merged identity” persists, life goals and daily activities are frequently inconsistent with the reality of the decedent’s absence. (p. 398)

How one defines oneself is a complicated entanglement of external and internal social actions and factors. One factor is social identity, which comprises how one attributes certain social norms, symbols, and behaviours to their sense of self. Many participants in the support group were the spouses of someone who had died by MAiD. As such the issue of how one defines themselves socially as a “spouse” is significant to this research. Many participants in the group experienced challenges reconciling this aspect of their identity following the loss of their spouse. During a session, one participant stated that they were lost in terms of developing an identity now that they were no longer someone’s spouse. They explicitly asked, “Am I still a spouse?” Others expressed worry about how to redefine

themselves without partners as a seniors, describing that it felt impossible to build a new life and meaning at their age. While these experiences are not unique to loss during COVID-19, they were certainly exacerbated and made more complex by the limitations imposed by the pandemic. Participants expressed that one key challenge to creating new identity was their inability to join groups of others in similar positions, such as “widows,” in order to begin developing this new identity as a “widow” rather than a “spouse.”

Finally, due to COVID-19, many patients had returned home to die, meaning and spouses had to take on the role of being caregivers. This was particularly true for individuals that were caring for persons with long illnesses. When addressing their role as caregivers rather than spouse, one participant stated:

I took care of them, I was their total care giver, and we had friends yes, but they were in so much pain we didn't go anywhere. The only thing the pandemic did was force the friends that we had... and I at our age they are far and few between, they couldn't come because then everyone is exposed to the covid. So... that was difficult. - *Participant 9*

This role of caregiver became very isolating during COVID-19 and left many feeling “empty” following the loss. “Empty” was a very common phrase that participants used to describe their emotions during the bereavement group.

#### 3.4.3.4 Risk Taking amidst Restrictions

During the focus group, a running joke amidst participants was their apparent “criminal history” of face-to-face meetings and close personal contact with people outside their household during the pandemic. Following their spousal loss, one participant described their experience of needing physical contact and stated that,

[Spouse] died on [date during pandemic] so... the only... I see my child. My child lives in [town] by themselves, so they come. And yes, I hug them. I said to them... if you don't hug me, nobody will!... if you don't hug me nobody will... so, they hug me every time. -*Participant 11*

This desire for physical touch amidst loss is not uncommon, however it violated the Reopening Ontario Act (2020). Another participant stated:

Today I met a guy in the grocery store whose spouse passed away in December and we did her service for virtually, and they were good friends of ours, and they were a part of our social group. And you know what? When we saw each other, we just hugged. And I said, "are we supposed to be doing that?", we had our masks on, we were in the grocery store, but it was like.. You know what? It was just... we need to hug each other, and we did. And we stood and chatted for half an hour but they're having a hard time too with the COVID... I mean, it's affecting a lot of people in different ways but as far as the MAiD went, then... and [SPOUSE] did the provision during the shut down... we were all here together. Because that was important to us. And I don't really care what anybody else thinks because we could all be dead next year. So we've [got to] live today. - *Participant 5*

Several participants whose loved one accessed MAiD during the lockdown accepted the legal risk in order to have their family present for the death. Several agreed that the risk was well worth the legal repercussions, with some participants travelling to different health regions to access their support network. One participant stated:

I have to turn myself in just like [Participant 5] because I drove to [city] to see my son and daughter in law and grandkids who came home from 2 different universities, of course they were in co-op housing... and of course my son greeted me with "well, what are we going to do here?" \*laughs\* you know? And I said, "you're going to give me a hug!" and that was it. We were going to hug and we were going to enjoy each other for the 5 days that I was there. And it was a wonderful time, and because my spouse and I had gone there for the last 20 years every Christmas, so, um... I live in [city] so you know... the drive was 4.5-5 hours, but it was worth every minute of it. - *Participant 14*

Many participants considered access to support networks to be a priority. Despite pandemic legislature prohibiting movement and close contact, those who accepted the risk

and met with their support networks expressed no regret and were happy to do so again as it had such significant impact of their grief experience.

#### 3.4.4 When MAiD Grief and COVID-19 Collide

A unique aspect and potential advantage of MAiD is the knowledge of the exact time and date of death, and the associated opportunity to ensure the attendance of the people who the person accessing MAiD desires to be present. COVID-19 removed this advantage by limiting those that could be present during and immediately after the death. At times, this created feelings of regret and guilt for those attempting to fulfill a patient's wishes.

*Participant 3* explained that their person could not come home from the hospital. As such, they did not have the opportunity to “break the rules” when it came to public health guidelines and regulations under Ontario’s COVID-19 Reopening Ontario Act (2020). Rather, certain family members waited in the car and were present for the passing of their loved one via WhatsApp. Such a scenario where there are limitations due to the loss occurring during COVID is not unique to MAiD.

*Participant 8* reflected on how it had become dangerous for their person to remain at home with only them. As a result, “they had to go back into hospital. Nobody could visit.” Often, these stories were told through tears or obvious frustration, as their impact was still felt. One participant ultimately drove their person to the hospital with their children to die by MAiD. They remarked on how challenging that experience was given they were expected to leave the hospital shortly afterward, feeling the absence of their person in the car acutely.



COVID caused MAiD practice, particularly the final MAiD procedure, lost its distinct advantage. It created a situation in which patients and family faced the burden of additional choices as well as cases where wishes could not be honoured in the way that the participants intended. In this manner, COVID appears to have layered additional challenges into the grieving process for MAiD-involved families.

One participant (3) spoke of growing challenges amidst their family as the needs of their loved one increased. They found it challenging to hear how others were connecting with their families during COVID as they felt it had only furthered the divide following a contentious loss. While not explicitly stated, it is feasible that the social distancing mandated by COVID has provided opportunities to further these divides. It is reasonable to expect that variations between different social family units will play a role in the synergistic experience of MAiD grief and COVID-19 isolation for surviving family. At the same time, the pandemic's impacts on MAiD-involved family seems clear, as it implied barriers to connection for a group that repeatedly expressed the desire to connect and an appreciation of connection, in the face of what they experienced as a unique loss.

## 3.5 Discussion

### 3.5.1 Disenfranchised Grief and the MAiD Experience

MAiD remains a controversial means of dying in Canada, which creates a potential for social isolation and disenfranchisement for those who support this choice. There remain many questions about how MAiD grief varies from that of other more conventional losses. One way that it theoretically varies is through the potential for disenfranchised grief (Doka, 2002). Doka (2002) outlined five key factors and experiences that are more likely to lead

to disenfranchised grieving: the relationship is not recognized, the loss is not recognized, the griever is not recognized, the death is disenfranchising, and the way an individual grieves is not recognized. Particularly important to the present study is the experience of the death itself being disenfranchising. Doka (1999) defines this as occurring when:

Circumstances of the death create such shame and embarrassment that even those in recognised roles (such as spouse, child or parent) may be reluctant to avail themselves of social support or may feel a sense of social reproach over the circumstances of death. (p. 38)

Our data suggest that some MAiD families are experiencing that their loved one's death itself is disenfranchising. Participant narratives that reflect the unwillingness to disclose the nature of the death, the severing of familial ties, and the fear of disclosure within a religious or spiritual community support the consideration of MAiD death as potentially disenfranchising. This finding provides an impetus for the development of MAiD-loss communities.

### 3.5.2 MAiD, COVID-19 and the Synergistic Potential

The experience of MAiD has the potential to be an isolating and disorienting process to navigate for both patients and families. COVID-19 can be isolating, generate uncertainty and worry, and create challenges in the creation and sustainability of relationships and communities. The combined effects of a MAiD loss and COVID-19 restrictions can produce a synergistic effect with respect to adaptive management of grief. This research found two key ways that MAiD grief and COVID-19 restrictions interact synergistically:

1. COVID-19 policy impacted the previously beneficial features of MAiD and created a significantly more complex environment at the time of death.
2. COVID-19 policy amplified isolation in a group exposed to heightened disenfranchisement as a result of the nature of their loss and thus enhanced their isolation during a vulnerable period of grief.

As discussed earlier, it was significantly easier to lose fragile support networks during COVID. However, this was doubly problematic for a group already at risk of disenfranchisement due to the nature of their loss. There are many reasons that social isolation occurred during COVID-19, including legislations established in Ontario and the collective trauma and hardship that everyone experienced living through a pandemic. Those grieving a MAiD loss were subject to these experiences as well.

Gillies and Neymeier (2006) describe the experience of bereavement in the following way:



Figure 1: Stroebe & Schut Dual Process Model (2001)

Commonly the bereaved experience missing, longing, and yearning for the deceased; intrusive thoughts, memories, and images of the deceased; intense emotional episodes of sadness, crying, loneliness, and fear; decreased energy and activity; loss of pleasure; social withdrawal and isolation; and feelings of meaninglessness and hopelessness (Burnett, Middleton, Raphael, & Martinek, 1997; Parkes, 1996). (p.33)

Gillies and Neymeier (2006) additionally addresses Stroebe and Schut's (2001) dual process model, wherein the grief is

integrated and identity is reconstructed following a loss. It is a non-linear process by which an individual can move freely between restoration and loss-oriented approaches in their grief. They state that:

According to the Dual Process Model (Stroebe & Schut, 1999, 2001), a bereaved person faces tasks in two distinct domains. The first, loss-oriented coping, refers to those activities that deal with separation from a lost attachment figure, and includes crying, missing, yearning, remembering, and all activities dealing with the loss itself—challenges often referred to as “grief work.” Restoration-oriented coping, on the other hand, refers to the activities by which one begins to build a new life and identity in which the lost person may be present in a spiritual and symbolic, but not physical way. Adaptation involves oscillating between these two opposing orientations in a dynamic give-and-take, until a point of satisfaction can be achieved and maintained in both areas. Stroebe and Schut (2001) recognized the central drive that motivates these tasks is the search for meaning, both in the lost relationship and in a newly (re)constructed life. (Gillies & Neymeier, 2006, p.36)

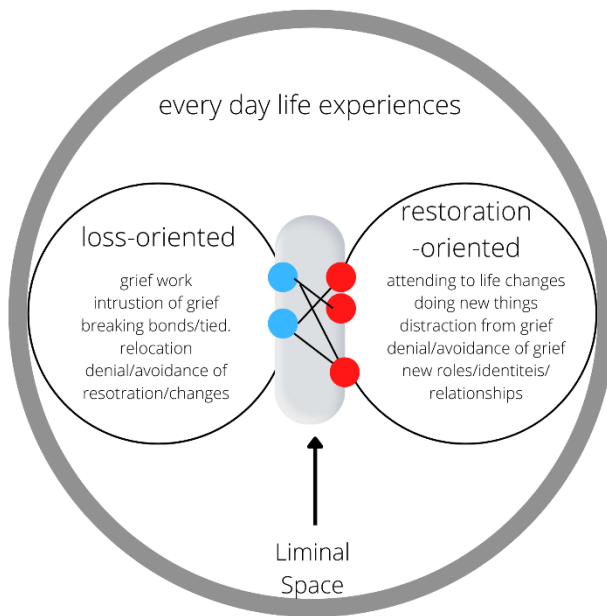


Figure 2: MAiD and COVID-19 as barriers to free movement between orientations

Both MAiD and the conditions imposed by COVID-19 have the potential to interfere with this process. While Figure 1 demonstrates the oscillation between both the loss and restoration tracks that occur in normative loss during “normal” times, Figure 2 demonstrates areas in which MAiD might interfere (blue) and COVID-19 might interfere (red). MAiD appears to predominantly impact the

loss-oriented track, while COVID-19 appears to have a greater impact on the restoration-oriented track. As you can see described in Figure 2, the blue and red areas create “barriers”

to the natural oscillation between both processes, leaving an individual to remain in a new third area; “liminal space.”

This “liminal space” orientation is derived from a concept in anthropology and meaning a space in between social identities and states of being (Roberts, 2018). Being in “liminal space” prevents an individual from fully engaging in their loss and their restoration. This caused them to remain static and hindered their capacity to move forward with their grief, their healing, and their lives.

MAiD poses challenges in terms of undertaking typical grief work such as non-MAiD bereavement support (e.g., group supports, supports through parish or church) and therapy for fear of disclosure and “outing” oneself. MAiD can impact the bonds and trust people share in families and social groups, especially if close relations voice their disapproval of this form of dying. Simultaneously, COVID-19 imposed isolation, caused an inability to engage socially or try new things. This led to challenges creating new social identities and meaning because those require social engagement to create. These limitations are synergistic, and create barriers to free movement between both orientations of grief management. This has the potential to lead to grief prolongation as one remains in the liminal space of the MAiD-COVID interplay and limit the development of new identity and meaning.

The capacity to re-integrate and reconstruct identity following a loss is critical with respect to grief. Diolaiuti et al. (2021) found that,

Among the protective factors, greater levels of social support may be expected to correlate with better grief outcomes (Chen, 2020; Romero et al., 2014). However social distancing may reduce the positive effects of social supports. In addition,

greater spirituality, defined as the search for and the construction of an existential meaning according to Bellingham and colleagues (1989), can have a protective role. (p. 3)

However, the pandemic has posed unique limitations upon this necessary process, as many had to grieve in isolation. This is dually true of those who experienced a MAiD loss, which is already subject to isolation and disenfranchisement (Frolic et al., 2020; Oliphant et al., N.D), in addition to the compounding and synergistic effects of isolation due to the COVID-19 pandemic. Diolaiuti et al. (2021, p. 2) additionally state that “It is reasonable to expect that a considerable part of these people will be unable to adaptively overcome these traumas and, consequently, they could face the development of psychopathological reactions and pathological pain, including complicated grief (CG) (Horowitz et al., 2003).” The health risks associated with complicated grief (CG) and prolonged grief disorder (PGD) are numerous and must be considered when approaching those at risk of grieving in isolation, particularly when synergistic features like a MAiD loss are included.

### 3.5.3 Recommendations and future research

A series of recommendations emerged from both this analysis and from the emerging literature. These recommendations include but are not limited to:

- 1) Create virtual, professionally managed MAiD spaces where psychological safety is prioritized to facilitate connection and community building in an evidence informed and professionally supported way.
- 2) Prepare families in advance of the MAiD procedure with respect to the unique features of MAiD, including what the loss will look like and what will be expected of them.

- 3) Ensure ready availability of resources that are specific to the needs of MAiD families.
- 4) Involve psychospiritual care, social work, and psychotherapists in advance of MAiD, particularly in the instance of family conflict.
- 5) Ensure these same resources and groups are available virtually throughout the duration of COVID-19.

Finally, it is important that research on the topic of MAiD grief during the COVID-19 pandemic continue because research can serve the important function of identifying specific resources that should be developed and sustained.

#### 3.5.4 Strengths and Limitations

This paper represents a unique contribution to the growing body of both MAiD and COVID-19 literature. Based on research within the Canadian context, it discusses how the social conditions, such as public health mandated isolation and the interaction of a controversial way of dying can prolong the grief experience and contribute to more challenging grief navigation for those experiencing a loss. Limitations of this paper include a small and specific sample size of participants who desired community to discuss their experiences with a MAiD loss, which has the potential to bias the participant pool towards those that seek community and social engagement. Member checking to ensure congruence with participant experience could further contribute to the rigor of this research.

### 3.6 Conclusion

There is a potential for those simultaneously experiencing a loved one's death by MAiD and the challenges imposed by COVID-19 response policy to experience additional synergistic hardship during their bereavement. MAiD has the potential to amplify disenfranchisement, isolation, and the loss of social bonds and connections. Similarly, pandemic guidelines increase isolation, decrease access to social engagement, and reduce people's ability to interact and create new social identity following a significant death. It is important to consider the factors that amplify bereavement challenges and to create meaningful infrastructure that can be adapted to the pandemic to support those who are grieving.

Throughout the eight weekly sessions and the two focus groups, participants were eager to discuss their experiences of MAiD, the pandemic, and their grieving processes. This manuscript reflects their desire to share this information. Resources for communities of grief, MAiD grief in particular, are uniquely essential during public health crises like COVID-19. This manuscript offers information about these challenges as well as scaffolding to facilitate the development of appropriate resources to support those experiencing a loss and to help them move beyond the liminal space between loss and restoration.

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## 4 Don't Shy Away: A Relational Ethics Approach to Understanding the MAiD Legacy and Experience with Health Care Providers through Narrative Analysis of Bereaved Family

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**Authorship:** AO conducted, analyzed and reported data and formed the structure of this manuscript. All authors provided intellectual material, guidance and support in the writing of this manuscript. The primary author contributed a minimum of 85% of materials and efforts.

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## 4.1 Introduction

MAiD (Medical Assistance in Dying) became legally accessible to eligible Canadians in 2016 following the Supreme Court of Canada decision in *Carter v. Canada*. This change to the criminal code, titled Bill C-14 at the time, established that Canadians who were suffering intolerably, had a foreseeable death, and were competent to make decisions with respect to their end of life could access assistance in dying. MAiD now accounts for more than 3% of all Canadian deaths annually (Government of Canada, 2022).

Quoting the Canadian Hospice Palliative Care Association, Gauvin and Lavis (2023, p. 14) state that “each death [in general] in Canada affects the immediate well-being of an average of five other people, or more than 1.25 million Canadians each year.” Though it is not currently known the average number of significant persons involved in MAiD care, this statistic is significant when considering the impetus for accessible loss and grief support to MAiD-involved family. MAiD patients often require family support and direct involvement through the MAiD process, which includes request, assessment, and provision

(Frolic et al., 2020). As the provision of MAiD increases in Canada, it is important to consider how to best support families involved with MAiD. There is emerging evidence that MAiD loss can be particularly challenging for surviving loved ones (Frolic et al., 2020). MAiD itself does not necessarily enhance or worsen the experience of grief because the death itself is sometimes seen as being better than other types of witnessed deaths (Holmes et al., 2018). However, people are more likely to experience isolation and disenfranchisement when grieving in contentious deaths such as those resulting from MAiD. These experiences can be reasonably expected to worsen grief outcomes (Wagner et al., 2012).

It is well established that maladaptive grief, such as complicated grief and bereavement, have notable health implications (Avis et al., 1991; Bowling, 1987; Stroebe, 1994; van der Houwen 2010). From a consequentialist perspective, the impact that MAiD has on patient family members thus constitutes an important factor to consider in the moral and healthcare delivery landscape of this end-of-life practice. Understanding the family experience is valuable because it allows MAiD programs both in and out of hospital settings to undertake evidence-informed steps for quality improvement (Frolic et al., 2020). It also further promotes the palliative care mission of facilitating whole-person care that incorporates the family (Government of Canada, 2018).

This article takes as its point of departure research conducted about a professionally facilitated, virtual grief and bereavement peer support group run for MAiD-involved families in Southwestern Ontario. There were two objectives at the core of this work: 1) to document and understand family experiences of MAiD deaths in this Canadian provincial health system, and 2) to assess the effectiveness of the peer bereavement support group for

this unique family population. The primary findings of this research, which are reported in a separate article (Oliphant et al., in preparation) indicate that the bereavement group had a positive impact on participants' ability to generate new meaning and personal identities following their loss. The present article seeks to explore secondary findings from participant narratives pertaining to their experiences with healthcare providers during and following their experience supporting a loved one through MAiD.

The primary author conducted non-participant observation of the bereavement group. During group sessions, study participants expressed a clear and apparent interest to have their experiences with clinical teams and hospitals documented in order to facilitate education and practice development. This manuscript seeks to honour that interest through a qualitative analysis and description of the narratives of bereaved individuals following their MAiD loss. This work employs a relational ethics perspective to draw on bereavement group participants' narratives to examine how clinician behaviour can impact the bereavement experience of MAiD families.

According to Ethical Research Involving Children (ERIC, 2022), "Relational ethics situates ethics within the context of relationships and respectful engagement characterized by recognition, support and acceptance of the other and their experiences." Relational ethics encompasses the dynamics of how clinicians engage in a therapeutic relationship, the outcomes of that relationship, and the moral and value-based elements of that relationship. Critically, a relationally-ethical practice will facilitate trust, which is essential when clinicians provide information (e.g., prognoses, options) to patients and families. This trust is crucial to patient and family members' ability to make informed decisions. Participants' accounts of their interactions with clinicians in the context of



MAiD makes it clear that attending to family is ethically important in and of itself. An awareness of the outcomes of relational elements of MAiD care can offer clinicians an opportunity to improve the bereavement outcomes (what *ought* we do to best serve this patient and their family, how *ought* we do it) and, from a wider perspective, the public health outcomes of MAiD-involved families grieving their loss as maladaptive, unsupported, or unrecognized grief can negatively influence the health of individuals experiencing bereavement.

## 4.2 Background

### 4.2.1 MAiD Practice and MAiD Families

In Ontario (the jurisdiction of this research), MAiD can be administered by either nurse practitioners (NPs) or physicians (MDs). The MAiD process and approval hinges heavily upon clinicians because clinicians can decide to make a patient aware MAiD as an option. They can also be approached by a patient interested in discussing MAiD. At this time, the College of Physicians and Surgeons of Ontario (CPSO, 2022, published online) direction states that “The federal government has noted that the federal legislation does not specify a timeline within which the referral to these services and/or treatment must take place.” This creates ambiguity about the potential obligations to refer patients for MAiD assessment and provision. In Ontario, the College of Physicians and Surgeons of Ontario (CPSO) and the College of Nurses of Ontario (CNO) require that clinicians who morally object to assessing for or providing MAiD provide patients with effective referral or transfer of care to a clinician who is willing and able to assess for and provide MAiD if they are approached by patients or family members seeking this service (CPSO, N.D; CNO,

2021). Bouthillier and Opatrny (2019) found in their study of conscientious objectors in MAiD practice that,

The majority of physicians who refused to participate did not oppose medical aid in dying. The reason most often cited is not based on moral and religious grounds. Rather, the emotional burden related to this act and the fear of psychological repercussions were the most expressed motivations for not participating in medical aid in dying. (p. 1212)

Finally, MAiD provision requires a clinician that is available and willing to provide MAiD. As such, a patient and family's access to MAiD and experience within the MAiD process hinges heavily upon their trust in and relationship with the clinician.

Families frequently choose to support the patient in their request for MAiD and to dedicate effort to ensure access to this service even if they themselves have moral objections to the practice (Holmes et al., 2018). Family and loved ones are often significantly involved as advocates and supporters and serve as points of contact throughout the process (Frolic et al., 2020). Since 2020 and as a result of COVID-19, family members have also needed to undertake additional roles as care providers in homecare settings while patients await their MAiD assessments and potential approval. Previous studies have identified particular features of MAiD that can impact patients' families, such as the known timing of death (Beuthin et al., 2021; Hashemi et al., 2021), the active role that family takes in the process (Beuthin et al., 2021), the challenges family members encounter related to disclosing the nature of the death (Goldberg et al., 2019), and the performative and practical challenges/elements of MAiD provision from the family perspective (Oczkowski et al., 2021). While some other works do address how clinician objection impacts the family at a high level (Hales et al., 2019), there is a notable paucity

of articles that address the impacts of the healthcare provider/clinician's relationship with the family affects family members' experience of bereavement following a MAiD loss.

#### 4.2.2 Relational Ethics and the Significance of Relationships

The choice of language, degree of involvement, and therapeutic relationship with a clinician can have lasting and meaningful impact on a family member. This work directly considered the impacts of the healthcare provider relationship (the normative ethical question of "what ought we do" in order to maximize benefit and reduce harm) with MAiD-involved family, and therefore falls within the framework of "relational ethics." This moral attention to relationship cannot be detached from the role of caregiving, particularly as it relates to fiduciary duties and acting in the benefit of another. In their study of Canadian nurses, MAiD, and relational ethics, Thiele and Dunsford (2017, p. 994) state that "[relational] ethics includes the awareness of the whole situation, one's contributions, and the effects of actions." For the purposes of this paper, relational ethics as it relates to MAiD-involved families incorporates family and physicians' interactions during the MAiD process, as well as the legacy of the MAiD experience that emerges in family members' bereavement narrative. A framework of relational ethics bridges the normative (what ought we do) with the relational (what ought we to do given this relationship, and how is the relationship impacted).

Based on the above definition, with each interaction between clinicians and family, it can be assumed that the therapeutic relationship is either fostered and grown, or not. This is not to describe the creation of relationships in healthcare as dichotomous, but rather as a spectrum wherein the social outcomes of patients and their loved ones are contingent upon the degree of trust building, familiarity, and willingness to engage with their clinician.

When there is a breakdown in relationships with health care providers as a result of conflicts such as moral disagreement, there is potential for ethical challenges to emerge such as poor communication, poor treatment planning, challenges meeting the standard of care, and discontinuation of the relationship altogether. While there is a paucity of evidence around the consequences of therapeutic relationship breakdown in the context of MAiD, it has been observed in other socially complex care such as anti-vaccination in the pediatric context (Fortune & Wilson, 2007). While there has been a preoccupation in the ethics literature pertaining to the relational impacts of MAiD requests on clinicians, most particularly clinicians who conscientiously object to MAiD (Heilman & Trothen, 2019), the relational impacts of clinician behaviour and engagement on family remain under-considered. This is a critical gap in understanding the relational ethics dynamics of MAiD practice.

### 4.3 Methods

This research initially intended to determine the efficacy of a MAiD-specific bereavement group through eight weeks of group observation, two focus groups with group members, and a psychometric tool called the Grief and Meaning Reconstruction Index (GMRI; Gillies et al., 2014). Findings presented in the present paper emerged in the periphery of the initial study intent. This paper is based on secondary analysis of bereavement group participants' narratives collected during focus groups, as well as through qualitative observation of MAiD-bereavement group focus groups. Secondary analysis is a form of research whereby researchers use pre-existing data that was collected for a separate purpose in order to "address new questions which were not a focus of the original study" (Irwin, 2013, p. 296). While more commonplace in quantitative data sets,

secondary analysis is an emerging practice in qualitative research where “For several decades, social scientist methodologists have pointed to the innovative potential of secondary analysis of qualitative data” (Sharpe & Munly, 2021, p. 44). In reviewing data from the bereavement group study, it became clear that participants regarded the clinicians involved in their MAiD process as influential in shaping their experiences of this process and their loss.

According to Saunders et al. (2017, p. 1893), theoretical saturation is “used in qualitative research as a criterion for discontinuing data collection and/or analysis.” Saturation, in this sense, occurs where the analysis of the data demonstrates repetition such that there is no additional need for data collection and inclusion of participants. Rowlands, Waddell and McKenna (2015, p. 43) describe a model of theoretical saturation that “assumes that the researcher collects sufficient interviews to provide a corpus from which they can draw qualitative conclusions.” This approach to theoretical saturation was present in this research. Saturation was determined to be reached after themes had emerged and been addressed by a variety of participants across the course of the focus group and observation.

The goal of the secondary analysis was to characterize the relationships and interactions between clinicians and MAiD-involved families, and to determine how these experiences impacted participants’ bereavement. This secondary analysis involved an inductive, conventional qualitative content analysis (Hsieh & Shannon, 2005) with data sourced from both focus groups, as well as the non-participant observations throughout the eight week sessions. The data were used to identify themes by constant comparison and open coding (Glaser, 1965). Focus group transcripts were thematically analyzed to generate codes and

data inclusive of the observation notes were then coded accordingly using NVIVO software.

## 4.4 Results

Overall, all 14 group members participated in the eight weekly bereavement group sessions and corresponding observation, as well as in focus groups (seven members per focus group). Themes that emerged from this qualitative data suggest that experiences with healthcare providers have an impact on bereavement, specifically in the following three ways:

- 1) the impact of a clinician's response to the request for MAiD (compassion or alienation);
- 2) the impact of how clinicians provide psycho-spiritual supports during and after the MAiD process, and;
- 3) the impact of how clinicians prepare families for MAiD (ie. The details of the MAiD process).

These considerations emerged in their narratives around their bereavement and are significant when considering how clinical teams and individual clinicians can proactively support families.

### 4.4.1 Demographics

The bereavement group and demographic data collection occurred between November 2020 and February 2021, with focus groups occurring in February 2021. The majority of the group self-identified as female, middle income, white, the spouse of the

deceased, and over the age of 65. All members were present at the time of death of their loved one. There was variation with respect to the timeline of their loss, with a majority having lost their loved one within the last two years.

#### 4.4.2 The impact of a clinician's response to the request for MAiD (compassion or alienation)

During the bereavement group and focus groups, participants discussed healthcare providers, specifically physicians, in a dichotomous way. Some participants worked with physicians who were supportive and thus discussed favourably and with a sense of appreciation, whereas others experienced physicians who were resistant and made loved-ones feeling alienated, ignored, or “difficult” if they were too insistent on access to MAiD care. One participant stated that:

The resident that we... oh, sorry she was a fellow, um.. That we had assigned to us an oncologist was very standoffish about it. Who... the person who told us about MAiD was the psychiatrist at [hospital] and that is a brand new program, they have never had a psychiatrist in that hospital before. So he was the one who mentioned it to us and when we brought it to the attention of the oncologist, she just didn't want to... that was not something she wanted to talk about and again, like I said in the group, um... on one phone call, made reference 3 times to me about how difficult this was for her... – *Participant 8*

In instances where the participant felt their loved one was being judged or met with clinician resistance, they felt it was their burden to carry in order to reduce the perceived psychosocial impact on their dying loved one. This same participant (**8**) stated that, “I never told [spouse] about that because they just adored her, and in terms of the medical piece and the medication and all that other stuff, she was providing great care.” Other participants stated that they were labelled as “difficult” or subject to other derogatory or unpleasant terms (*Participant 9*) if they pushed for their loved one's expressed wishes against the

recommendations of the health care provider. Some participants reported feeling that they were perceived as “difficult,” both explicitly through name-calling and implicitly through a series of non-verbal cues and outright demonstrations such as active avoidance (eg. clinicians leaving the room/area to avoid the family member). This led them to feel distanced and alone as they attempted to care for their loved one at the end of their life, and this anger was carried into their experience of post-loss bereavement.

Family members filled the roles of advocates for their loved one, which is not an uncommon role for family to assume when a patient is critically ill. It is in this advocacy role that they experienced frustration and abandonment when clinicians did not want to address the option of MAiD. One participant stated:

The family doctor was not really on board with [spouse]’s care and they weren’t really ready to sign off on it so we went directly to MAiD... and it's just the small things you know? You call and you leave a message and think wow... will anybody call you back? It's talking to a machine... - *Participant 7*

Others found that the unwillingness to discuss MAiD was systemic, and within the system where they were attempting to access this legal service, current practices created unnecessary barriers and eroded the trust between them and their clinical team. Participant 9 stated:

I had everybody... from our first doctor to the second psychiatrist... down here in [city] it’s a whole different world. They are about 35 years behind times [...] it’s true, the medical system down here... and I am a part of it, is archaic. I mean I have been retired for a number of years but um... They are not open. They don’t discuss things. They shy away from everything. And if you suggest something different, it's like you’re ostracized. - *Participant 9*



These experiences were discussed ruefully, fatigue and frustration evident through the tone of their voice and registering on their faces, and sometimes emphasized through exasperated sighs.

Conversely, when participants discussed their experiences with involved, supportive, and facilitative healthcare providers and clinicians, they discussed their experiences with a sense of peace and fondness. One member began to cry during the first bereavement group session when describing the compassion of the physician that supported them in this process. This compassionate approach is deeply valued and remembered by those who experience it. One participant described in session five how they voluntarily corresponded with clinicians after their loss. The clinician had been supportive of their loved one's decision by verbally acknowledging that this was an appropriate choice for them, and thus provided a sense of peace around the decision. There was evident value in reconnecting following the loss, as this reconnection was identified as meaningful and helpful. One participant stated:

Their [spouse's] palliative care doctor called me about a week after [spouse] passed away to reassure me that [spouse] did the best for themselves and the best for their family, and they (doctor) reached out to see if we needed any counselling, then they could set it up. Plus the hospice, their hospice group, the director of [region] hospice, they reached out and said that they could set things up. – *Participant 5*

When healthcare providers made an effort to connect and create support around the request or decision for MAiD, participants discussed their involvement with appreciation. Affirmation of choice made a substantial difference for this particular participant and allowed them a sense of peace around their loss.

#### 4.4.3 Impact of Clinician Psycho-Social Supports on Family Bereavement Experience

When reflecting upon their experience, participants indicated that questions emerged during their bereavement that could have been addressed earlier in the care plan and the trajectory of illness. This suggested the importance of early grief education beginning before a death occurs. As this research specifically involved bereft participants, they reflected upon the bereavement group itself as a post-loss resource, describing the curriculum and how it impacted them. This is pertinent to clinician behaviour because it is important to recognize that observing a death and experiencing a loss is an often hidden and undiscussed experience that is not routine for the public. Clinicians have an ability to provide insight, support, education and referral to supportive services in advance of a death. One participant (*12*) described the impact and significance when clinicians addressed the experience of a loved one's death directly and provided adequate psychoeducation and death-normalization in a supportive setting. They stated that:

The first, I think 3 [of the MAiD bereavement group], sessions were basically little lessons on grief... and like, I don't know. A lot of things we went over were answers to questions I didn't even really know I had. Figuring out like, oh, what I've been experiencing is a grief burst, or like, you know... or, like, I don't know. Like, there's a name for the kind of grief I am feeling! Like, it was just really... it brings... and when you're that emotional, when you're that lost and like that... any kind of validation or information is ... it's just so necessary. It was just really helpful. Very validating, very informative. – *Participant 12*

Some participants described clinicians that incorrectly assumed MAiD grief is unique (*Participant 5*) and were thus asserted that they were not able to provide adequate support and education for them. Another participant reflected on the general lack of grief and bereavement support provided through settings such as hospitals and stated that:

I think grief education is something we... don't... do... and so, you know, if we can kind of put it out there and ask people to read it and think about it, and you know... they are going to face this sooner or later – *Participant 2*

Many participants reported feeling “weak” after their loss. They spoke of their sadness and grief with guilt, like they failed to be strong (Session 1 observation). Efforts to normalize grief responses before their loss may have had the potential to ameliorate some of these more negative associations. One member suggested the use of MAiD companioning or of support from a navigator role throughout the process. Nods were observed amidst the group in response to this expressed desire to have a MAiD knowledgeholder who understands the system and what to expect accompany families through the process and advise them accordingly.

During the sixth session, one participant described an experience where their family doctor was supportive but felt they were unable to be a MAiD provider or refer a MAiD assessor. This left the participant with questions and a lack of answers about available resources as their loved one oscillated between desire for MAiD and a frustration with being in a position where this was felt to be their only viable option, all of which resulted in confusion and complex feelings. This participant identified the role of a MAiD support team member as someone who could offer clarification and support for the family and patients in accurately describing processes and experiences in order to be better understood while having their needs more appropriately met.

#### 4.4.4 The Impact of Clinician Education/Transparency re: MAiD Process for Family Bereavement

There are particularities in the MAiD process that can be communicated and described early on to patients and family in order to clarify the process while reducing anxiety and

the potential for surprise or shock. Participants expressed a degree of upset over seeing a MAiD death and how it appeared, as well as about the behaviour of their loved one on the day of the procedure. This suggests that some clinicians lack awareness about the needs, preparedness, or past experience of the family member; or that they did not engage with family member expectations questions. *Participant 12* stated that:

For me, I think I got a little bit of... I mean I'm not a doctor, I'm not a psychologist, but I think I have a little bit of PTSD, like, I've never seen someone die before... I had never seen a dead body... and that affected me in ways that other deaths haven't... have never and would never affect me. – *Participant 12*

Another participant reflected upon the immediate process leading to death, and stated that:

Because we specifically chose that [spouse] would not die at home, for our kids, what a... what a weird thing to do, to prepare to leave the house... get the kids... the kids were coming, my parent was coming... I drove... I have no recollection of that whatsoever. Just knowing what is going to hap...like, there are procedural steps? I will apologize for my language but it is a complete mindfuck. Just... having all... they tell you what's going to happen and then it happens and it's like... that just happened... – *Participant 8*

Neither of these two participants was aware of how the procedure and death would physically appear or of what emotions might follow, including numbness, shock, peacefulness, and ambivalence. While this range of emotions is normal and expected, it is not commonly described to family facing an imminent loss in the Canadian context. As a result, families expressed a sense of confusion over their feelings immediately after the death. Participant 12 experienced their parent behaving unusually normal, as if the day of their MAiD provision was a routine appointment, and that was felt to be off-putting. However, in MAiD practice, it is not necessarily abnormal for a person to behave happily or normally on the day of the procedure, as it is suspected they are experiencing some relief at the premise of their suffering ending (Frolic et al., 2020). During the sixth bereavement

group session, a participant described their shock as the speed of the MAiD procedure itself, and described it as being “over too fast.” Participants did not describe that clinicians provided any information about immediate grief normalization or any other psychosocial responses that may follow witnessing a death of a cherished person. However, they did describe a desire for such information, which suggests that little or none was provided. This is something that can be addressed and described by clinicians in advance, particularly with clinician administered MAiD. The procedure is quite often very quick and quiet and this has the potential to be unsettling for participants who may expect a longer time between administration of the medication and death.

## 4.5 Discussion

There is a moral dimension that exists in all healthcare practices by virtue of the fact that humans with unique values, stories and experiences are providing and receiving care (Wright et al., 2009). Each individual will understand needs, wants, refusal and tolerances differently. Herein lies a challenge. It is at the clinicians’ discretion to determine if they can provide MAiD care without sustaining moral injury. However, we must also consider that a clinician’s decision to remove I from the therapeutic relationship, or in certain circumstances to act as a barrier can result in adverse impacts on the trust and relationship formed between the clinician and the family and patient. There are opportunities to foster this relationship, maintain trust, and provide emotional support beyond the context of MAiD, as MAiD care provision is not an “all or nothing” system and a clinician can still offer therapeutic and relational benefit to the patient and family without directly engaging in a morally risky practice for themselves.

Creating relationships framed within the context of beneficence (how can clinicians best support the family using available skills and resources) and non-maleficence (not doing harm by socially withdrawing from the relationship with the family nor creating hostile environments), while not participating in specific practices (eg. direct provision of thanatic medications, performing MAiD specific assessments) that can be morally injurious to the clinician, has the potential for better patient and family outcomes. Finally, there is a persistent ethical impetus to maximize autonomy, which can be done through exploration of patient and family needs, experiences, values and what they determine to be harmful within their own worldview. As such, a relational ethics approach can also facilitate patient and family autonomy through open, good-faith conversation and engagement in the therapeutic relationship.

In a Canadian study by Thiele and Dunsford (2017), four foundational pillars of relational ethics practice are identified within the context of MAiD care from the perspective of nursing leadership. They identified mutual respect, engagement, environment, and embodiment. The pillars of mutual respect, engagement, and environment are most applicable to considerations of the clinician-family relationship, whereas embodiment was a pillar described within the patient context and does not translate effectively to the experience of family members.

In their description of the pillar of mutual respect, Thiele and Dunsford (2017) state that,

relational ethics takes mutual respect to involve acknowledgment of power differences, values, beliefs, knowledge, and experiences. With respect to MAiD,

this can play out in a struggle between the patient's right to request an assisted death and a nurse's [or other care provider's] right not to provide or participate in it. (p. 994)

With respect to bereavement, it is important to recognize that no matter how losses occur, a family will need support and understanding. Support and understanding can be provided through the lens of mutual respect. A compassionate clinician can facilitate resource access, provide psychoeducation prior to the losses, and offer psycho-emotional support to a family whether they feel the method of dying aligns with their values or not. A clinician does not have to support MAiD to support a family, normalize their experience, provide emotional validation, and to help guide and care for them during and after a death. Instead, they can foster the therapeutic alliance and build relationships with family members through effective referral, self-reflection, and continued support for the family and patient's other practical, social and psychological needs.

It is evident in the findings of this research that clinicians have enormous potential to improve family outcomes during bereavement by fostering an effective relationship, respect, and trust with family prior to their losses, while bringing interprofessional resources into the care of families to support their needs before and after their loved one has died. Opportunities to provide grief education and facilitate grief literacy were also suggested in the narrative of the family members. MAiD itself does not necessarily impact bereavement, but isolation, grief illiteracy, fear of the unknown, as well as experiences of shame, guilt, judgment and fear of reprisal certainly can (Wagner et al., 2012). As noted throughout this article, clinicians and health teams are uniquely situated to proactively support families and address these factors that can worsen bereavement. It is important for

the above reasons that a healthcare provider examine their own biases and experiences as an ongoing element of practice improvement and ethical engagement in their practice.

Thiele and Dunsford (2017, p. 995) state that engagement “requires effort to understand the situation, perspective, and vulnerability of another person.” Caring for a family as they support a MAiD patient is not an act of euthanasia. There is substantive care that can be provided that does not fall within the strict dichotomy of omission or commission. Facilitating an effective MAiD referral means alleviating families of the burden of navigating the uncertainties of a system without support. This referral process is not actively participating in MAiD. It is simply ensuring that a patient is given access to the opportunity to make an informed decision while exploring all legally available options. Referral gives the family the opportunity to support a loved one without having to further manage feelings of judgment, and sparing their loved one additional suffering or fear of not having their wish validated or granted. Undergoing preventable emotional labour to navigate barriers throughout the healthcare system can indeed be harmful, psycho-socially injurious, and cause suffering that persists into bereavement for family members acting as advocates.

Thiel and Dunsford (2017, p. 996) critically address the environment in which relational ethics can be enacted, stating that “relational ethics requires an organization where ethical reflection happens. The organization’s environment is affected by the ethical moments that arise in the course of a day. The ability to attend to these moments, explore their complexity, and then engage to achieve a resolution results from an environment of mutual respect.” Clinicians working in an environment that is supportive of family must reflect on their own capacity to provide care, what life experiences and values they possess



that enable or prevent their participation, the needs of the team and family, and how they can best facilitate those needs.

One tool by which a team can act to support a family is interprofessional engagement. Interprofessional engagement and collaboration are found to be a strong, supportive model of MAiD care (Oliphant & Frolic, 2020). It has strengths by virtue of the fact that the expertise of diverse health professionals, including psychospiritual care and social work, can offer supports that are well-suited to families experiencing non-pathological psychosocial hardship such as an imminent loss.

Other research suggests that by taking an interprofessional approach to MAiD care provision, families and patients are better supported as a whole person (Frolic et al., 2021). One way by which interprofessional collaboration has proven beneficial to MAiD-families is through the inclusion of psychology. One paper discussed how,

psychologists working within the hospital settings have been shown to act as a mediator of communication between patients, their families, and health care providers and provide psychoeducation to family members, in addition to applying basic behavioral principles to improve health within broader familial units. (Singer et al., p. 91)

This could certainly benefit families involved in MAiD care, as psychology, social work or spiritual care could all provide information regarding grief; act as an intermediaries between the clinical team and the patient or family; normalize the grief and bereavement experience; and provide psychoeducation resources and referrals for community services that would best meet the unique needs of the families. While these papers consider

psychosocial care provision within the hospital context, there remains a gap in the literature pertaining to how to bridge services so that a family remains in contact with a trusted care provider during and after their time within the walls of a hospital. Though research pertaining to the efficacy of post-death support groups varies in terms of impact, it is clear through research on pre-death intervention that:

Optimal bereavement support begins with significant others being a part of the dying process, and recognized as members of the health care team, regardless of their roles of responsibility and assistance in the care. Empirical evidence shows that early intervention provided to a distressed family before the death of a terminally ill patient can ease their bereavement and reduce depressive symptoms. A study of a support group programme for relatives during the late palliative phase revealed a sense of belonging, created by sharing similar experiences and not being alone. (Näppä et al., 2016, p. 7)

If these pillars of relational ethics can be met through interprofessional engagement, self-reflection, perspective-taking, trust and engagement with families, there is increased likelihood of improved family outcomes in bereavement. When met with a request for MAiD, clinicians and healthcare providers are uniquely positioned to support families, and that care can have lasting impacts. It is understood that shame, guilt and maladaptive grief can have long-term physiological and psychological impacts (Avis et al., 1991; Bowling, 1987; Stroebe, 1994; van der Houwen 2010). Simultaneously, we also understand that these risk factors for maladaptive grief can be identified and proactively supported prior to the loss (Stroebe et al., 2010). As such, supportive and attentive clinicians and healthcare providers who actively undertake this relational ethics framework in their practice and are armed with the correct tools and training to identify these risk factors for challenges in bereavement have the potential to influence and support improved health outcomes in a broader and more inclusive sense (Breen et al., 2020). This is a logical thought process,

though Logan et al. (2018, p. 471) state that “although social support is consistently reported to be one of the most significant predictors of psychological outcomes following bereavement (Burke & Neimeyer, 2013), studies have found that bereaved persons often do not receive sufficient or timely informal support to moderate their grief experience.”

#### 4.5.1 Strengths and Limitations

This research is limited by the self-selection of group participants, as they voluntarily enrolled in the bereavement group and thus felt they had a need for additional support in their bereavement. This information emerged organically through the observation of the bereavement group and the focus groups and is interpretive in nature. These findings constitute the families’ interpretations of events and experiences and may not consider the clinical requirements or constraints. Further research regarding effective family support is essential to furthering MAiD practice in Canada and to ensuring that the goals established in the Canadian Palliative Care Guideline with respect to care for families are appropriately met. Member checking to ensure congruence with participant experience could further contribute to the rigor of this research.

#### 4.5.2 Recommendations for Practice

Several recommendations emerged both from this research and through family feedback. The following are the key recommendations distilled from the data:

Theme	Practice Recommendation
1) The impact of a clinician’s response to the request for MAiD (compassion or alienation)	<ul style="list-style-type: none"> <li>Engage in reflective practice regarding your own unique values and how they arose. Explore your fears with respect</li> </ul>

	<p>to MAiD practice and determine if you have knowledge gaps.</p> <ul style="list-style-type: none"> <li>• Recognize that your language, tone, and body language can impact family members who are vulnerable in either a positive or negative way. Act with beneficence in mind.</li> <li>• Families expose themselves to risk or reprisal, abandonment, shame, and relationship breakdown when advocating for information about and discussion of MAiD. Recognize that families are attempting to act in the patient's best interests and to fulfil the patient's expressed wishes.</li> <li>• Do not shy away from difficult conversations. Families have come to you as a trusted health professional, and this trust is essential to the ongoing therapeutic relationship with the family and the patient, acting in the patient's best interests, and meeting fiduciary duties.</li> <li>• Familiarize yourself with mechanisms for effective referral, MAiD-specific resources, and information to better inform patients and ensure that MAiD is being explored appropriately without unnecessary delay. MAiD is a time-sensitive practice, and delays can cause substantial physical and psychological harm to the patient, and thus the families</li> </ul>
<p>2) The impact of how clinicians provide psycho-spiritual supports during and after the MAiD process</p>	<ul style="list-style-type: none"> <li>• Proactively prepare the family adequately with resources for grief literacy and bereavement while exploring their own psychological support. MAiD is fraught with guilt over doing too much, too little, or not enough for their loved one, and this guilt can carry into their bereavement.</li> </ul>

	<ul style="list-style-type: none"> <li>• If available in your organization or community, offer psychoeducation to the family prior to the death of their loved one. Grief, loss, and death experiences and natural grieving behaviours are rarely inherently understood. Grief normalization can offer families the knowledge that these are “normal” experiences as they move forward in their bereavement.</li> </ul>
<p>3) The impact of how clinicians prepare families for MAiD (ie. The details of the MAiD process)</p>	<ul style="list-style-type: none"> <li>• Describe how the death will appear, what the family can and cannot do during and following the death (e.g., hold hands, stay at the bedside, care for the body, accompany the body to the morgue).</li> <li>• Use clear, concise, and specific language such as “death.”</li> <li>• Normalize behaviour that may be observed, such as the patient appearing happy and improved on the day of provision.</li> <li>• Provide information on immediate reactions following a death and normalize the shock, confusion, or lack thereof that may follow. All reactions are appropriate and normal.</li> <li>• Describe the process of MAiD in detail from assessment to provision to limit surprise or uncertainty as much as possible. Be available to answer questions about the process.</li> </ul>

## 4.6 Conclusions

This study is distinct from other studies of the MAiD family experience because it specifically addresses the relational ethics implications for MAiD practice. It forms a novel contribution to the literature through its consideration for the potential impacts of relationships between healthcare providers and families of MAiD patients. To this team’s

awareness, no other literature to date has considered the potential impact of relationships between healthcare providers and MAiD-involved families. Indeed, even in our initial study, we had not planned to explore those relationships specifically; the significance of these experiences resonated strongly enough in our data to merit their own analysis. Experiences with clinicians have a legacy; they are carried beyond the walls of the hospital and are evident in the anger, frustration, guilt, uncertainty, and/or sense of support expressed during the participants' bereavement.

The findings of this research uniquely consider the legacy of clinician behaviour as described in the bereavement narrative of MAiD-involved families. This paper addresses this legacy through a relational ethics framing of the longitudinal impacts of clinician behaviour on family members. A relational ethics approach to the impacts clinician behaviour on the family experience is appropriate because a single death can resonate with multiple individuals in a family unit. With this knowledge, tailoring clinician behaviour to attend to the needs of these families during the MAiD process can have beneficial public health implications.

This manuscript discusses the impetus to construct relationships with patients, regardless of moral position regarding euthanasia, in order to provide ethical and appropriate care that supports families. Ruptures to the therapeutic relationship with family can follow into their bereavement process, and an unwillingness to continue to engage in the care of their loved one can be potentially harmful and contribute to avoidable suffering. There are indeed opportunities for interprofessional involvement, psychoeducation, and grief support to facilitate high-quality care for families. While it is unclear at this time if standard protocols and resources exist that offer a continuum of care between the hospital

and the community for MAiD-loss support, it is clear that there is a desire for this ongoing support and community. Recommendations such as ensuring a clear understanding of the MAiD process, while offering resources for navigation of this process to families were reiterated by those bereaved by MAiD. Though MAiD itself did not appear to contribute to worse grief outcomes, challenges encountered throughout the process such as disengaged or morally opposed medical staff and a lack of MAiD specific community and resources was found to be problematic. Both during care and after a patient loss under their care, healthcare providers have the potential to act as a support or as a barrier to resources (e.g., therapists, support groups) and care for the involved family. It is imperative that this relationship be recognized with respect to the potential for adverse or adaptive grieving experiences and outcomes. This relationship, within the spectrum of supportive or adversarial, has lasting psychological, emotional, and practical impacts on the family members of those seeking an assisted death.

Overall, the experience of MAiD and the relationship between family and healthcare providers both directly involved in and at the periphery of MAiD practice from the family perspective has opportunities for improvement. The ability for clinicians and healthcare providers to proactively support, listen attentively, act compassionately and non-judgmental facilitate resource access for families is likely to improve their bereavement experience after they depart from the location of their loved one's death and into their futures.

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## 5 Conclusions

### 5.1 Relevant Findings

Overall, this research indicates that there are unique elements to the experience of MAiD bereavement that may, under certain circumstances, require the support of a community of individuals with similar experience in order to openly discuss the nature of their loss.

At the core of this PhD research is a MAiD bereavement group that operated from November 2020 to February 2021. It was the first of its kind in Southwestern Ontario. The structure of the bereavement group was well-received by its 14 participants and the program itself offered supports to the participants that they deemed effective and helpful in their experience of grief and bereavement. Details pertaining to the impact and efficacy of the bereavement group for participants and a proposal on the apparent effectiveness of such programs to facilitate meaning-making following the death of a significant person by MAiD are outlined in the first manuscript (Chapter 2). Many programs continue to rely on volunteer and peer facilitation; however, the container created by this group structure and the psychoeducation may be beneficial. As we write, a second iteration of this program is being considered, with the intent to publish a “playbook” on how to operationalize and sustain a similar program within institutions such as this one in SWO. It is the understanding of this author that members of the original bereavement group continue to meet and that a trip together is in the works.

The second manuscript in this dissertation (Chapter 3) discusses the synergistic effect of MAiD loss, and the challenges that were experienced throughout the pandemic as a

result of legislated stay-at-home orders and social distancing. In this chapter, we report that the combination of MAiD and the pandemic likely amplified the experience of isolation overall. The pandemic posed additional challenges in terms of maintaining and renewing contact with others following the death of a significant person. This had an effect on some members' ability to reconceptualise their identity, find and engage in new interests, and be socially supported. Groups such as the one assessed as the primary focus of this research can act as a means to create a community of loss virtually so that members can feel engaged and integrated socially without fear of reprisal, legal concerns, or health concerns.

Finally, this research explored the impacts of clinician behaviour on the experiences of family members supporting a significant person through the MAiD process. These findings are captured in Chapter 4. Here, we report on findings that participants experienced anger and resentment at clinicians that acted as barriers to access or who expressed their disapproval. Participants carried these feelings into their bereavement, where they emerged as frustration without an outlet. Conversely, participants who were supported and offered resources, and who had their experience affirmed spoke of their experience positively and suggested that they did not "second guess" themselves during their bereavement. This lends itself well to consideration of these interactions through a lens of relational ethics, wherein a clinician can foster or inhibit their relationship and either benefit or do harm to a family through their engagement with them on a relational level.

## 5.2 Contributions to the Literature

These findings make meaningful contributions to the body of Canadian literature on MAiD, as it considers the family perspective as the primary locus of the research. Few

articles to date center the family experience, and our federal data does not collect or reflect the family experience beyond the scope of how they serve the patient.

This research offers practical and evidence-based recommendations for how to best support MAiD-involved families, and implement infrastructures that offer meaningful supports that are desired in this community. While the use of the GMRI remains contentious, the tool it acts as a “jumping-off” point for understanding the impacts of bereavement group involvement and qualitative data remains essential to augment the GMRI in the interpretation of the results. Member checking to ensure congruence with participant experience could further contribute to the rigor of this research.

Finally, there is generalizability in terms of support group structures that can be created for a myriad of types of loss. This work indicates that a hospital can, in fact, operate a free of charge and professionally supported bereavement program for families that had a significant person die in their organization. This evaluation demonstrates the impact and efficacy of this resource.

### 5.3 Final Reflections

Throughout the course of this research, I learned a great deal about the nature of grief and the expectations of those who are bereaved. This opportunity to explore the depth and breadth of the experience of a MAiD death will be an experience I will carry forward into my professional practice. Through the openness and candor of the participants I was granted insight in to the challenges and hopes they encountered in clinical contexts and beyond. Though I maintain a primary orientation as a qualitative researcher, I learned a great deal about the complexity of mixed methods research and the values and pitfalls of

this approach. In particular, I agree with the assertion that grief and the experience thereof remains challenging to address and describe through research. However, the pragmatic aim of determining through research if the support was well-received offers an ethical impetus for continuing to navigate these complex waters. As always, I remain grateful for the opportunity to learn and for the trust I was granted by the bereavement group membership. I foresee future opportunities to explore the experiences of MAiD from the patient perspective, as that remains an area of interest and the final stakeholder in the MAiD process that I have yet to address. My desire has always been to engage in work that can provide data to meaningfully shape and effect practice based on the interests of those most affected, and I hope this thesis accomplishes some small part of that aim.

## 5.4 Concluding Remarks

MAiD remains a contentious practice, despite Canadians being able to access this medical service since 2016. Families, often acting as advocates, caregivers, and emotional supports for MAiD patients, remain under considered in the literature despite the exponential growth of patients accessing MAiD annually and the reasonable expectation that this means a growing number of involved family tied to the patients. There is an impetus to provide whole person, whole family care in accordance with the 2019 palliative care guidelines, which is inclusive of family members. Supports can be created, sustained, and accessible as well as evidence informed and professionally facilitated for families experiencing a loss through MAiD. Clinician behaviour can be adjusted if the harms done are made clear. Resources can be provided when events occur that drive wedges between members of our community. This research offers insights into these areas, and proposes methods to address these concerns that are practical and low cost. There is more that can

be done to support MAiD-involved families, and it is ethically imperative that their experiences be given consideration and addressed. As MAiD continues to advance with the inclusion of new patient populations (Track 2 patients under Bill C-7, MI-SUMC, pediatric patients, etc.), further supports and research may be necessitated to assess and meet the needs of families in to the future and advance our understanding of what constitutes best practices and high-quality whole-person MAiD care.



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## Appendices

### Appendix 1.0: Grief and Meaning Reconstruction Index

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## APPENDIX: GRIEF AND MEANING RECONSTRUCTION INVENTORY

Name: \_\_\_\_\_ Date: \_\_\_\_\_

The following statements refer to thoughts, beliefs, feelings, and meanings some bereaved people experience following their loss. Please circle the number that rates the degree to which each of these experiences has been true for you **in the past week**, on a scale from 1 to 5:

- |                                |                    |
|--------------------------------|--------------------|
| 1 = Strongly disagree          | 4 = Agree          |
| 2 = Disagree                   | 5 = Strongly agree |
| 3 = Neither agree nor disagree |                    |

1. The time I spent with my loved one was a blessing.	1	2	3	4	5
2. I do not see any good that has come from this loss.	1	2	3	4	5
3. Since this loss, I'm more self-reflective.	1	2	3	4	5
4. I value family more.	1	2	3	4	5
5. I will see my loved one again.	1	2	3	4	5
6. Since this loss, I find myself more alone and isolated.	1	2	3	4	5
7. I've been able to make sense of this loss.	1	2	3	4	5
8. Since this loss, I'm a stronger person.	1	2	3	4	5
9. I can't understand this loss.	1	2	3	4	5
10. I was prepared for my loved one to die.	1	2	3	4	5
11. My loved one was a good person; he/she lived a good life.	1	2	3	4	5
12. I value and appreciate life more.	1	2	3	4	5
13. Since this loss, I've changed my lifestyle for the better.	1	2	3	4	5
14. Memories of my loved one bring me a sense of peace and solace.	1	2	3	4	5
15. This death brought my loved one peace.	1	2	3	4	5
16. I've lost my innocence.	1	2	3	4	5
17. This death ended my loved one's suffering.	1	2	3	4	5
18. I miss my loved one.	1	2	3	4	5
19. Since this loss, I make more effort to help others.	1	2	3	4	5
20. I feel empty and lost.	1	2	3	4	5
21. I cherish the memories of my loved one.	1	2	3	4	5
22. Since this loss, I value friendship and social support more.	1	2	3	4	5
23. My loved one was prepared to die.	1	2	3	4	5
24. Whenever I can, I seize the day. I live life to the fullest.	1	2	3	4	5
25. Since this loss, I'm a more responsible person.	1	2	3	4	5
26. I believe my loved one is in a better place.	1	2	3	4	5
27. I feel pain from regrets I have in regard to this loss.	1	2	3	4	5
28. I've come to understand that life is short and it gives us no guarantees.	1	2	3	4	5
29. Since this loss, I've pursued new avenues of knowledge and learning.	1	2	3	4	5

<i>Factor</i>	<i>Item #'s</i>
1. Continuing Bonds	1, 5, 11, 14, 18, 21, 26
2. Personal Growth	3, 8, 13, 19, 22, 25, 29
3. Sense of Peace	7, 10, 15, 17, 23
4. Emptiness & Meaninglessness*	2, 6, 9, 16, 20, 27 [*these items are reverse scored]
5. Valuing Life	4, 12, 24, 28



## Appendix 2.0 Qualitative Instruments

### Semi-Structured Focus Group Script and Questions

Hello everyone and thank you for attending this virtual focus group this morning/afternoon/evening. My name is Allyson Oliphant and I am doctoral candidate at Western University, who has partnered with the Office of Ethics and Care Ecologies at HHS for this research. During the focus group today, I would like to hear your experience of a virtual care environment for MAiD bereavement. During the discussion please reflect upon the experiences you've had during this bereavement group, your overall experience of bereavement following a MAiD death, and the impact of 2020 and the virtual care environment on your experience. The discussion will last approximately 90 minutes, and will be digitally recorded. The recording of our discussion today will be transcribed by me, and any identifying details will be de-identified in the final transcript. Only myself, and my supervisory team will have access to the de-identified transcript, and if this research is presented or published, data from this discussion it will be completely de-identified. Before we begin, I'd like to establish a few 'ground rules' for our discussion:

- Speak one at a time
- Identify yourself by name each time you speak to facilitate tracking of comments throughout the discussion and avoid misattribution (explain process to protect identity). You can make up a name if you prefer, as long as you use it consistently throughout this focus group
- Respect the confidentiality of the discussion – what is said in this conversation is not to be shared outside of this focus group
- Respect views that may be different from their own – the purpose of the focus group discussion is to explore and capture the perceptions and experiences of the people in the room- we hope that those who have a view that is different from others will share it!
- Turn off your cell phones. Unless you are using a cellphone, in which case please mute your background notifications
- Encourage participants to avoid the “round robin” Q/A approach and discuss questions amongst the group

Does anyone have any questions before we begin?

- 1) What were your thoughts about joining a virtual bereavement group like this?
  - a. Probe: what were your worries?
  - b. Probe: what were your hopes?
  - c. Probe: where any of your hopes or worries realised?
- 2) How did the pandemic affect your bereavement?
- 3) How did this group, being entirely online, effect your experience?

- 4) What impact did your participation in this group have on your understanding of the role of grief in your life?
- 5) Did you seek support (formal or informal) after your loved one died?
  - a. Probe: Who did you speak to?
  - b. Probe: Why? Why not?
- 6) Besides this group, was there support offered to you following your loss by any clinicians/groups/friends/etc.?
- 7) Did this support group meet your needs/expectations?
  - a. Probe: What needs were unaddressed before this group? Unaddressed during this group?
  - b. Probe: What were your expectations?
  - c. Probe: Why?
  - d. Probe: why not?
- 8) Did you find the facilitators where effective?
  - a. Probe: did they meet your expectations?
  - b. Probe: did they provide the experience you were looking for?
- 9) What was done well?
  - a. Probe: what did you like about it?
- 10) What could be improved?
- 11) Did you find the weekly emails with resources helpful?
- 12) Have members of your family benefited from your involvement in this program?  
If so, how?
- 13) Are there any other thoughts you would like to add?

## **Observation Guide**

1. Description of Setting, Participants, Researcher
2. Occurrences during observation (tensions, function, receptivity to the material, and impact of the material, areas for improvement, areas of success, etc.)
3. Reflections on Observation
4. Patterns observed thus far

## Appendix 3.0: HIREB and WREM Approval Letters



Nov-10-2020

**Project Number:** 12583

**Project Title:** Medical Assistance in Dying(MAid) and Meaning The Impacts of a Professionally Facilitated Bereavement Group on Meaning Generation and Psycho-Social Outcomes Following a MAid Loss

**Principal Investigator:** Dr. Andrea Frolic

This will acknowledge receipt of your letter dated October 19, 2020; November 9, 2020 and November 10, 2020 which enclosed revised copies of the Information/Consent Forms, Recruitment Poster, Questionnaire, Interview Recruitment Email, Protocol and the Application Form along with a response to the additional queries of the Board for the above-named study. These issues were raised by the Hamilton Integrated Research Ethics Board at their meeting held on October 7, 2020. Based on this additional information, we wish to advise your study had been given *final* approval from the full HiREB.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Participant Records and Codebook	Aug-27-2020	1
V.1 Post-Group Questionnaire	Aug-27-2020	1
V.1 Pre-Group Questionnaire	Aug-27-2020	1
V.1 Semi-Structured Facilitator Interview	Aug-26-2020	1
V.1 Observation Guide	Aug-26-2020	1
V.1 Invitation to Pre-Questionnaire	Aug-27-2020	1
V.1 Invitation to Focus group and Final GMRI	Aug-27-2020	1
V.2 Poster	Oct-19-2020	2
V.2 Interview Recruitment Email - Facilitators	Oct-15-2020	2
V.2 Focus Group Questions	Oct-14-2020	2
Version 4.0 Research Protocol	Nov-09-2020	4
V.4 LOI-C Facilitators	Nov-09-2020	4
V.4 LOI-C Group Members	Nov-09-2020	4

The following documents have been acknowledged:

Document Name	Document Date	Document Version
Frolic TCPS2	Aug-27-2020	1
Approval Letter WREM	Oct-19-2020	1

**In light of the current COVID-19 pandemic, while this study has been reviewed by HiREB and given final approval status, the actual conduct of the research needs to be performed in accordance with institutional restrictions with respect to Corona virus (which may mean new subjects cannot be actively enrolled and most research staff will be limited with respect to access to other data sources for the time being).**

**Please Note:** All consent forms and recruitment materials used in this study must be copies of the above referenced documents.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the HiREB meeting on October 7, 2020. Continuation beyond that date will require further review and renewal of HiREB approval. Any changes or revisions to the original submission must be submitted on a HiREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

**PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE**

Sincerely,

A solid black rectangular box used to redact the signature of the sender.



Chair, Hamilton Integrated Research Ethics Board

The Hamilton Integrated Research Ethics Board (HIREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton, and the Faculty of Health Sciences at McMaster University and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Healthcare Hamilton, HIREB complies with the Health Ethics Guide of the Catholic Alliance of Canada



**Date:** 19 October 2020

**To:** Professor Elysee Nouvet

**Project ID:** 116606

**Study Title:** Medical Assistance in Dying(MAiD) and Meaning The Impacts of a Professionally Facilitated Bereavement Group on Meaning Generation and Psycho-Social Outcomes Following a MAiD Loss

**Application Type:** HSREB Initial Application

**Review Type:** Delegated

**Meeting Date / Full Board Reporting Date:** 03/Nov/2020

**Date Approval Issued:** 19/Oct/2020

**REB Approval Expiry Date:** 19/Oct/2021

Dear Professor Elysee Nouvet

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

**Documents Approved:**

Document Name	Document Type	Document Date	Document Version
V.1 Pre-Group Questionnaire	Online Survey	26/Aug/2020	1
V.1 Post-Group Questionnaire	Online Survey	26/Aug/2020	1
V.1 Semi-Structured Facilitator Interview	Interview Guide	26/Aug/2020	1
V.1 Observation Guide	Non-Participant Observation Guide	26/Aug/2020	1
Poster	Recruitment Materials	26/Aug/2020	1
V.1 Invitation to Focus group and Final GMRI	Recruitment Materials	27/Aug/2020	1
V.1 Invitation to Pre-Questionnaire	Recruitment Materials	27/Aug/2020	1
V.2 Phone Call Screening Tool	Telephone Script	15/Sep/2020	2
V.2 Focus Group Questions	Focus Group(s) Guide	14/Oct/2020	2
V.2 Interview Recruitment Email - Facilitators	Recruitment Materials	15/Oct/2020	2
Version 3.0 Research Protocol	Protocol	15/Oct/2020	3
V.3 LOI-C Facilitators	Written Consent/Assent	15/Oct/2020	3
V.3 LOI-C Group Members	Written Consent/Assent	15/Oct/2020	3

**Documents Acknowledged:**

Document Name	Document Type	Document Date	Document Version
References	References	26/Aug/2020	1

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

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C,

Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

A solid black rectangular box used to redact the signature of the sender.

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

## Curriculum Vitae

**Allyson van Kessel (Oliphant), MA. PhD (C.)**

### Degrees

**2018/9 - 2022/8**      Doctoral Thesis, PhD - Health and Rehabilitation Sciences,  
Western University

*In Progress, Candidacy Granted, anticipated completion September 2022*

Supervisors: Dr. Elysée Nouvet, Dr. Kenneth Kirkwood

Committee: Dr. Maxwell Smith, Dr. Carrie Arnold

**2015/9 - 2017/11**      Masters Thesis, Master of Arts - Medical Anthropology, McMaster  
University *Completed*

Supervisors: Dr. Ellen Badone, Dr. Andrea Frolic

**2009/9 - 2014/10**      Bachelors with Honours, Bachelor of Arts - Anthropology, Wilfrid  
Laurier University

*Completed*

### Clinical Experience

#### *Fellowships*

**2021/09-2022/08**      Clinical Ethics Fellowship, Hamilton Health Sciences (HHS)  
Program for Ethics and Care Ecologies (PEaCE)

#### *Internships*

**2016-2020**      Clinical Ethics Internship, Hamilton Health Sciences, Program for Ethics  
and Care Ecologies (PEaCE)



## Certificates

### *Research Certificates*

- 2020/08** Tutorial for Researchers Conducting Retrospective Review of Health Records *Complete*
- 2019/2** CITI GCP - Good Clinical Practice Certificate, Collaborative Institutional Training Initiative *Complete*
- 2016/8** TCPS2: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, McMaster University *Complete*

### *Teaching Certificates*

- 2019/1 - 2021/04** Western Certificate in University Teaching and Learning, Western University *Complete*
- 2020/1** TESOL-Teaching English to Speakers of Other Languages Certificate, International Open Academy *Complete*

### *Professional Development*

- 2022-2023** Project Management Professional, McMaster Continuing Education *In Progress*
- 2021/01- 2021/04** Certificate in Motivational Interviewing, Monarch System, Western University *Complete*
- 2020/11** Certificate in Health Equity Impact Assessment, Public Health Ontario *Complete*

## Continuing Education

### *Courses Taken*

- 2021/06** *Project Management: Essential Elements I & II, Complete*

- 2021/01 – 2021/04** SGPS 9105 Promoting Resilience in Graduate School and Beyond, *Complete*
- 2021/02** Creating Accessible Visual Aids, *Complete*
- 2020/06** Developing a Culturally Affirming Teaching Practice, *Complete*
- 2020/06** Leadership in Wellness, *Complete*
- 2020/01 – 2020/04** SGPS 9500 The Theory and Practice of University Teaching, *Complete*

### **Research Experience**

#### ***Investigator***

**2020/06- 2021/08** Co-Primary Investigator - At the Front of the Front-Line: Ontario Paramedics' Experiences of Risk, Safety, and adapted patient care protocols during the 2020 COVID-19 pandemic

*Primary Investigators: Ms. Allyson Oliphant, Dr. Elysée Nouvet, Dr. Cathy Faulds*

**2020/03 – Present** Co-investigator – Triaging Critical Care During COVID-19: Global Preparedness, Socio-Cultural Considerations, and Communication

*Primary Investigators: Dr. Elysée Nouvet, Dr. Lisa Schwartz, Dr. Patricia Strachan, Dr. Sonya DeLaat, Dr. Dr. Lydia Kaporiri*

*Co-Investigators: Dr. Michela Luciani, Dr. Alessio Conti, Ms. Allyson Oliphant, Ms. Erin Monette*

#### ***Research Assistant***

**2017- 2021** Research Assistant, Medical Assistance in Dying Program - Hamilton Health Sciences, Program for Ethics and Care Ecologies (PEaCE)

*Supervisor: Dr. Andrea Frolic*

**2020/01-2020/04** Research Assistant, drOTS P.S.: Drones in Madagascar, Western University

*Supervisor: Dr. Elysée Nouvet*

***Journal Reviews***

**2020/10** British Medical Journal (BMJ) - Journal of Medical Ethics (JME)

**2017/11** NEXUS, The Canadian Student Journal of Anthropology

**Publications**

***Journal Articles***

*Published*

**2022/08** Dr. Priscilla Medeiros, **Ms. Allyson Oliphant**, Mr. Steven Barrow, Ms. Priyanka Gill. Anthropological Engagement with Global Health: A Comparative Review. *Medicine Anthropology Theory*

**2022/01** **Ms. Allyson Oliphant**, Dr. Cathy Faulds, Ms. Samara Bengall, Dr. Elysée Nouvet. At the Front of the Front-Line: Ontario Paramedics' Experiences of Occupational Safety, Risk and Communication During the 2020 COVID-19 Pandemic. *International Journal of Emergency Services*

**2022/02** **Ms. Allyson Oliphant**. The Invisible Ethnographer: Trust, Ethics and Community in a Digital Bereavement Group During COVID-19. *SAGE Qualitative Methods*

**2021/07** Dr. Michela Luciani, Dr. Patricia Strachan, Dr. Alessio Conti, Dr. Lisa Schwartz, Dr. Lydia Kapiriri, **Ms. Allyson Oliphant**, Dr. Elysée Nouvet. (2021). Methodological and practical considerations in rapid qualitative research: Lessons

learned from a team-based global study during COVID-19 pandemic. *International Journal of Qualitative Methods*.

**2020/11** Dr. Andrea Frolic, Ms. Marilyn Swinton, Ms. Leslie Murray, **Ms. Allyson Oliphant** (2020). Double-edged MAiD death family legacy: a qualitative descriptive study. *British Medical Journal (BMJ)- Supportive and Palliative Care*

**2020/04** **Ms. Allyson Oliphant**, Dr. Andrea Frolic. (2020). Becoming A Medical Assistance in Dying (MAiD) Provider: An Exploration of the Conditions that Produce Conscientious Participation. *British Medical Journal (BMJ) - Journal of Medical Ethics*.

*Submitted and Peer Reviewed*

2022 A.Frolic, P. Miller, W. Harper, **A. Oliphant** - MAiD to Last: Creating a Care Ecology for Sustainable Medical Assistance in Dying Services, HEC-Forum

2022 A. Frolic, **A. Oliphant** - Introducing Medical Assistance in Dying in Canada: lessons on pragmatic ethics and the implementation of a morally contested practice, HEC-Forum

2022 A. Frolic, M. Swinton, L. Murray, **A. Oliphant** - Access Isn't Enough: Evaluating the Quality of a Hospital Medical Assistance in Dying Program, HEC-Forum

*In Progress*

2022 **A. Oliphant**, E. Nouvet, K. Kirkwood, M. J. Smith, C. Arnold. A. N. Frolic. - Forming a Community of Loss: A Mixed-Methods Evaluation of the Experience and impact of a Medical Assistance In Dying (MAiD) Bereavement Group

2022 **A. Oliphant**, E. Nouvet, K. Kirkwood, M. J. Smith, C. Arnold. - Love, Limitations and Loss: The Unique Experience of MAiD Grief in the Time of COVID-19 from the Perspective of Directly Involved Family

2022 **A. Oliphant**, C. E. Dougherty, A. N. Frolic, E. Nouvet, K. Kirkwood, M. J. Smith, C. Arnold. - Relational Ethics and the Ethics of Relationships: Identifying family

experience with health care providers and health systems through narrative analysis of MAiD-Involved Family

### ***Thesis/Dissertation***

#### *Masters*

**2017/09** Ms. Allyson Oliphant (2017). “If Not Me, Then Who?” The Narratives of Medical Aid in Dying (MAiD) Providers and Supporters Around Their Professional Identity and Role in MAiD. MacSphere, McMaster University

### ***Reports***

#### *Published*

**2021** Ms. Allyson Oliphant, Dr. Cathy Faulds, Ms. Samara Bengall, Dr. Elysée Nouvet (2021). "At the Front of the Front Lines": Paramedics Experiences During the COVID-19 Pandemic, Ontario Paramedic Association (OPA)

**2020** Dr. Elysée Nouvet, Dr. Patricia H. Strachan, Dr. Michela Luciani, Dr. Sonya DeLaat, Dr. Alessio Conti, **Ms. Allyson Oliphant**, Ms. Erynn Monette, Dr. Lydia Kaporiri, Dr. Lisa Schwartz (2020). Triage and COVID-19: Global Preparedness, Socio-Cultural Considerations, and Communication. Humanitarian Health Ethics (HHE)

**2018** Dr. Andrea Frolic, Ms. Marilyn Swinton, Ms. Leslie Murray, **Ms. Allyson Oliphant**, Dr. Paul Miller (2018). MAiD to Last: Creating sustainable interprofessional teams to provide high-quality medical assistance in dying. Canadian Foundation for Healthcare Improvement.

### **Funding**

#### ***Research***

**2021/04-2022/04** CAMAP (Canadian Association of MAiD Assessors and Providers) Knowledge Translation Grant

Funding Total: \$2000

*Principal Applicant: Dr. Andrea Frolic*

*Co-Applicants: Ms. Allyson Oliphant, Ms. C. Elizabeth Dougherty,  
Ms. Ann Vanderberg*

**2020/09 – 2021/08** Ontario Graduate Scholarship,

Funding Total: \$15,000

*Principle Applicant: Ms. Allyson Oliphant*

**2020/05 – 2021/08** Western Research Catalyst Grant,

Funding Total: \$43,096

*Principle Applicant: Dr. Elysée Nouvet*

*Co-applicants: Ms. Allyson Oliphant, Dr. Cathy Faulds*

**2019/11 – 2021/3** Associate Medical Services (AMS) Phoenix Fellow Support Fund,

Funding Total: \$5,000

*Principle Applicant: Dr. Andrea Frolic*

*Co-applicants: Ms. Anne Vandenberg, Ms. C. Elizabeth Dougherty,  
Ms. Allyson Oliphant*

***Conference Travel***

**2019/01** Faculty of Health Sciences Graduate Student Travel Award

Funding Total: \$250

*Principle Applicant: Ms. Allyson Oliphant*

**2019/01** Health and Rehabilitation Sciences Graduate Student Conference  
Travel Award

Funding Total: \$500

*Principle Applicant: Ms. Allyson Oliphant*

**2017/04** Graduate Student Travel Award, Department of Anthropology  
McMaster University

Funding Total: \$600

*Principle Applicant: Ms. Allyson Oliphant*

## **Presentations**

### *Conferences*

#### *Podium*

**2022/04** Dr. Andrea Frolic, Ms. C. Elizabeth Dougherty, Ms. Ann Vanderberg, **Ms. Allyson Oliphant**. *Care Beyond Walls: The Implementation and Evaluation of a Medical Assistance in Dying-Specific Bereavement Support Group for Caregivers*. Hospice Palliative Care Ontario, Toronto

**2021/04** Dr. Andrea Frolic, Ms. C. Elizabeth Dougherty, Ms. Ann Vanderberg, **Ms. Allyson Oliphant**. *Play-Book for Creating, Sustaining and Resourcing a MAiD Bereavement Group*. Canadian Association of MAiD Assessors and Providers (CAMAP) Research Forum, Online. Canada.

**2020/11** **Ms. Allyson Oliphant**, Dr. Elysée Nouvet, Dr. Cathy Faulds, Ms. Samara Bengall. *Paramedics, Power, Politics and Precaution: Lessons from SARS*

and COVID-19. CAPA - Canadian Association of Physical Anthropology. Online, Canada

- 2020/11** **Ms. Allyson Oliphant**, Dr. Andrea Frolic. *Medical Assistance in Dying (MAiD) and Meaning: The Impacts of a Professionally Facilitated Bereavement Group on Meaning Generation and Psycho-Social Outcomes Following a MAiD Loss*. CAMAP (Canadian Association of MAiD Assessors and Providers) Research Forum. Online, Canada
- 2020/06** Dr. Elysée Nouvet, Dr. Patricia Strachan, Dr. Michela Luciani , Dr. Sonya de Laat, Dr. Alessio Conti, **Ms. Allyson Oliphant**, Ms. Erynn Monette, Dr. Lydia Kapiriri, Dr. Lisa Schwartz. *Transparency in the Time of COVID-19*. International Conference on Communication in Healthcare (ICCH). Online, Canada
- 2020/06** **Ms. Allyson Oliphant**, Dr. Andrea Frolic. *Becoming A Medical Assistance in Dying (MAiD) Provider: An Exploration of the Conditions that Produce Conscientious Participation*. Canadian Bioethics Society 31st Annual Conference. Toronto, Canada
- 2019/10** Dr. Andrea Frolic, Ms. Leslie Murray, **Ms. Allyson Oliphant**, Ms. Marilyn Swinton. *MAiD to Last: Exploring Family Members' Experiences Accompanying their Loved Ones through the MAiD Process*. American Society for Bioethics and Humanities. Pittsburgh, United States
- 2018/05** Dr. Andrea Frolic, Dr. Paul Miller, Ms. Marilyn Swinton, **Ms. Allyson Oliphant**, Ms. Leslie Murray. *MAiD to Last Engaging Health Professionals, Leaders and Physicians to Shift Culture and Create Sustainable MAiD Programs*. Canadian Association for Medical Assistance in Dying (MAiD) Assessors and Providers. Ottawa, Canada
- 2017/11** **Ms. Allyson Oliphant**, Dr. Andrea N. Frolic. *Medical Anthropologists and Medical Assistance in Dying: The Effect of Anthropological Research*



*on Hospital Policy and End of Life Care.* American Anthropological Association. Washington, DC, United States

- 2017/05** Dr. Andrea N. Frolic, **Ms. Allyson Oliphant.** *Contextualizing Cross-Cultural Conceptions of Childhood in Relation to Health Care Decision Making.* Annual Canadian Bioethics Conference. Montreal, Canada

***Poster***

- 2017/04** Ms. Allyson Oliphant, Dr. Priscilla Medeiros. *HIV: The Effect of Assisted Dying Bill C-14.* CAHR the 26th Annual Canadian Conference on HIV/AIDS Research. Montreal, Canada

***Knowledge Translation***

- 2018/06** Dr. Andrea Frolic, Ms. Marilyn Swinton, Ms. Leslie Murray, Ms. Allyson Oliphant, Dr. Paul Miller (2018). *MAiD to Last - Creating Sustainable Interprofessional Teams to Provide High-Quality Medical Assistance in Dying.* St. Peters Hospital, Hamilton, ON

***Academic Competitions***

- 2019/03** Three Minute Thesis - Assisted Death: Saving the Heart of Medicine. University Finals for Top 20 Competitors, Western University

***Media Interviews***

- 2021/03** Paramedics and COVID-19, concepts of risk and safety during the pandemic, Western Gazette
- 2020/01** Medical Assistance in Dying (MAiD) and the impact of MAiD specific grief on involved loved ones, GradCast Western, PodBean

**Awards**

**2022/04** HPCO Oral Presentation Awards, *Care Beyond Walls: The Implementation and Evaluation of a Medical Assistance in Dying-Specific Bereavement Support Group for Caregivers*

## **Teaching Experience**

### *Guest Lectures*

**2021/07** ANTHROP3H13 Anthropology of health, lecture title: causes of disease and health disparities. Guest Lecture, *McMaster University*

**2021/02** Health Promotion Seminar, Guest Lecturer. *Western University*

**2020/11** Health Policy and MAiD, Guest Lecturer. *Western University*

**2020/04** Medical Assistance in Dying, an Exploration of Practice and Ethics in Canada and Abroad, Guest Lecturer. *Western University*

**2020/03** MAiD and Canadian Health Policy: History, Context and Where We Go Next, Guest Lecturer. *York University*

**2019/11** HS2801 Qualitative Research, Guest Lecturer. *Western University*

**2019/03** Medical Assistance in Dying, an Exploration of Practice and Ethics in Canada and Abroad, Guest Lecturer. *Western University*

**2018/03** Anthropology of the Body. Guest Lecturer, *McMaster University*

## **Research Supervision**

**2020/06-2021/09** “At the Front of the Front Line: Paramedics’ experience of risk and safety during the COVID-19 Pandemic”. Co-Investigator and Research Lead

Western University

*Total Students Supervised: 2*

### Special Activities and Mentorship

**2021/02-Present** Canadian Council for Global Health Research (CCGHR)  
Mentorship Program

*Total Mentees: 1*

### TA Positions

**2021/01 - 2021/04** CSD 9649 Clinical Applications of Evidence Based Practice for  
Clinicians Communication Sciences, Western University

**2021/01 – 2021/04** HS 3721 Aging globally, Lessons from Scandinavia. Health  
Sciences, Western University

**2020/01 - 2020/04** CSD 9649 Clinical Applications of Evidence Based Practice for  
Clinicians. Communication Sciences, Western University

**2019/09 – 2019/12** HS 2801 Research Methods in Health Science. Health Sciences,  
Western University

**2019/01-2019/04** GRDP AHS 9008 Health and Well-Being in Childhood and Youth.  
Applied Health Sciences, Western University

**2017/01-2017/04** 1AA3E Anthropology of Sex, Food and Death. Anthropology,  
McMaster University

**2016/09 – 2016/12** 2GO3 Readings in Indo-European Myth. Anthropology, McMaster  
University

**2016/01-2016/04** 1AA3E Anthropology of Sex, Food and Death. Anthropology,  
McMaster University

**2014/01-2014/04** AN101 Introduction to Anthropology. Anthropology, Wilfrid  
Laurier University

### Volunteer Positions

- 2018/11- Present** University Graduate Student Representative, Canadian Bioethics Society
- 2018/9 - 2019/1** Group Facilitator, Eva Rothwell Community Center After-School Program, McMaster University
- 2016/09 - 2017/04** Executive Member, McMaster University Anthropology Graduate Society (McMAGS)