An examination of the perspectives of Canadian hospice workers regarding medical aid/ assistance in dying

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Abstract

Background

The modern hospice movement and assisted dying both aim to provide end-of-life patients with a good death. The modern hospice movement has historically opposed assisted dying. It has asserted that its conceptualization of a good death provides patients and families with benefits at the end-of-life while avoiding the harms of assisted dying; these harms include the diversion of societal focus and resources from hospice care, the potential of assisted dying to be used inappropriately on vulnerable patients, and denying patients and families of meaningful end-of-life experiences by truncating the dying process. As such, hospice communities have been hesitant to integrate assisted dying into the care they provide, often citing conflict with its commitment to neither hasten nor prolong death. However, the good deaths offered by hospice communities and assisted dying have the common aim of providing patients with control over the dying process, and are rooted in the values of patient dignity and the relief of suffering. Proponents of assisted dying and some end-of-life scholars have argued that given these common aims and values, some form of co-operation between hospice communities and assisted dying could improve patient choice for a dignified death.

In Canada, the 2016 legalization of medical aid or assistance in dying (MAID) has created a new reality for Canadian hospices in which MAID is now a healthcare option for many end-of-life patients, including for those in hospice care. Literature on hospices in jurisdictions where assisted dying is legal highlighted that legalization has created new challenges for these hospices to navigate, many of which have arisen from the shared and conflicting aims and values between the hospice community and assisted dying. There have been no academic studies exclusively examining how the legalization of MAID has impacted Canadian hospices, including how shared aims and values between the two could create opportunities for these hospices.

Aim

This study was designed to understand the new reality in which Canadian hospices find themselves by identifying the challenges and opportunities hospice workers think MAID brings to a hospice.

Methods

This qualitative descriptive study included four focus groups and four semi structured interviews with Canadian hospice workers at two hospice sites, one in Alberta and another in Quebec. The Alberta hospice site allows MAID, while the Quebec one does not. A total of 23 staff members were recruited, from professions including managers, physicians, registered nurses, licensed practical nurses, and resident care aides. Participants were asked to discuss the opportunities and challenges MAID brings to hospice practice. Using the theoretical framework of *hospice as a place* as a sensitizing concept, thematic analysis was used to generate themes that explained these challenges and opportunities.

Results

We constructed five themes: 1) The availability of MAID on-site challenges a hospice's identity; 2) Hospice staff struggle to understand patient interest in MAID given staff beliefs in the abilities of hospice care; 3) The availability of MAID for hospice patients results in challenging clinical situations involving hospice patients and families; 4) Differing hospice responses to the legalization of MAID creates unique challenges; and 5) Allowing MAID on-site provides opportunities for a hospice to improve the end-of-life experience of patients and families.

Discussion and Conclusions

The results of this study provide insight into the new situations and possibilities faced by Canadian hospices since the legalization of MAID. These results, in combination with existing literature, suggest that for hospices navigating their new reality, allowing MAID on-site with the understanding that it is not a part of hospice care could be beneficial to patients, while also allowing a hospice to maintain its unique identity. It is hoped that the results of this study will provide guidance to Canadian hospices, while also laying the groundwork for future research.

Résumé

Contexte

Le mouvement moderne des maisons de soins palliatifs et l'assistance à la mort visent tous deux à offrir aux patients en fin de vie une bonne mort. Le mouvement moderne des maisons de soins palliatifs s'est historiquement opposé à la mort assistée. Le mouvement a affirmé que sa conceptualisation d'une bonne mort procure aux patients et aux familles des avantages en fin de vie tout en évitant les inconvénients de l'assistance à la mort ; ces inconvénients comprennent le détournement de l'attention et des ressources de la société des soins palliatifs, la possibilité que l'assistance à la mort soit utilisée de manière inappropriée sur des patients vulnérables et le fait de priver les patients et les familles d'expériences de fin de vie significatives en tronquant le processus de mort. En tant que telles, les communautés des maisons de palliatifs ont hésité à intégrer la mort assistée dans les soins qu'elle dispense, invoquant souvent un conflit avec son engagement à ne pas hâter ni prolonger la mort. Cependant, les bonnes morts offerts par les communautés des maisons de soins palliatifs et l'assistance à la mort ont pour objectif commun de permettre aux patients de contrôler le processus de la mort et sont ancrés dans les valeurs de la dignité du patient et du soulagement de la souffrance. Les partisans de la mort assistée et certains spécialistes de la fin de vie ont fait valoir qu'étant donné ces objectifs et valeurs communs, une certaine forme de coopération entre les communautés des maisons de soins palliatifs et la mort assistée pourrait améliorer le choix du patient pour une mort digne de leur fin de vie.

Au Canada, la légalisation en 2016 de l'aide médicale ou de l'assistance à la mort (MAID) a créé une nouvelle réalité pour les maisons de soins palliatifs canadiens, dans laquelle le MAID est désormais une option de soins de santé pour de nombreux patients en fin de vie, y compris pour ceux qui sont dans des maisons de soins palliatifs. La littérature sur les maisons de soins palliatifs dans les juridictions où l’aide à la mort est légale souligne que la légalisation a créé de nouveaux défis pour ces maisons de soins palliatifs, dont beaucoup sont nés de ces valeurs et objectifs communs et contradictoires. Aucune étude universitaire n’a examiné exclusivement les répercussions de la légalisation du programme MAID sur les maisons de soins palliatifs canadiennes, notamment la manière dont les objectifs et les valeurs communs à ces deux organismes pourraient créer des opportunités pour ces centres.

Objectif

Cette étude a été conçue pour comprendre la nouvelle réalité dans laquelle se trouvent les maisons de soins palliatifs canadiennes en identifiant les défis et les opportunités que les travailleurs des centres de soins palliatifs pensent que MAID apporte à une maison de soins palliatifs.

Méthodes

Cette étude descriptive qualitative comprenait quatre groupes de discussion et quatre entretiens semi-structurés avec des travailleurs canadiens dans deux maisons de soins palliatifs, l’une en Alberta et l’autre au Québec. Le site de l’Alberta autorise MAID, tandis que celui du Québec ne l’autorise pas. Au total, 23 membres du personnel ont été recrutés, parmi les professions suivantes : gestionnaires, médecins, infirmières autorisées, infirmières auxiliaires autorisées et aides-soignants résidents. Les participants ont été invités à discuter des opportunités et des défis que MAID apporte à la pratique des soins palliatifs. En utilisant le cadre théorique de la maison de soins palliatifs comme lieu comme concept de sensibilisation, une analyse thématique a été utilisée pour générer des thèmes qui expliquent ces défis et opportunités.

Résultats

Nous avons construit cinq thèmes : 1) La disponibilité de MAID sur place remet en question l’identité d’une maison de soins palliatifs; 2) Le personnel des maisons de soins palliatifs a du mal à comprendre l’intérêt des patients pour MAID étant donné les croyances du personnel dans les capacités des soins palliatifs; 3) La disponibilité de MAID pour les patients des maisons des soins palliatifs a entraîné des situations cliniques difficiles impliquant les patients des centres et les familles; 4) Les différentes réponses des maisons de soins palliatifs à la légalisation de MAID ont créé des défis uniques pour ces maisons; et 5) Permettre à MAID d’être utilisé pourrait fournir des opportunités à la maison de soins palliatifs d’améliorer l’expérience de fin de vie des patients et des familles.

Discussion et conclusions

Les résultats de cette étude donnent un aperçu des nouvelles situations et possibilités auxquelles sont confrontés les maisons des soins palliatifs canadiens depuis la légalisation de MAID. Ces résultats, combinés à la littérature existante, suggèrent que pour les maisons qui naviguent dans leur nouvelle réalité, permettre à MAID d’être présent sur place en sachant qu’il ne fait pas partie des soins palliatifs pourrait être bénéfique pour les patients, tout en permettant aux maisons de soins palliatifs de conserver son identité unique. On espère que les résultats de cette étude

fourniront des orientations aux maisons des soins palliatifs canadiens, tout en jetant les bases de futures recherches.

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Contributions

I, James Mellett, am the primary author of all chapters within this thesis. I designed the empirical study and completed the IRB forms, recruited hospice sites and participants, conducted the focus groups and interviews with the help of Ms. Lindsay Jane Williams and Mr. Manav Preet Singh Saini, transcribed the interviews and focus groups, coded the transcripts, drafted the narrative summaries of the focus groups and the synthesis of all the narrative summaries, interpreted the data in the synthesis to develop themes, and drafted and formatted all chapters in this thesis. My supervisor, Dr. Mary Ellen Macdonald, helped to design the study, reviewed the forms for IRB submission, reviewed the narrative summaries and synthesis of the focus groups and interviews, provided suggestions for data analysis, as well as provided edits and suggested revisions for all chapters. Mr. Martin Morris helped to design the literature review (chapter 2). Mr. Martin Daigle edited the French version of the abstract. The consent forms used in this study were based off those from a previous study in the Macdonald lab conducted by Konstantinos Mastorakis and Kevin Liu. The interview reflection form used during this study was provided by Dr. Macdonald.

Chapter 1: Introduction

1.1- Introduction

Across Canada, more than 175 free-standing hospice institutions provide care to those in life's final stages.[1, 2] Inspired by Dame Cicely Saunders' modern hospice movement, Canadian hospices work to support both patients at the end of life and their families in a home-like, inpatient setting.[1, 3, 4]

The modern hospice movement arose out of the unwillingness of acute healthcare to meet the needs of end-of-life patients and their families, and is grounded in providing a certain death and dying experience.[5-7] In this experience, the hospice patient's end-of-life needs are addressed through holistic comfort care, allowing the patient to find meaning as they face their upcoming death alongside their family and friends.[5, 8] This experience is a version of the 'good death,' which is a moral construct that specifies conditions of death and dying that are conducive to the patient and family's well-being.[9, 10]

Assisted dying has been proposed by the right-to-die movement as another conception of the good death.[11-15] Saunders and the modern hospice movement have historically opposed assisted dying.[7, 11, 16, 17] They argue that hospice care can already meet the end-of-life needs of patients, and that assisted dying deprives patients and families of meaningful end-of-life experiences, diverts societal focus and resources away from hospice care, and could be inappropriately used on vulnerable populations, such as end-of-life patients who have been judged by society or their caregivers to be a burden.[7, 11, 16-19] Given the perceived harms arising from both assisted dying and acute care for end-of-life patients, a commitment to neither hastening nor prolonging death has become a philosophical pillar of the modern hospice movement, guiding, distinguishing and protecting its approach to care, and the good death this care facilitates.[17, 20] Hospice communities have been hesitant to include assisted dying into the care they provide, often citing the conflict between assisted dying and their principle of neither hastening nor prolonging death.[17, 21, 22]

Despite this opposition, the good deaths offered by hospice communities and assisted dying share the common aim of providing patients with control over the dying process, and are rooted in the values of patient dignity, and the relief of suffering.[17, 23, 24] Some proponents of assisted dying, as well as some end-of-life scholars, believe that given these common aims and values, co-operation between hospice communities and assisted dying could improve patient access to a dignified death.[17, 23]

Recent changes in the Canadian political and legal arenas have created a regulatory environment in which some patients may seek assistance from physicians and nurse practitioners in ending their lives.[25] Canadian hospices now face the reality that assisted dying is a healthcare option for many hospice and other end-of-life patients, despite its conflict with the conception of a good death traditionally espoused by the hospice community, and the hospice principle of neither hastening nor prolonging death that is designed to protect this good death.[17, 25]

Literature on the experiences of hospices in other jurisdictions where assisted dying is legal showed that legalization has created new challenges for these hospices, many of which stem from these shared and divergent aims and values. Research on the experiences of Canadian hospice palliative care workers since legalization has also shown the creation of new challenges. There have been no academic studies exclusively examining how the legalization of assisted dying, known in Canada as medical aid or assistance in dying (MAID), has impacted Canadian hospices. Moreover, the shared aims and values between the hospice community and MAID may create opportunities for Canadian hospices. This thesis hopes to address these knowledge gaps to better understand the reality in which Canadian hospices have found themselves since legalization.

1.2- Researcher's interest in the topic and positionality

I became interested in this research topic while volunteering in palliative care after MAID had been legalized in Canada. In my discussions with palliative care workers, I was told that the availability of MAID for palliative care patients had created challenges for staff. A cursory search of the literature revealed a dearth of knowledge on the subject, especially on how MAID had affected stand alone hospices, and I took the decision to pursue this topic for my thesis project. At the beginning of the study I was aware of the benefits that MAID and hospice care could have for patients. As the study progressed, I began to realize the immense potential that collaboration between the two could have in improving options for patients at the end-of-life and their families. That said, I also began to better understand the philosophical and practical challenges MAID posed for the Canadian hospice community, which for several decades had filled a crucial need in the Canadian healthcare system by providing its conception of the 'good death'. I hope that this thesis conveys and illustrates the ethical complexity I came to appreciate while completing this project.

1.3- Outline of chapters

The following chapter will review what is known about the reality in which Canadian hospices find themselves given the legalization of MAID. As such, it will review the unique history and philosophy of the modern hospice movement, its relationship with assisted dying, and changes in Canada's political and legal arenas leading to the legalization of MAID. Moreover, it will examine the experiences of hospice and hospice workers in jurisdictions in which assisted dying has already been legalized, as well as limited research on the experiences of Canadian hospices since legalization. This chapter aims to better understand the new reality of Canadian hospices, as well as to identify gaps in the literature to better develop the objective of the empirical study.

The third chapter outlines the design of this thesis' empirical study. This outline includes a discussion of this study's research question and aim, its paradigm, theoretical framework, and methodology. This chapter also reviews this study's recruitment strategy, data collection and analysis process, as well as ethical considerations.

The fourth chapter showcases the results of the empirical study. The results highlight that for these hospice workers, MAID has created new situations in their hospices that have manifested as challenges and opportunities. Thematic analysis revealed five themes that provided an in-depth description of these challenges and opportunities. The first theme highlights how the availability of MAID on-site challenges a hospice's identity. The second theme highlights how hospice staff struggled to understand a patient's decision to choose MAID given the abilities of hospice care. The third theme explores how the availability of MAID for hospice patients whether on or off-site has led to challenging clinical situations involving hospice patients and their families. The fourth theme highlights how the differing responses of the participating hospices to the legalization of MAID have created unique challenges for these hospices. The last theme explores how the availability of MAID on-site provides opportunities for a hospice to improve the end-of-life experience of patients and their families.

The fifth chapter outlines this study's limitations, discusses the empirical results within the context of existing literature and offers recommendations for the response of Canadian hospices to the legalization of MAID, as well as for areas of future research. The final chapter provides a comprehensive summary of this thesis.

Chapter 2: Literature Review

2.1-Introduction

The new reality faced by Canadian hospices since the legalization of MAID is embedded in the history and philosophy of the modern hospice movement, its relationship with assisted dying, and changes in Canada's political and legal arenas leading to the legalization of MAID. This chapter will review the history of the modern hospice movement and the 'good death' it aims to provide, the history and current state of MAID in Canada, and the hospice community's historical opposition to assisted dying. As Canada is not the first jurisdiction to legalize forms of assisted dying, it will also examine the experiences of hospices and hospice workers outside of Canada where assisted dying is legal. Lastly, this chapter will review the limited literature on the experiences of Canadian hospices and hospice workers since legalization. This literature review chapter aims to better understand the new reality facing Canadian hospices created by the legalization of MAID, and identify gaps in the literature to help develop this study's research question.

Going forward, this thesis will use 'assisted dying' to refer to the general act of a physician or other healthcare provider prescribing and/or administering life-ending medications to a patient upon their request. MAID refers to assisted dying as permitted under Quebec's *An Act Respecting End of Life Care* and Canada's *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying).*

2.2-History of the modern hospice movement

The term ‘hospice’ can been traced to ancient Rome, where hospices referred to places of rest for travellers and the sick.[26, 27] The modern conception of hospice, however, is most associated with the work of Dame Cecily Saunders, a British nurse, social worker, and physician who founded London’s St. Christopher’s Hospice in 1967.[26, 28] In 1948, Saunders met David Tasma while she was working as a social worker in a London hospital.[6, 26] Saunders discussed with Tasma, who was dying of cancer, the idea of a new end-of-life care facility, which she described as “somewhere which would help people in his predicament; somewhere more suited for the need of symptom control and, above all, where there was a chance to come to the terms with the situation more easily than in a busy surgical ward” (p. 7-8).[6]

Saunders became committed to realizing such an institution.[6, 7] While working as a volunteer at St. Luke’s Hospital in London, she witnessed and was inspired by the facility’s treatment for end-of-life pain.[3, 29] After completing her medical degree, Saunders continued to explore different methods of pain control while performing postgraduate research.[6, 7, 29] All the while, Saunders talked to and completed formal interviews with end-of-life patients about their experiences.[6, 7] Through these interactions, Saunders developed the concept of ‘total pain,’ which she described as the experience of “physical, social and emotional pain and the spiritual need for security, meaning and self worth” (p. 9).[6] Saunders was also inspired by the values espoused by ancient hospices, which emphasized a relationship of hospitality and individual attention between the host and strangers who visited.[6, 26]

Saunders went on to found St. Christopher’s Hospice in 1967.[26] This institution, and all other hospices born out of the movement that followed, shared what Saunders described as the “common aim that people should be helped not only to die peacefully, but to live until they die with their needs and their potential met as fully as possible" (p. 8).[6] According to sociologists David Clark and Jane Seymour,[26] St. Christopher's practiced "a new approach to the care of dying people which [] harness[ed] together medical innovation in pain and symptom management with wider concerns for the practical and social needs of patients and families, as well as a responsiveness in spiritual matters" (p. 72). The care at St. Christopher's involved the use of interdisciplinary teams to address the concept of total pain,[30] and consideration of both the patient and the family as the 'unit of care.'[31]

In 1975, Dr. Balfour Mount established the palliative care unit at Montreal's Royal Victoria Hospital.[32] Mount and his colleagues had studied the care of end-of-life patients and their families at the Royal Victoria hospital, finding that many of their needs were not met.[33] They later visited St. Christopher's Hospice and sought to transplant its model of care to an inpatient care setting.[4, 33, 34] Rather than the free-standing model seen in England and the United States, Mount aimed to integrate the hospice approach within hospitals.[32] Mount's push towards integration was due to greater ease of securing government funding for units within acute care institutions,[32] the accessibility of hospice professionals to those in other hospital units, and his fear that residential hospices would become what he described as a "haven of mediocrity in medical care" (p. 472).[35] Partially due to the connotations of the word 'l'hospice' in French with poverty, Mount redefined the concept as palliative care, rooted in the latin verb 'palliare,' meaning to cloak or shield.[4, 26] The modern hospice movement continued to grow world-wide, and while the hospice communities it created manifested differently across the world, with hospices in some regions taking the form of stand-alone residences, while in others, hospices refer to inpatient and home-based care programs, the movement and the communities inspired by it were united in providing the holistic, end-of-life comfort care provided at St. Christopher's.[2, 6, 36]

In the years following the establishment of the palliative care unit at the Royal Victoria hospital, community-based hospice societies began to form across Canada.[4] Syme and Bruce[4] argue that the slow growth of palliative inpatient units across Canada led to the creation of community-based hospice societies to address unmet needs for end-of-life care. This shift also appears to have occurred as hospital-based palliative care units were criticized for perpetuating traditional medical values and practices towards death and dying.[32] Today, free-standing hospices provide end-of-life care to Canadians alongside palliative care units and teams in hospitals and long-term care homes, as well as home-based palliative care teams.[1, 2] Since its creation at the Royal Victoria Hospital, palliative care, both in Canada and worldwide, has evolved beyond its original goal of providing St. Christopher's holistic approach to care to end-of-life patients in a hospital.[37, 38] It now looks to provide this approach to those at the end-of-life who reside outside of hospices or hospitals, and to those with chronic conditions who may not be at the end of life, but whose quality of life could benefit from this care.[37, 38] Despite this divergence between palliative and hospice care in Canada, the latter focusing on end-of-life patients in residential hospices, in Canada, hospice and palliative care are often referred to as the single entity, 'hospice palliative care.'[4, 37, 38] This merging of the Canadian hospice and palliative care communities follows a similar trend internationally,[37] however, this integration has not been without tension.[4]

2.3-History of a 'good death'

The modern hospice movement is grounded in providing a 'good death' to its patients and their families.[9, 10, 24] The good death is a moral construct that specifies conditions of death and dying that are conducive to the well-being of patients and their families.[9, 10] The pursuit of a good death and dying experience by persons at the end of life, however, predates the hospice movement, and the content of these experiences varies across time and culture, shaped by the ideologies towards death and dying that are found in their particular contexts.[10, 24, 39] Hart et al.[10] note that the concept of a good death originated with French historian Phillipe Aries, who wrote extensively on death and dying in the Middle Ages. Aries, as cited in Hart at al,[10] described how the ideal dying experience during that time was a public event; those at the end of life were prominent in the community as they sought farewells, and death occurred at home surrounded by family and friends. He termed this dying experience a 'tamed death,' for people during that time did not view death with fear or as something that needed to be hidden.[10] Aries compared this conception of the good death to that of modern Western society, where the ideal dying experience is private and discrete, with the aim of minimizing the pain for surviving family and friends.[10] He termed this death and dying experience as the 'wild death' given the obsession of modern society to hide it.[10]

Walters[24] argues that the wild death, which he calls 'the modern good death,' arose in the late eighteenth century in response to developments in medical science that resulted in the reduction of many preventable deaths. He asserts that the occurrence of death thus became viewed as a failure in the face of increasing medical progress.[24] However, he writes that since the start of the twenty-first century, perspectives towards death have begun to change.[24] Death has become an event that is viewed as a normal and universal aspect of life, and also something that can be controlled.[24] This 'postmodern' view of a good death, argues Walters, underpins hospice care and assisted dying.[24]

2.4-A good death through hospice

At the core of the hospice good death is a belief that death and dying are a natural and normal part of the human experience, and as such, the modern hospice movement embraces these phenomena by focusing on holistic comfort care to improve the patient's quality of life, rather than curative care or assisted dying.[5, 16, 17] To the modern hospice movement, a good death requires patients have their physical, spiritual, and emotional needs met by hospice's holistic and interdisciplinary care, so that they can begin a journey towards death.[5, 8, 40] For the patient, this journey involves acceptance and awareness of death, resolution of one's remaining personal or interpersonal concerns, open communication with those around them,[40] and the realization of meaning.[5, 8] This meaning can be achieved by the patient living their remaining life in a way that is consistent with their values, and finding comfort and support in their family and caregivers.[5, 8, 24] To protect, distinguish, and guide hospice care and the good death it facilitates, the modern hospice movement has adopted a commitment to neither hastening nor prolonging death.[16, 17] Walters argues that the hospice good death provides patients with some control over the dying process through symptom management.[24] However, the hospice community has been criticized for imposing its conception of a good death on its patients.[5, 24]

2.5-A good death through assisted dying

Assisted dying has been proposed by the right-to-die movement as another option for those with unmanageable end-of-life suffering.[12, 13, 15] Proponents of assisted dying argue that it allows for a good death rooted in principles of patient autonomy and self-determination, allowing the patient to control the timing and manner of their death when they believe their suffering has become intolerable.[12, 15, 17, 24] Walters argues that like a hospice good death, a good death through assisted dying provides patients with control over the dying process, but that its locus of control surrounds the timing of death.[24]

2.6- Assisted dying in the Canadian context

Prior to 2016, it was illegal under Canadian criminal law for healthcare professionals to either prescribe or administer medications that would end a patient's life.[25] Despite this prohibition, public support for assisted dying was strong in the decades leading up to 2016.[25] Between 1991 and 2009, twelve private member bills seeking to legalize assisted dying were introduced in Canada's parliament, though none were passed into law.[41] In 1993, the Supreme Court of Canada (SCC) ruled in *Rodriguez v Canada,* finding that Canada's criminal prohibitions against assisted dying were constitutional.[42] However, the push to legalize assisted dying continued, and starting in 2013, a series of events in Canada's political and legal arenas ended Canada's criminal prohibition on assisted dying.[25, 43, 44] Today, certain patients may seek assistance from physicians and nurse practitioners to end their lives.[25, 43, 44]

In June 2013, *An Act Respecting End of Life Care* (the Quebec Act) was introduced in the Quebec provincial legislature.[25] This proposed legislation eventually became law in December 2015 following a decision by the Quebec Court of Appeal that it did not conflict with Canada's Criminal Code.[25, 45] The Quebec Act creates a right for eligible patients to receive medical aid in dying or *l'aide medicale à mourir*. [44] In conjunction with palliative care, medical aid in dying forms part of the law's vision "to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy."[44] Medical aid in dying is defined under the Act as "care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient's request, in order to relieve their suffering by hastening death" (chapter 2, section 3).[44] To receive medical aid in dying under the Quebec Act,[44] a patient must:

> (1) be an insured person within the meaning of the Health Insurance Act (chapter A-29);
>
> (2) be of full age and capable of giving consent to care;
>
> (3) be at the end of life;
>
> (4) suffer from a serious and incurable illness;
>
> (5) be in an advanced state of irreversible decline in capability; and
>
> (6) experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable (chapter 2, section 26).

Nearly two years after the Quebec Act was initially introduced to the Quebec legislature, the SCC released its decision in *Carter v. Canada*.[46] In its February 2015 judgement, the SCC found that the ban on assisted dying created by sections 14 and 241(b) of the Criminal Code was unconstitutional in the context of physician assisted dying.[46] The SCC ruled[46] that Canada's ban 'unjustifiably infringed' on section 7 of the Canadian Charter of Rights and Freedoms for the following persons:

> [A] competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. (para. 4)

In the aftermath of the Carter decision, the federal government introduced *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (the

Federal Act).[25] The Federal Act was given Royal Assent in June 2016 and established the new federal regulatory regime with regards to physician assisted dying.[25, 43] The Federal Act differs from its Quebecois counterpart as its conception of legal assisted dying, which it calls medical assistance in dying, allows both physicians and nurse practitioners to either directly administer the medications to end a patient's life, or prescribe the medications for the patients to self-administer.[43, 44]

The eligibility criteria outlined in the Federal Act are also slightly different than those in the Quebec Act, and is more restrictive than those described in *Carter*.[25] The Federal Act[43] states that patients are eligible to receive medical assistance in dying if:

> (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. (section 241.2(1))

The Federal Act[43] defines someone as having a 'grievous and irremediable medical condition' if:

> (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. (section 241.2(2))

These criteria have been criticized as being too restrictive and not compliant with the SCC ruling in Carter.[25, 47] In September 2019, the Superior Court of Quebec ruled that the criteria in Bill C-14 and Law 2 unjustifiably violated S.7 of the Charter.[48] The Quebec government has indicated that it will not appeal this decision.[49] In February 2020, the federal government tabled new legislation on MAID in response to this ruling and other concerns that eligibility requirements for MAID were too narrow.[50] However, the 2020 Coronavirus pandemic has stalled the passage of this proposed legislation.

2.8-Hospice's historical rejection of assisted dying

Historically, Saunders and the modern hospice movement have opposed assisted dying.[7, 11, 16, 17] They argue that assisted dying is both unnecessary given the abilities of hospice care to meet the needs of end-of-life patients, and that it is harmful to both end-of-life patients and society at large.[7, 11, 16-19] They assert that assisted dying denies patients and families of meaningful end-of-life experiences, decreases access to hospice care by diverting societal resources and attention, and could be inappropriately used on vulnerable populations, such as end-of-life patients who have been judged by society or their caregivers to be a burden.[7, 11, 16, 17] As such, the modern hospice movement argues that its version of a good death is superior to that offered by assisted dying.[7, 11, [16, 18] Hospice communities often responded to calls for the integration of assisted dying into the care it provides by citing the conflict between assisted dying and the hospice commitment of neither hastening nor prolonging death.[17, 21, 22] That said, the good deaths provided by assisted dying and hospice communities both aim to provide the patient with control over the dying process, and are rooted in the values of patient dignity and the relief of suffering.[17, 23, 24] Some proponents of assisted dying and end-of-life scholars argue that given these shared aims and values, some form of co-operation between hospice communities and assisted dying could improve end-of-life options for patients.[17, 23]

2.9-Hospice response to assisted dying: A consideration of hospice values and identity

Despite the modern hospice movement's historical opposition to assisted dying, hospices in Oregon and Washington have responded to legalization by instituting various degrees of participation in assisted dying.[51, 52] Researchers argue that while hospice communities have historically opposed assisted dying, their shared goals and values have created value conflicts that hospices must resolve.[51-54] To bioethics scholar Bruce Jennings,[54] the value conflict faced by the hospice movement is grounded in an understanding that:

> Legalization would liberate dying people from what hospice had been teaching could be a meaningful and valuable time of life. On the other hand, a major part of the quality of living while dying that hospice champions is autonomy, respect, and dignity. How could hospice stand against that?" (p. 4).

Campbell et al. [51-53] argue that this variation in hospice response to assisted dying is due to hospices coming to different conclusions on the boundaries of 'hospice' identity as they attempt to resolve these value conflicts, while also balancing the legal obligations that legalization has created for them. [51-53]

Before continuing, it is important to note that hospices in Washington and Oregon differ from Canadian hospices in two ways. Firstly, assisted dying legislation in Washington and Oregon only allows physicians to prescribe life-ending medication, which the patient self-administers.[55, 56] Secondly, while they are all inspired by the modern hospice movement's approach to care, Canadian hospices provide hospice care in brick and mortar facilities, while hospices in Oregon and Washington are agencies that provide hospice care in the patient's home.[1, 51, 57]

2.10-Varying hospice participation in assisted dying in Oregon

Campbell and Cox argue that the responses of Oregon hospices fall within four general models of hospice participation in assisted dying.[53] These models are 'full participation within the parameters of the law,' 'moderate participation,' 'limited participation,' and 'non-participation or non-cooperation permitted by law.'[53] Differences between these models include how the act of assisted dying is described, what information is given to patients who inquire about assisted dying, how the external physician who writes the patient's prescription for life-ending medication is alerted to the patient's request, and if hospice staff can be present when the patient ingests the life-ending medication.[53]

Full participation hospices describe the act as a 'physician assisted death,' which still creates some 'moral distance' between hospice and assisted dying, conceptualizing the act as involving the patient's external attending physician, and not the hospice.[53] When asked by the patient about assisted dying, hospice staff provide the patient with information about the law and patient eligibility requirements, and discuss with the patient their desire to receive an assisted death.[53] These hospices instruct the patient to contact their external attending physician, and discuss patient support organizations that can help with the process to receive a physician assisted death.[53] While these hospices will not procure the life ending medication that the patient self-administers, it allows staff members to be present when the patient ingests the medication.[53] Should complications arise, staff members can assist with the patient's 'human needs,' but will not help to hasten the patient's death.[53]

Moderate participation hospices also refer to the act as a 'physician assisted death.'[53] When asked by a patient, select staff members may provide information about the law and eligibility requirements to patients, and instruct patients to contact their external physician, but will not discuss patient support groups.[53] These hospices permit staff to be present when the patient takes life ending medication. [53]

Limited participation hospices describe the act as 'physician assisted suicide,' framing any form of hospice participation in the act as being morally problematic as the hospice would be facilitating a suicide. [53] These hospices direct patient requests for information on assisted dying to the patient's external attending physician, and do not allow staff to be present for the final act. [53] However, these hospices continue to provide care to patients seeking an assisted death and provide bereavement support to family members. [53]

Non-participation hospices describe the act as 'physician assisted suicide.' [53] These hospices do not discuss assisted dying with patients, and do not refer patients to their external physician or to patient support groups. [53] Staff are not allowed to be present for the final act, though these hospices provide care to patients seeking an assisted death.[53] However, these hospices affirm that physician assisted dying is unnecessary given the care they provide, and ask patients to respect the hospice's opposition to assisted dying.[53]

2.11-Hospice participation in the Netherlands

The Netherlands is another jurisdiction wherein hospices have had to formulate a response to the legalization of assisted dying. In the first two years following legalization, nearly all high care in-patient hospices responded by prohibiting the act within their institutions, citing conflict with the Christian ideals upon which these facilities were founded.[58] The majority of smaller, community-based hospices, known as 'almost at home homes,' responded by asserting that physician assisted dying is a medical matter between the patient and their general practitioner, and as such have taken a neutral position on the issue.[58] However, it is unclear whether assisted dying is permitted within these institutions.

2.12-Perspectives of hospice workers on assisted dying: Oregon

Studies on the experiences of hospice workers in jurisdictions that have legalized assisted dying provide additional insight into the impact of assisted dying on hospice. All studies found by this review examined the experiences of Oregonian hospice workers.

Ganzini et al.'s[59] survey of Oregon hospice nurses and social workers found that 45% of respondents had a patient of theirs seek physician assisted dying. Fifty-nine percent of respondents supported Oregon's assisted dying legislation, while 26% were opposed.[59] Nurses reported that the primary reasons for a patient wanting to seek assisted dying were "a desire to control the circumstances of death, a desire to die at home, the belief that continuing to live was pointless, and being ready to die" (p. 584).[59] Social workers similarly noted that the main reasons were "the desire to control the circumstances of death, the wish to die at home, loss of independence or fear of such loss, and loss of dignity or fear of such loss" (p. 584). [59] Eighty-five percent of nurses noted that family members of patients prescribed life ending medication were aware of the prescription, and 90% believed family members accepted the patient's decision.[59] Respondents reported that "families of patients who received prescriptions for lethal medications were more accepting of and prepared for the patient's death, although they were somewhat more likely to be distressed than were the family members of other hospice patients." [59]

Miller et al.'s[57] secondary analysis of Ganzini et al.'s survey found that the majority of respondents supported allowing hospice patients who were seeking assisted dying to remain under the care of hospice. Similarly, the authors found that 95% of respondents believed that hospice should be either neutral or supportive of a patient's request.[57] Few social workers and nurses would transfer a patient to the care of another provider upon learning of their request for an assisted death.[57] Social workers were found to be more supportive of assisted dying than participating nurses.[57] Nearly two thirds of respondents stated that they had discussed physician assisted dying with a patient, though 22% of these respondents were uncomfortable with these conversations.[57]

Carlson et al.'s[60] survey of Oregon hospice chaplains found that 54% of respondents had a patient of theirs seek assisted dying, while 36% had a patient who had received an assisted death. Respondents were split regarding support for assisted dying, with 42% of respondents supporting Oregon's Dying with Dignity Act, and 40% indicating that they were opposed.[60] That said, the majority of respondents felt that hospice chaplains should provide non-judgemental support to patients seeking assisted dying, and all would continue to provide support to the patient.[60]

Chaplains reported that patients sought assisted dying “to control the circumstances of their death, feared loss of dignity, or had pain or feared worsening pain” (p. 1163).[61]

Norton and Miller’s[62] focus group study of Oregon hospice social workers found that social workers struggled to balance the values of the patient, the hospice, the state, and themselves when patients requested an assisted death. Participants felt that many hospices did not have policies surrounding how hospices and their workers should respond to requests for assisted dying, which could create uncertainty for social workers on how to respond, though also allowing them greater autonomy to act in these situations.[62] Participants noted that social workers were being consulted in policy changes surrounding assisted dying in hospices, and that policies were changing to allow hospice staff to attend when a patient ingested life ending medication.[62] Participants felt that there was a growing comfort with assisted dying in the general community, that social workers were becoming involved in policy discussions surrounded assisted dying, and that state laws appropriately regulated assisted dying, including making modifications where necessary.[62] However, participants felt that social workers were still unsure of their role surrounding physician assisted dying.[62]

2.13-Experiences of Canadian hospices since legalization

There have not been any academic studies that have primarily focused on the experiences of Canadian hospices since legalization. However, media reports, press releases and government reports provide a partial outline of how legalization has affected Canadian hospices. Across Canada, some hospices have decided to allow MAID on their premises, while others have not.[63-66] Health Canada’s Fourth Interim Report on MAID found that between 1 January and 31 October

2018, 77 MAID procedures were performed in British Columbia hospices, 16 in Alberta hospices, 8 in Ontario hospices, and less than 7 MAID procedures were performed in hospices in each of Saskatchewan, Manitoba, and the Atlantic provinces.[65] Similar data for Quebec hospices was not included in the report.[65]

This literature review was unable to identify policies for most provinces that detail whether hospices have a legal obligation to provide or allow MAID on their premises. In Quebec, free standing hospices are not required to provide or allow MAID on their premises.[67] In British Columbia, if a hospice receives more than 50% of its funding from the provincial government, it must allow MAID on-site or lose provincial funding.[66]

Antonacci et al.[68] did examine the perspectives and experiences of hospice palliative care workers and volunteers working in hospice and palliative care. While 21% of participants worked in free standing hospices, the remaining participants worked in other facilities or programmes, such as home or long-term care.[68]

In their survey, the researchers found that 71% of respondents had a patient or family member in their institution or program who asked for MAID, and 35% noted that MAID had been performed at their workplace.[68] The responses of participants to survey questions indicated concern about: the general public and healthcare workers confusing hospice palliative care and MAID, public backlash regarding a facility's decision to either allow or prohibit MAID; a lack of staffing and resources to provide both hospice palliative care and MAID; unclear or non-existent policy surrounding MAID; and emotional difficulties for staff and volunteers arising from MAID.[68] Thirty-nine percent of respondents felt that psychosocial support for hospice workers surrounding MAID was inadequate.[68]

Thematic analysis on the survey's open-ended question found that respondents felt that there was insufficient support for workers and volunteers to address the challenges MAID creates within their workplace. Specifically, respondent physicians and nurses believed that there was inadequate support surrounding conscientious objection.[68] Respondent nurses also felt that, following a medically assisted death, there were not enough debriefing sessions facilitated by a trained counsellor available to them.[68] Lastly, respondent volunteers noted that there was inadequate support for cultural needs surrounding MAID.[68] For example, respondents were concerned that patients in faith-based facilities may not have adequate support when trying to reconcile their interest in MAID with their own religious beliefs.[68]

2.14-Summary

This literature review has highlighted the modern hospice movement's historical opposition to assisted dying due to conflict with its conception of a good death. Despite this opposition, the good deaths offered by hospice communities and assisted dying share common aims and values, leading to calls for co-operation between the two in order to increase accessibility to a dignified death.

In jurisdictions outside of Canada where assisted dying is legal, hospices have had to balance their values that both align and conflict with assisted dying while also meeting their legal obligations. This deliberation has led to a variable response by hospices in Washington and Oregon to assisted dying. In the Netherlands, nearly all high care hospices have prohibited MAID due to conflicts with the hospices' Christian values. In Oregon, hospice workers reported encountering patients who had sought assisted dying, and believed that despite the historical tension between the hospice community and assisted dying, their hospices should continue to care for these patients. However, some of these workers struggled to reconcile the values of hospice, assisted dying, patients, the state and themselves, and were unsure of their role surrounding assisted dying.

Existing research on the experiences of Canadian hospices since legalization similarly showed that Canadian hospice patients have sought MAID. This research also highlighted that legalization has created challenges in the workplaces of hospice palliative care workers, and that these workers do not feel supported in responding to these challenges. Many of these challenges appeared to be the result of conflict between the values and goals of hospice palliative care and MAID. However, there have been no academic studies exclusively examining the experiences of Canadian hospices and hospice workers since legalization, and as such, there remains a large knowledge gap on how the legalization of MAID has affected Canadian hospices.

Chapter 3: *Empirical Study*

3.1 Introduction

As described in the previous chapter, literature on the experiences of hospices in other jurisdictions where assisted dying is legal showed that legalization has created new challenges for these hospices to navigate, many of which stem from the common and conflicting aims and values between the hospice community and assisted dying. Existing research on the experiences of Canadian hospice palliative care workers with MAID similarly highlighted that legalization has created new challenges within their workplaces, many of which also appeared to be the result of conflicting aims and values between MAID and hospice palliative care. However, there have been no studies exclusively examining the experiences of Canadian hospices and hospice workers since legalization. As such, there remains a large knowledge gap on how the legalization of MAID has affected Canadian hospices. Moreover, the shared aims and values between the modern hospice movement and MAID may provide opportunities for the Canadian hospice community. This thesis hoped to explore these knowledge gaps to better understand the reality Canadian hospices have faced since the legalization of MAID. Given that hospice workers are well positioned to provide insight into how MAID has impacted Canadian hospices, a qualitative methodology was employed to gain insight into their perspectives and experiences. This insight provided an opportunity to fill the aforementioned knowledge gap by understanding the challenges and opportunities MAID brings to hospice.

3.2 Research question and aim

This study initially set out to answer the following question: ‘What challenges and opportunities for hospice workers does MAID bring to the hospice approach to care?’ As the study progressed, participant discussions framed the availability of MAID as a phenomenon that is more expansive than just bringing challenges and opportunities to the hospice approach to care. These discussions portrayed MAID as having created novel possibilities and situations that have manifested as challenges and opportunities for the hospice and those within it, including but extending beyond the provision of hospice care. This study's research question was then changed to better incorporate and understand the data generated from focus groups and interviews. This study's research question was revised to: "What challenges and opportunities do hospice workers think MAID brings to a hospice?" The study's aim was: "To identify the challenges and opportunities hospice workers think MAID brings to a hospice." This decision to modify the study's research question as data is generated and analysed is an accepted practice in qualitative research.[69] Continuous reflection on the part of the researcher is integral to ensure that the research project is designed to understand the experiences and perspectives and participants, which can include modification of the study's research question.[69]

3.3-Theoretical framework

The theoretical framework served as the 'lens' used by Dr. Macdonald and myself by orientating how we approached the study.[70, 71] We used the theoretical framework to design the study and its research question, as well as in the generation, analysis and interpretation of data. [71] The theoretical framework also served to connect this study and its results to broader theories and discussions in the academic literature and public life.[71, 72] This study's theoretical framework provided a sensitising construct to which participant descriptions of legalization could be compared to see how it created challenges and opportunities for a hospice.

This study's original research question looked to see how legalization impacted the hospice approach to care. Hospice ethicist Timothy Kirk's[8] 'Hospice Care as a Moral Practice' provides a framework for reflection on the core values and principles of hospice, and how these values and principles determine what activities are acceptable or unacceptable within hospice care. As such, hospice care as a moral practice was initially adopted as this study's theoretical framework.

In describing hospice as a moral practice, Kirk draws on the definition of practice' proposed by philosopher Alastair Macintyre.[8] To Macintyre, a practice is a group pursuit of 'standards of excellence' through the achievement of 'internal goods' that are unique to the practice.[73] Attainment of these goods is governed by rules that are established and modified by an authority comprised of those knowledgeable of the practice and its history.[73] This authority may also change these "internal goods" if needed to allow the practice to respond to new circumstances.[74]

Kirk argues that as a moral practice, hospice's standards of excellence would be the provision of 'good hospice care.'[8, 73] Achievement of good hospice care would thus require hospice practitioners to realize hospice's internal goods, which could include goals, skills, values and principles that are unique to hospice.[8] Kirk asserts that by providing good hospice care, hospice as a moral practice will culminate in providing the patient and their family with a good death.[8]

However, as participant responses highlighted the impact of MAID on their hospice institutions, they also noted a deep connection between hospice care and the hospice. Our sensitizing construct thus needed to include both hospices and those within then, as well as the deep connection between hospice and hospice care. To do so, I developed the concept of 'hospice as a place' with my supervisor (Dr. Macdonald) by combining Hospice Care as a Moral Practice with Yi-Fu Tuan's Humanist Perspective on Place.

Tuan writes how place is a location that has been given meaning by people.[75] Hospice facilities would fall under the category of places Tuan calls ‘fields of care.’[75] Tuan notes how the meaning ascribed to fields of care is derived from the activities that occur within the place, and that the place’s physical features anchor, sustain, and shape these activities.[75] The meaning attached to a hospice could thus be understood through the activities that occur in hospices among hospice staff, their patients, patients’ families and external healthcare staff visiting the facility. Participant discussions highlighted how the pursuit of hospice moral practice and the care this practice informs was among the most prominent of these activities, and as such was an integral part of the meaning and identity of a hospice. The connection between hospice care and hospice facilities could be understood through this meaning. By combining Tuan’s and Kirk’s theories, I was able to develop a more nuanced conceptualization of a hospice institution by understanding it as a place with meaning, and that this meaning is informed by the activities that occur within the place. Hospice as a place encompassed the hospice, those within it, and the connection between a hospice and hospice care, and was thus adopted as this study’s theoretical framework.

3.4-Paradigm

The paradigm of this study consisted of its ontological and epistemological commitments.[76] Ontology details the nature of reality, while epistemology involves knowledge and its acquisition.[77] This study’s paradigm was our worldview, guiding how we generated knowledge by influencing our choice of methodology and methods.[78] The aim of this study required a paradigm that recognized the importance of the perspectives and experiences of hospice workers, and then used these perspectives and experiences to understand the challenges and opportunities MAID brings to a hospice. This study thus adopted a naturalistic paradigm, which, as nursing scholars

Bradshaw et al.[79] write, looks to “create[] an understanding of a phenomenon through accessing the meanings participants ascribe to [it]” (p. 2).

A naturalistic paradigm is rooted in ontological relativism, which is committed to the subjectivity of reality. [79] Such an ontological stance influences this paradigm’s epistemological basis of subjectivism and social constructionism. Grix, as cited in Bradshaw et al.,[79] describes that a study’s ontological assumption of multiple and unique realities means that there can be no knowledge of the world separate from how we perceive and interact with it, thus establishing an assumption of epistemological subjectivism. This assumption portrays knowledge production as a process involving social actors, highlighting the role of social construction in knowledge generation and communication.[79-82]

Central to the naturalistic paradigm is an understanding that while the study aims to identify and understand the perspectives of hospice workers, the researcher’s presence is part of the social construction of knowledge.[79] As such, we embraced an ‘emic stance,’ in which we were aware and reflexive about the impact of our presence on knowledge production, and we used participant responses as the starting place for explaining phenomena during data analysis.[79]

3.5-Methodological framework

Achieving this study’s aim through a naturalistic paradigm necessitated that we identified the perspectives and experiences of hospice workers surrounding MAID, and then used these perspectives and experiences to describe and understand the challenges and opportunities they felt MAID brought to a hospice. Qualitative description allowed us to realize these goals given its emphasis on explaining phenomenon through participant responses, as opposed to other methodologies that, for example, seek to develop theories.[79]

3.6- Sampling, recruitment, and participants

This project employed two interrelated sampling processes: one for the selection of hospice sites, the other for the selection of hospice workers. Purposeful sampling was used to include hospice sites that were information rich, so as allow for thorough study of the research aim. [83] Purposeful sampling was achieved through the use of maximum variation sampling, which selects for cases that vary with regards to a key dimension of interest.[83, 84] In this study the key dimension of interest was whether or not a hospice offers MAID on site.[83, 84]

Two hospice sites participated in the project, one that offers MAID (Site 1) and one that does not (Site 2). Site 1 is located in Alberta, Canada, and Site 2 in Quebec, Canada. By including sites that have taken different approaches in responding to the legalization of MAID, this project was able to gather a range of participant experiences and perspectives surrounding MAID. Selecting one hospice that offers MAID and one that does not also allowed the study to compare and contrast the impacts of MAID legalization on each hospice. The two hospices selected for this study were ultimately chosen because my supervisor and I already had professional connections with key informants in both facilities. These key informants assisted with the recruitment, and helped me to quickly build rapport with hospice management and participants.

With regards to the selection of individual hospice workers within the two sites, the study was advertised to all hospice staff; that is, across the range of professions and occupations within the facilities. Individual participants were then conveniently selected on a ‘first come, first serve’ basis, but with attention to maximum variation as well.[85] Fortunately, the final sample at both sites included participants across a range of professions; given the interdisciplinary nature of a hospice, it was important that the study include the perspectives and experiences of hospice workers of different occupations. This approach allowed for a comprehensive understanding of what opportunities and challenges hospice workers believe MAID brings to a hospice.

Twenty-four workers participated in the study, including physicians, registered nurses, licensed practical nurses, resident care aides, managers, palliative care education workers, social workers, spiritual care workers, unit clerks and administrative support workers. Thirteen participants were recruited from site one, and eleven from site two. Recruitment was primarily performed by way of key informants, who advised on effective recruitment strategies for each hospice and distributed advertisement posters through the organizations' internal email. In addition, I spent time at one of the research sites to discuss the study with staff and ask if they were interested in participating in the study.

3.7-Data generation

With the help of two research assistants, I conducted four semi-structured focus groups and four semi-structured individual interviews, with two focus groups and two individual interviews occurring at each site. Focus groups were the study's primary method of data generation, as they allowed participants to share and reflect upon their perspectives and experiences with each other.[86] As such, focus groups generated data that allowed the researcher to better understand the collective experiences of each hospices' staff with MAID.[86] However, individual interviews were offered to those who were uncomfortable participating in focus groups, or for those whose schedules prevented them from participating in them.[86] In contrast to that generated by focus groups, data from individual interviews focused more on the individual participant's beliefs and experiences.[86]

Data generation occurred between August 2019 and February 2020. Focus groups ranged from three to seven participants and lasted between 60-90 minutes. Individual interviews ranged in length from 30-90 minutes. All focus group and individual interviews were audio recorded and transcribed, and my research assistants and I also took field notes. All focus groups and three individual interviews were conducted at the hospice sites, while one individual interview was conducted over the phone. Working with my supervisor, I initially drafted the interview guides with an eye to the study's research question, and questions were open ended so as to allow participants the freedom to describe experiences and perspectives they believed relevant to the study. These guides were modified throughout the research study to better explore novel perspectives and experiences relevant to the research question that were raised in focus groups and interviews. For example, based on the responses of Site 1 participants about the challenges created through the use of an external team, we asked Site 2 participants to reflect on the potential impacts of using either an internal or external team to provide MAID. A copy of the final interview guide is available in Appendix A.

3.8-Data analysis

Working with my supervisor, I reflected on each focus group and interview to identify novel perspectives and experiences relevant to the research question that were raised in order to explore them better in upcoming focus groups and interviews. This reflection was partly facilitated using an interview report form. A copy of this form can be found in Appendix D.

The method of data analysis used to create descriptive categories was derived from the 'summary and analysis' method created by McGill University's VOICE team.[87] Following transcription, the data was analyzed through thematic analysis with the aim of sorting the data into themes. This study initially employed qualitative content analysis to develop descriptive categories given the exploratory focus of the project.[88, 89] However, as the analysis unfolded, my supervisor and I realized that thematic analysis could allow for a more theoretical understanding of the data that would provide a greater contribution to the literature. Working with Dr. Macdonald, I employed thematic analysis to identify both descriptive and latent patterns in the data.[89] During thematic analysis, I assigned a code using *QDA Miner Lite* to each segment of the data that was relevant to the research question. I named each code so as to briefly describe what was said by participants in the data segment. I then wrote a narrative summary of each focus group or individual interview, in which similar codes were grouped together, their respective data segments combined and summarized, and a descriptive category name assigned that described the summary. Data segments that were not like other segments were summarized and categorized as 'other' or 'miscellaneous'.

Dr. Macdonald reviewed each narrative summary to confirm whether it accurately represented the data. I then wrote a synthesis of all narrative summaries that combined similar descriptive categories and their respective data summaries. Data from focus group and individual interviews was integrated by connecting responses from individual interviews to collective discussions that had occurred in the focus groups.[86, 90] Working with Dr. Macdonald, I then interpreted and combined descriptive summaries through the lens of our theoretical framework to develop themes that described the challenges and opportunities participants believed MAID brought to a hospice. These themes are described in Chapter 4.

3.9-Ethical considerations

This project presented two major ethical concerns. Firstly, due to the personal and potentially controversial nature of these discussions, the perspectives and identities of participants could negatively impact their personal and professional lives.[91] For example, if patients became aware that their healthcare provider supported MAID, this could decrease their trust in the provider. As such, the confidentiality of both individual participants and the hospice sites was paramount.[91] Field notes and transcripts of the data identified hospice sites as either Site 1 or Site 2, and identified individual participants through a pseudonym. Paper copies of field notes, transcriptions, and consent forms were kept in a locked filing cabinet in the locked office of Dr. Macdonald at McGill University. Electronic copies of audio-recordings and transcriptions were kept on a password protected folder on Dr. Macdonald's McGill server. Prior to the start of each focus group, participants were asked, and verbally agreed to, keeping the perspectives and experiences of fellow focus group attendees confidential.

Secondly, the study asked participants to reflect upon and discuss a subject that has significant interplay with their personal and professional moral commitments. As such, these discussions had the potential to elicit emotions within participants, including anxiety and distress.[91] The research project enlisted the help of mental health supports affiliated with both hospices and the researcher was ready to refer participants to these supports if needed.

This study was reviewed and received approval from the Institutional Review Board at McGill University's Faculty of Medicine, study number A06-B36-19B. Management at each hospice gave written permission for the study to occur at their sites.

Each participant provided verbal and written consent prior to participating. The consent process first involved myself reading aloud the consent document with participants. Participants were then asked if they had any questions about the study, and the researcher answered these questions. If participants were comfortable participating, they were asked to give verbal consent and fill in two copies of a consent form, one kept by the participants and one kept securely in the study files. Focus groups and individual interviews commenced after completion of this process

3.10-Summary

This research project set out to answer the question of: ‘What challenges and opportunities do hospice workers think MAID brings to a hospice?’ This study consisted of four focus group and four individual interviews with hospice workers of diverse occupations at two hospice sites, one that offers MAID, and one that does not. Our conceptualization of hospice as a place, a naturalistic paradigm, and a qualitative description methodological framework guided the study. Ethical concerns surrounding confidentiality and participant distress were managed through data management procedures and arranging mental health supports for participants.

Chapter 4: Results

4.1- Description of Sites and participants

Focus group and individual interview participants were recruited from two hospices, one in Alberta (Site 1), and one in Quebec (Site 2). Both hospices are specialized units that only admit patients who are at the end of life, and focus on providing comfort care. Both facilities are staffed by a multidisciplinary team that includes physicians, registered and licensed practical nurses, resident care aides, spiritual care workers, social workers and volunteers. Most of the funding at Site 1 is provided by Alberta's Healthcare Insurance Plan, while Site 2 primarily relies on donations.

Each hospice has responded uniquely to the legalization of MAID. At Site 1, MAID is allowed on site, though both patient assessments for MAID and the procedure itself are carried out by an external team operated by the provincial health authority, Alberta Health Services (AHS). Except for a manager who acts as a liaison between the AHS and hospice teams, hospice staff are not involved in the provision of MAID. Should a hospice patient request MAID, hospice staff direct the patient to the AHS MAID website. Moreover, as per hospice policy, hospice staff will not bring up the option of MAID with a patient.

Site 2 does not allow MAID on-site. Patients who request MAID are transferred off-site to receive the procedure. Staff may help the patient start the paperwork, and will continue to provide care for the patient until the day of the procedure when the patient is transferred off-site.

Twenty-three participants were recruited for the study, with 13 coming from Site 1, and eleven from Site 2. Participants belonged to a wide range of occupations, including physicians, registered nurses (RNs), licensed practical nurses (LPNs), resident care aides (RCAs), managers, social workers, spiritual care workers, unit clerks, administrative support personnel and outreach workers. The recruited samples at both Sites were generally similar in terms of the occupational range of participants, with Site 2 including more administrative and outreach workers. While Site 2 was in Quebec, a mostly French-speaking province, all quotations used in this chapter have been rendered in English. However, MAID at Site 2 is kept as the French acronym, AMM, which stands for *l'aide medicale à mourir*¸ as it is used in both English and French in Quebec. Site 2 participants also used the terms *palliative care*, and *soins palliatifs* (French for palliative care) to refer to the type of care that has been characterized as 'hospice care' in the literature.

4.2- Modification of the research question

This study initially set out to answer the research question: 'What challenges and opportunities for hospice workers does MAID bring to the hospice approach to care?' However, as the data collection and analysis processes unfolded, working with my supervisor I realized that my research question was not broad enough to capture the data that was being generated during the focus groups and individual interviews. Participant descriptions of MAID portrayed its impact on hospices as broader than focusing only on the hospice approach to care. These descriptions portrayed MAID as having created novel possibilities and situations that have manifested as challenges and opportunities for the hospice and those within it, including but extending beyond the provision of hospice care. For example, participants described MAID as creating challenging scenarios involving patients and their families that were not related to staff providing them with hospice care. Moreover, while some participants felt that MAID could potentially bring a positive alternative to some patients and families, they did not see MAID as an element of 'hospice care' despite being offered in a hospice. The research question was thus changed to: "What challenges and opportunities do hospice workers think MAID brings to a hospice?"

This study's theoretical framework was iteratively compiled as Dr. Macdonald and I designed the study and analyzed data. This framework integrated both Kirk's Hospice Care as a Moral Practice[8] and Tuan's Humanist Perspective on Place.[75] When combined, these two theories provide the conceptualization of *hospice as a place,* allowing us to distinguish the hospice from hospice care, while highlighting the interplay between the two, as well as all the activities that occur within the hospice and those involved in these activities. Using hospice as a place as our theoretical framework allowed us to unify and understand hospice workers' descriptions of the challenges and opportunities MAID brings to a hospice.

As described in Chapter 3, Kirk's Hospice as Moral Practice described how the provision of 'good hospice care' required the realization of certain 'internal goods,' or certain goals, skills, values, and principles by hospice staff.[8] According to Kirk, good hospice care will culminate in the patient experiencing a good death.[8] Tuan's Humanist Perspective holds that places are physical spaces with meaning.[75] Under Tuan's framework, hospices would fall into a category of places known as 'fields of care.'[75] The meaning of a field of care is derived from the activities which occur at that place, and the place's physical features, in turn, anchor and influence these activities.[75] Hospice as a place thus conceptualized hospices as places with meaning that is derived from the activities that occur within it, and the physical features of hospice shape these activities and the meaning they create for hospice.

Our conceptualization of hospice as a place aligned with participant descriptions of their facilities and their work therein. These descriptions portrayed hospice as an institution that was purposefully built to provide hospice care in an intimate, home-like setting. A Site 2 nurse elaborated on the nature of hospices:

> I don't know what it's like in the hospitals, or in other places in Canada, but I know that for us because the ratio is much smaller, and it's more intimate, I think it allows for better care for patients, so that also helps. And they're often saying that they're just so grateful to be here, it's like paradise.

Participants outlined the elements, goals, and commitments of hospice care that are practiced within a hospice. They described hospice care as aiming to provide “comfort,” “compassion,” “dignity,” and improved “quality of life” to hospice patients. They characterized the care as being “personalized,” “holistic,” interdisciplinary, and centered on both patients and their family members. Participants also noted how hospice care was committed to “focusing on the living.”

This commitment had three intertwining elements. The first was a belief among participants that hospice care aimed to help the patient find meaning and ways to enjoy life while being close to the end of it. The second was a view that the dying process was normal and natural, and could be beneficial to the patient and their family by giving them time to both process the patient’s upcoming death, and to spend the patient’s final moments together. The third element was a belief in the hospice principle of not hastening death, which for many participants was informed by their views regarding the normalcy of the dying process.

These characteristics of hospice care highlight how those in a hospice experience a certain death and dying experience. During this experience the patient receives holistic comfort care from dedicated caregivers who help the patient and family find opportunity and meaning as the patient progresses toward their death. These elements of hospice care and the type of death they facilitate were the same as the elements of hospice care and the hospice conception of a ‘good death’ that were described in Chapter 2. As such, the good death participants hoped to provide was positioned to conflict with that offered by MAID.

4.3- Overview of themes

Participant responses highlighted how the legalization of MAID had created both challenges and opportunities for a hospice. Through the thematic analysis, Dr. Macdonald and I have constructed five themes that condensed and explained these challenges and opportunities.

4.4- Theme 1: MAID on-site challenges a hospice's identity

This theme explores how the availability of MAID on-site for hospice patients challenges a hospice's identity. Participant responses highlighted how this challenge is rooted in three concerns. Firstly, they felt that MAID posed a challenge to a hospice's purpose of providing hospice care and the death this care facilitates. Secondly, participants were concerned that the availability of MAID on-site could change the role of a hospice in the healthcare system. Thirdly, participants felt that allowing MAID on-site could negatively impact community perceptions of a hospice.

4.4.1- MAID challenges a hospice's purpose of providing hospice care

Participants at both sites believed that a hospice's purpose was to provide patients and families with hospice care and the type of death and dying experience this care facilitates. They also believed that MAID was not a part of hospice care, with many arguing that it conflicted with hospice care's commitment to life over death. Some participants felt that the suddenness of MAID rendered it "utilitarian" and "expedient" in comparison to compassionate hospice care, that it was a "one shot deal" in which staff were not given the opportunity to provide care. Many participants thus believed that the availability of MAID on-site challenged the entire purpose of a hospice given divergence and conflict between the goals and commitments of hospice care and MAID. For example, a Site 1 LPN said:

> To me, MAID is totally opposite from what we're trying to do here, because MAID just puts a finish to everything, and we're actually here to not necessarily give people a longer life, but to that quality of life right, and, and their comfort, so...

Another Site 1 participant similarly described MAID and a hospice as having “completely different agendas,” stating: “We’re not here to hasten death, and, you know, the scenario of MAID is to hasten death.” She also noted that instead of assisted dying, hospice staff aim to talk to the patient about their fears, and explore hospice care options other than assisted dying that could be used to address these fears.

Site 1 participants felt that this challenge to a hospice’s purpose had created moral conflict for staff: They were trying to work in a hospice that allowed MAID despite believing that it was not part of the care that they were there to provide. For example, one RCA participant described that for staff, allowing MAID on-site surfaced a fundamental challenge: “Why do we do what we do?”

Some participants described how this conflict could take on an additional dimension for staff: They understood why a patient would want MAID, but still felt it conflicted with hospice care. A participant noted that at times staff wondered: “Should I be agreeing that it, that it would be ok in certain scenarios?” Some participants wrestled with the “intellectual” understanding that MAID was a patient’s choice, that there were symptoms hospice care may be unable to control, but also that they had the “emotional” understanding that MAID was not part of the care they were there to provide.

Participants at both Sites described how this tension has and could result in staff deciding to no longer work in a hospice that offers MAID. A Site 1 participant stated: “I've seen, where people have left palliative care, where they feel that if MAID is going to be done, that they don't want anything to do with it.” A nurse at Site 2 predicted that if MAID was introduced at her hospice, many staff would leave her hospice to work elsewhere.

Moreover, participants believed that the availability of MAID on-site would make it more difficult for them to provide hospice care and the benefits brought by this care and the death it facilitates. They worried that instead of trying hospice care, patients would instead “jump” to MAID. A Site 2 RN felt that hospice patients:

> …wouldn't be open to trying different things, cause if they know that 'I can get MAID here, well I just want it, I don't care what you do to me, don't even bother trying to get my pain under control, just give me the needle and it will be over with.’

Some Site 1 participants found that patients who wanted MAID were focused only on the procedure, and would not open up to staff to discuss how hospice care could help them. One participant noted that it was difficult to help patients find new meaning and opportunity during their time in hospice when they had decided on MAID. She said:

> Often what I find is those who have already contemplated or pre-decided that MAID is their choice, often they're not open to having discussions about the here and now, ‘what do I do between now and when MAID is actually done?’ So actually [I] find it a hindrance to having conversations about ‘What about right now? How do we celebrate that you're here? and, How do we celebrate you?

These participants were concerned that by not trying hospice care, patients would forfeit its benefits. They worried that patients would lose the opportunity to see if hospice care could improve their quality of life to the point that they would not want MAID. For example, these participants believed that many of the patients seeking MAID were doing so for “existential” or “psychosocial” reasons that hospice care could address. One participant noted:

> Well, in my little experience, most people who ask for MAID are actually in emotional distress, there's some sort of an anxiety, and they don't most of the time they don't want to be a burden, or they are afraid of suffering, and they don't realize that we can actually help with the symptoms and actually treat them.

However, one participant felt that this phenomenon of patients not engaging staff was due to due to the difficulty of navigating the MAID process. She felt that due to this difficulty patients become overtly focused on arranging MAID at the expense of exploring the options available to them in a hospice. She hoped that if this process was more streamlined patients would be less focused on MAID.

These participants also described that by choosing MAID and bypassing hospice care, patients and families would forego the inherent benefits of a hospice good death. During a Site 1 focus group, participants discussed how the availability of MAID on-site prevented patients and families from enjoying the benefits of the uninterrupted dying process. The following is an excerpt of that discussion:

> Participant 4: My perspective spiritually is that often towards the end, even when the patient is unconscious, there are wonderful, spiritual holy moments that take place, often the patient can come back to clarity for a little while, and it's a really wonderful gift to the family. The family can come together and bond in a way, that they're there outside of the regular work day and the work world, and they're there in this little isolated bubble, right, and its very beautiful, and it's very holy, and people have really fond memories of their time in hospice as long as the symptoms are managed. And, it just seems to me a shame to, forego that opportunity …

> Participant 5: Death is a process, and, if you just practically end it, you don't give the patient or the family, or whoever's around them the opportunity to gradually let go
>
> Participant 4: That's right, that's right
>
> Participant 5: Right, you just take that away, and I think for families that that are left behind that would be even more difficult in a way
>
> Participant 4: That's right, exactly … It takes a while to process what's happening and you're always kind of a step behind
>
> Participant 5: Right, and then, it's more, it's more real to you because you can actually feel the process, or, go through it yourself, right?
>
> Participant 4: Yep, you're right.

Even when a patient had uncontrollable symptoms, these participants felt that the use of palliative sedation possessed more benefits for patients and their families than MAID. Palliative sedation is used in hospice care to address otherwise unmanageable symptomology, and involves the use of medications to reduce a patient's consciousness until their death.[92] Participants believed that palliative sedation gives families "a different kind of relief," as it allows them to see the patient resting and at peace.

Site 1 participants felt that the possibility of patients opting out of hospice care could also cause emotional difficulty for staff. They described how the provision of hospice care involved staff developing a close personal relationship with the patient, and that it was emotionally difficult for staff to become so heavily invested in a patient's care only for them to choose MAID.

4.4.2- MAID on-site could change the role of a hospice in the healthcare system

Participants similarly worried that allowing MAID on-site could change the role of a hospice in the healthcare system to a “drop-in” centre for MAID. A Site 2 participant said:

> I wouldn't want to receive an application saying: ‘Joan wants to come in for MAID tomorrow.’ I don't want a person just to come die here. If we have someone here who, we've done our best, we've tried, sometimes we can't do more, and it's out of our hands, they've made the decision, then we'll perform it here. But, not to be a drop-in centre. I wouldn't, that would be too hard.

Site 2 participants were concerned that if MAID was allowed on-site, hospitals could pass off patients who had requested MAID to hospice staff for them to provide MAID. Participants at Site 1 felt that their hospice was already beginning to be used by hospitals for such a purpose. One participant believed this was because hospitals thought hospices could provide the “biopsychosocial support that’s needed around MAID.”

Site 1 participants were concerned that these transfers unnecessarily burdened patients at the end of life, and that doing so was a poor allocation of healthcare resources as healthcare staff had to travel to the hospice to provide MAID. However, these participants also opposed these transfers because they felt that if a patient was not interested in hospice care, they should not be in a hospice. One LPN participant felt that this belief could cause her colleagues to view patients who have come to hospice with the intent of receiving MAID differently from other patients in the hospice. She believed that staff may wonder the following:

> Why are they here to begin with if they've chosen MAID? Right, that's not our hospice approach, so, why are they here, right? So there might be some, almost, backlash probably, from it, because of people are unsure of what to do with it.

4.4.3- MAID on-site challenges community perceptions of a hospice

Participants at both Sites were also concerned that allowing MAID on-site could negatively impact community perceptions of a hospice. They were concerned that the lay community already had a misconception that hospices expedited the death of their patients, and that allowing MAID on-site could exacerbate these concerns. A Site 2 participant stated that allowing MAID on-site:

> Could send mixed messages that 'oh as soon as you step inside the hospice, the palliative care, well, in a week from now they will give you the shot and you'll be gone,' you know. So this is not the image obviously we want to, to be associated with the palliative care. It's not the place, you know, where you euthanize dog that is sick or something.

One RN participant worried that allowing MAID on-site could change how she is viewed by her community. She said: "If people find out that I work where I work, and then they find out that well we do MAID, well then, they might see me as someone who just does [MAID]."

A Site 2 participant felt that as MAID was increasingly described in larger society as the dignified way to die, hospices would become increasingly associated with MAID, alongside the likelihood of community misconceptions about hospices. Participants at both Sites also felt that this portrayal of MAID as the dignified way to die was an idealization, and that MAID was co-opting the ideal of a good death at the expense of the hospice and palliative care communities. One participant stated:

> Well that's a way the people were told, you know, like, *l'aide medicale à mourir*, that's the only way to, the best way to die, which, I mean when you've been in the field for 10, 15 or 20 years you know that there was also another solution. The good care was also good palliative care.

In sum, this theme has explored how the availability of MAID on-site in a hospice challenges a hospice’s identity. Participants highlighted how the availability of MAID on-site challenges a hospice’s purpose of providing hospice care, and were worried that MAID on-site could also change the role of a hospice in the healthcare. Moreover, they were concerned that the availability of MAID on-site could negatively impact how a hospice and its workers are viewed by the lay community.

4.5- Theme 2: Staff struggle to reconcile a patient’s interest in MAID given the abilities of hospice care

As described in the previous theme, many participants felt that a hospice death holds inherent benefits for the patient and their family. Moreover, they believed that hospice care was able to provide a comfortable and relatively pain free end-of-life experience for most patients. Amid these background beliefs on the abilities of hospice care, some Site 1 participants struggled to understand a patient’s interest in MAID. This struggle was a challenge for participants, with some experiencing emotional difficulties and frustration as a result.

In response to this discrepancy between their beliefs and patient actions, these participants held varying opinions about the patient’s reasons for wanting MAID, and for how a patient should proceed. Some participants felt that patients who were considering MAID should explore other options to see how hospice care could help them. Others believed that those who chose MAID did not do so to relieve physical suffering, but for psychosocial reasons; they were old and did not want to live anymore, or they wanted to avoid the dying process. Still others felt that patients chose MAID because they found the care to be insufficient, leading to feelings of offence and failure among staff. A Site 2 RN predicted that she would experience similar feelings if a patient chose MAID, stating:

> I would be frustrated by that if one of my patients opted for MAID, and then I would feel like I had failed them and not done my job well enough, or, sufficiently, like, where did I go wrong? What could I have done better?

On a broader level, this participant found government pressure to introduce MAID in hospices offensive, feeling an implication that the care the hospice provided was not sufficient. She stated:

> From like, a government or an administrative point of view, if you're bringing in MAID you're basically telling me that I'm not doing my job properly, and that you don't think it's sufficient, that's how I see it.

This participant felt that if MAID was introduced at her hospice she would try to "convince" patients of hospice care by trying to provide the highest quality care. She noted that this action would be an attempt to prevent patients from deciding to receive MAID. However, a Site 2 participant felt that perceptions were changing, and staff were beginning to see requests for MAID not as a failure of care, but as the patient's choice. She said:

> … when we had our first case, the response from the nursing staff mainly, and the medical staff, was: 'What could we have done better so that they wouldn't ask us to do this?', like 'we failed.' That was the feeling of everyone, we failed to provide enough care for this patient that they asked to die immediately. That was in 2015. Now, the feelings have changed. Thoughts have changed, I mean its been a whole evolution, like I could go on for an hour about it, but, the [staff's] thoughts are 'ok, well, you know yeah it's there choice, yes we can still care for them, yes we can still do this, yes we can still do that.'

Several participants expressed a similar view that hospice patient requests for MAID were not the result of a failure of care, but rather an expression of patient preference for a different end-of-life experience. Indeed, one participant described how a hospice patient who received MAID told the participant he was “satisfied” with the hospice care that he had received. These views are more fully explored in theme 5.

In summary, this theme highlighted how participants struggled to reconcile a patient’s interest in MAID with their beliefs in the abilities of hospice care. Participants attempted to reconcile this discrepancy by insisting that these patients should consider hospice care, or by believing that a patient’s interest in MAID was for a reason other than physical suffering. This struggle was a challenge for participants, with some experiencing distress and frustration. However, participant responses also highlighted that some hospice staff were beginning to see requests for MAID not as a failure of care, but as an expression of the patient’s end-of-life preferences.

4.6- Theme 3: MAID creates challenging clinical situations involving patients and families

This theme explores participant descriptions on how the availability of MAID for hospice patients, either on or off-site, has resulted in challenging clinical situations involving hospice patients and their families.

4.6.1- Clinically challenging situations involving hospice patients

Participants described how the availability of MAID had created challenging situations involving hospice patients. Specifically, they described cases in which staff worried that patients who received MAID were not themselves convinced they wanted it or did not have the capacity to consent, where the patient had refused pain medications to satisfy eligibility criteria, and lastly, when things went wrong during the actual MAID procedure. Unlike in the previous themes, many of these situations did not appear to be inherent to MAID, but were rather the result of problematic provisions in Canada and Quebec's MAID laws, or perceptions among staff that procedures were not being followed. At times, these situations were emotionally difficult for staff, in part because they did not agree with what was occurring.

Participants at both Sites raised concerns that some patients who had received MAID were not themselves convinced that they wanted it, or that they did not have the capacity to consent. A participant at Site 1 noted that she had seen patients "go back and forth" on the decision to have MAID, and that patients had asked the families of other patients at the hospice about whether they should have it. Other Site 1 participants described seeing family members "encourage" their relative to receive MAID. These participants also worried that some patients did not have the capacity to consent, because of mental illness or delirium. One participant stated: "Sometimes I think there's no way that person consented, they could not have consented, they're not talking to anyone else, they're like in a coma." Some Site 1 participants found these situations to be emotionally distressing because they could not understand how the patient fit the eligibility criteria for MAID. A Site 2 participant described a similar case in which a patient received MAID despite concerns among staff and the patient's family that the patient was "confused."

Site 1 participants described witnessing patients and their families refuse pain medications so that patients could give consent for MAID as pain medication can reduce a person’s cognitive capacities. These participants were concerned that patients were therefore suffering from pain in order to consent to MAID. For example, one participant felt that because of capacity requirements MAID was a “hindrance” to symptom control, and that patients “suffer” until the procedure is carried out. Another stated that these situations were emotionally difficult: “You know there's something to be done…and they're holding out for what they think is right, right?” Participants noted that the sometimes weeks long length of the assessment process could leave patients without adequate pain control for a long period. Participants at both Sites also said that many patients believed that the MAID assessment process would be quick after making a request, but that the long length of the process did not match their expectations.

Site 1 participants felt that these situations were even more emotionally difficult when a family member requested that staff withhold medications; participants felt family members were influencing the patient to endure discomfort and in order to undergo MAID. One participant stated: “Families will say: 'Don't give my father his [medication] this morning because I want him to be able to give consent.’ So you're willing to let your father suffer in pain because you want to kill him?” She added: “It's usually the family members who are saying 'no, don't give 'em anything'. Those patients, at the end of life, they're quite not able to speak for themselves so.”

Lastly, a Site 2 participant recounted problems during the actual MAID procedure of a hospice patient who was transferred off-site. She stated that one of the nurses who took part in the procedure was so distressed by what occurred that she took time off. The participant said that the nurse thought that:

> …she's gonna start the IV and she's gonna be present and she'll hold the lady's hand, and will give this and then she'll go to sleep. Not how it happened. And this woman did not die as quickly as she should have. There was some resistance, so the whole scenario, wasn't what it should have been.

She noted that while MAID procedures were portrayed in larger society, such as the media, as going well, she had heard of procedures that did not go well.

4.6.2- Family conflict, anxiety, and stress

Participants were concerned about the impact of a patient's decision to receive MAID on their family. Participants felt that this decision could cause disagreement and conflict within families, as well as stress and anxiety for individual family members. Participants at both Sites described cases in which this had occurred, including at Site 2, where MAID is not allowed on-site. For example, Site 2 participants described the case of a hospice patient who had asked for MAID, but her husband and son were opposed to MAID for personal and religious reasons. This tension caused so much distress for the family members that the patient decided to withdraw her request, because, as one participant stated: "She didn't want her son to remember her as having that, so even though she wanted it, as a mother or whatever, she gave him that gift."

Participants at both Sites felt that family conflict over MAID could be due to patients and family members disagreeing over how they believed the patient's end-of-life experience should occur, which at times could be influenced by the religious commitments of family members. One RCA felt that this conflict was often the result of:

> One [family member] believes and one doesn't, or...Nobody wants to see a parent or a loved one give up, I don't think, in general people want to see their loved ones to hang on and do what they can to live, and, maybe that person that's trying to hang on is done hangin' on.

A Site 2 participant was concerned about the effects of this disagreement on the family's mental health and grieving process after the procedure. This participant noted that during her time working at a hospital, she had seen family members referred to mental health programs for anxiety and PTSD following family conflicts and disagreements over MAID. Indeed, Site 2 participants noted that a family had experienced "complicated grief" after their relative had received MAID despite concerns among the staff and family over the patient's capacity.

A Site 2 LPN participant felt that family members could still experience anxiety without family conflict or disagreement over MAID given the scheduled nature and abruptness of it. She said:

> For the family, it's like when you wait with your dog and you know that the vet will come at two o' clock. You know, it's 1:30 and you say 'oh, I only have half an hour left, it's the same thing with [families of those receiving MAID]. They come with the bottle of wine two hours before or whatever and let's celebrate. Fine, you know, but, I mean, I'm sure there must be a lot of anxiety inside.

Some Site 1 participants noted that hospice staff had become involved in family conflict and disagreement over MAID. One LPN participant described that staff could become caught in this conflict and did not have direction on how to proceed. She said: "We're stuck in the middle trying to deal with that like... what do we do then?" Another participant described that family members had come to the participant with concerns about a patient's choice to receive MAID. The participant noted that it was:

> …very difficult if there's people.. that are coming and saying they can't even cope with this happening with their family member, because there are people doing that, just saying 'I don't know how I will live with this if my family member decides to do this.'

That said, participants at both Sites noted that there had been families who completely supported the patient’s decision to receive MAID. Site 1 participants described a case where a patient’s death from MAID brought “peace” to the family because they knew that was what their relative wanted. They also noted how some family members were distressed when the patient did not receive MAID, with one participant noting that the family member wanted the patient to have received it so that he could have been present for the death.

Site 2 participants also described that institutional rules surrounding confidentiality dictate that if a patient did not want their family to know about their decision to have MAID, staff could not pass on this information. They noted that these rules had created awkward situations involving families in which family members have arrived at the hospice to visit after a patient had been transferred off-site for MAID.

This theme has highlighted how the availability of MAID for hospice patients, either on or off-site, has resulted in challenging situations involving hospice patients and their families. Participants described how challenging situations surrounding patients involved concerns that the patient was not fully convinced that they wanted MAID or that they did not have the capacity to consent, and a concern that the patient suffered after refusing pain medications to satisfy capacity criteria. Participants noted how a patient’s decision to have MAID could also cause conflict and disagreement within families, as well as anxiety and stress for individual family members.

4.7- Theme 4: Different hospice responses to the legalization of MAID leads to unique challenges

This theme explores how the differing responses to the legalization of MAID taken by Sites 1 and 2 have created unique challenges for each hospice. Site 1 participants described how employing an external team to provide MAID on-site has resulted in disjointed communication between the hospice and MAID teams. This lack of communication has created disruptive situations for staff, with both contributing to a perception among participants that MAID is a secretive and intrusive activity in their hospice. Furthermore, some participants felt that the use of an external team placed unwanted demands on staff from patient families and the AHS team, and prevented hospice staff from being present at the MAID procedure despite their relationship with the patient.

Site 1 participants described that the separation between the AHS MAID team and hospice has resulted in communication problems. For example, participants noted that communication between the MAID liaison and the AHS MAID team has often broken down, and that when the MAID team has arrived at the hospice, they have not checked-in with hospice staff. Amidst this background of limited communication, hospice staff described that when a MAID procedure has taken place, the MAID team has at times arrived at the hospice, closed the patient's door, performed MAID, and then has left the patient's body, at times in a manner deemed disrespectful by staff, such as by covering the patient's head. One participant noted: "They covers the face, they wrap like-like that with the blanket. When I came say: 'Oh my god,' it hurts so much." Participants found this process to be disruptive and upsetting. One LPN participant stated:

> What's upsetting to me is that there's sort of disconnect between what we're trying to do and the MAID team, and there's no real communication. And to me, I just get told that morning and then somebody shows up and they're dead. And I'm going: 'Oh crap.'

She added: “They do the procedure, and then they leave the patient with all the lines in and they just walk out, and then we're left going 'okay, now what do we do?'”

Participants also noted that the AHS team does not update the chart of those who have received MAID, leaving “holes” in the patient’s documentation. One participant expressed concerns as to the legal implications of these holes, saying:

> I really think it creates a red tape conflict, for lack of a better word, like when I said when they come in, and do their thing, and they don't document anything, and then we go in and we find a dead body. So, like if there's ever an inquest on one of these cases, it's like I charted at 7:30 in the morning when I received patient in the ‘care and comfortable,’ and the next thing I've discharged them to the funeral home and there's nothing. Like what happened to them in between that? That puts us all, I think, in a very vulnerable situation with absolutely no support other than each other. Because, it's a legality, somebody has to pronounce them dead, and if I find them dead, like, if we know the MAID team has been here, where is the documentation?

This lack of communication and the disruptive situations it has created have both contributed to a perception among participants that MAID provision is a secretive and subversive activity within their hospice. Some participants compared the MAID process at their hospice to a “conspiracy theory,” asking why MAID was shrouded in such secrecy if it was supposed to be an “okay thing.” One participant described this secrecy as contrary to the nature of hospice:

> We're in a very caring, supportive environment for each other and everything that goes on here. So, this sort of stealthily coming in, for lack of a better term, just seems to go against so much of what we represent.

This lack of communication between the hospice and MAID teams may also explain why some participants describe the AHS MAID team as being “cold and heartless,” and having no relationship with the patient and their family. One RN participant noted how the development of this separation model and its subsequent fallout was initially due to staff opposition to MAID. She said:

> We as a hospice, I think we've made it pretty clear at the beginning we didn't want anything to do with MAID, and I think now we're realizing the position that's put us in, that MAID is happening here, and they're not talking to us.

A participant noted how her hospice’s response has created “difficult” situations with family members because they approach her with questions and complaints about MAID, even though AHS is responsible for MAID. She also said that that despite the separation between hospice and MAID, hospice staff have experienced unwanted requests from the MAID team to be more involved in the MAID process, for example, by giving their opinions on MAID assessments.

Other participants noted that their hospice’s response to MAID has prevented staff from attending the MAID procedure, and expressed a wish to be present so that the patient could be with staff members whom they know and trust. One RCA participant noted: “Maybe those patients would have liked one of us in there because they know us, they trust us, they care for us. Instead of…there's three strange men just came in my room, it's like a bad movie.”

Despite the problems created by the separate on-site model, one RN participant noted that she would not like to become more involved with the work of the MAID team, saying that greater knowledge about the MAID process and where a patient is in it would make the participant feel "more complicit" in MAID. She felt that while the current model has resulted in a perception of "secrecy" towards the MAID process: "I don't wanna be in bed with them type of thing, like, I don't wanna play with their team."

Site 2 participants raised concerns that the transfer system employed at their hospice negatively impacted the end-of life experience for patients and families. They felt that it harmed the continuity of care for patients and families, judged a patient's choice to receive MAID, and hindered patients from receiving hospice care before MAID, or from receiving MAID in a nice hospice. Moreover, they felt that transfers were emotionally difficult for staff.

Participants worried that the transfer system prevented patients and their families from receiving the personalized care offered at a hospice. One participant said:

> The only reason that I would like to see it done here, is because I think, I don't like the fact that we transfer them to another facility, who knows how they're being taken care of, and if they stay here we can still give them really good care, physical care, psychological support, before.

Some Site 2 participants noted that was is very difficult on staff to transfer a patient off-site after developing a bond with them and their families. They felt that they had abandoned the patient, and that the bond between the patient and the MAID team off-site was not a strong as the one that they developed with hospice staff. Interestingly, a Site 1 participant described similar feelings at that hospice prior to allowing MAID on-site. She said:

> We had situations, where before [we had] MAID provisions happen here, then we were having to send people out. And so, and I know in meeting, you know, in the other hospices, that they felt the same way, that, they didn't want to send people out. I can tell you when we did send people out I got a call within minutes, the family phoned me, and said, oh, you know, 'thank you for everything,'

> and I just, you know, was able to say 'well, come back [laughs], you know, come back we're here, we want to give you a hug, we want to be here for you.' And they did, and they just came right back as soon as they could, so, in seeing that, we saw that we absolutely wanted them to be here.

Some Site 2 participants felt that the hospice's current policy on MAID judged the patient's choice. One participant noted:

> I feel personally when [transfers] happens that, it's like if we judge the patient. If like, if we say: 'Well if you don't, if you don't think that what we do here is good enough for you, well, you know, you're gonna go have your option elsewhere.' And, I don't like this message that we send the patient or their families. It's like if we say: 'Well, we don't accept your option, we don't endorse it as a group." So, I don't know it must feel very, it's like if you have a teenager who asks for abortion and then people say: 'Well, you're not gonna have this in our hospital because, you know.' So it's a, it's very judgemental at one point, it's almost discriminatory that we have to send him elsewhere so that it doesn't happen under our roof. I don't like that.

This participant also felt that the hospice's MAID policy hindered patients who may be considering MAID but were still interested in receiving hospice care from being admitted to hospice. She described how her friend's mother was not admitted to their hospice because she eventually wanted to receive MAID, but that she also wanted to receive hospice care before the procedure. She said that this person:

> …had ENT cancer and … her end of life would be choking. And she said, 'I want to be able to have, to ask for AMM when I know that this is coming, but meanwhile, I'd like to have decent and dignified palliative care, can I be admitted in palliative care?' And then, because she knew that this place didn't allow it, she deprived herself of being admitted here and had her end of life in the hospital. And the daughter said: 'Well because of your stupid rule, well my mother had maybe two

> or three months that she could have enjoyed the place here, but because she knew and she announced it, that she wanted the AMM, well then it wasn't the right place for her.'

Some Site 2 participants also believed that the transfer policy moved hospice patients to receive the procedure in settings that were not as nice as their hospice. One participant noted: "It's like in a room in the emergency room, it's not the place where people should die, especially after they came here, right."

A Site 2 participant described how the hospice's policy regarding MAID had already evolved to address some of these concerns. She described that in the past patients were transferred as soon as they passed the first MAID assessment, up to a week before the actual procedure was to take place. She noted that patients now stay at the hospice until the day before the procedure, so that staff can continue to provide care to the patient and family. That said, a Site 2 participant expressed support for the current transfer system as it minimized the involvement of hospice in MAID by keeping it off-site.

In sum, this theme detailed how the responses taken by the two participating hospices to the legalization of MAID have created unique challenges for each hospice. Participants described how Site 1's use of an external team to provide MAID on-site has resulted in disjointed communication between the hospice and MAID teams. This lack of communication has created disruptive situations for staff, which together have contributed to a perception among participants that MAID is a secretive and subversive activity in the hospice. Moreover, some participants felt that the use of an external team placed unwanted pressure and demands on staff from patient families and the AHS team, and prevented hospice staff from attending their patient's MAID procedure. At Site 2, Participants were concerned about the use of a transfer system to move patients who have requested MAID off-site as it negatively impacted continuity of care for patients and families, judged a patient’s choice, and hindered patients from receiving hospice care before MAID or from receiving MAID in a nice hospice. Additionally, they felt that transfers were emotionally difficult on staff. Despite these challenges, some participants endorsed the responses of their hospices to MAID because it reduced the involvement of the hospice and its staff by either keeping MAID off-site or getting an external team to provide it.

4.8- Theme 5: MAID on-site provides opportunities for a hospice to improve the end-of-life experience for patients and families

This theme highlights the opportunities for a hospice created by the availability of MAID on-site for patients and their families, and explores considerations to streamline the introduction of MAID to a hospice.

As described in the previous themes, many participants felt that the possibilities and situations created by the legalization of MAID has manifested as challenges. Some participants felt that MAID should not be allowed in a hospice as these challenges were too great to overcome, specifically the challenge allowing MAID on-site poses to hospice identity. One RN participant said: “In my opinion the only thing that will make [MAID] easier is to have MAID elsewhere. But, I honestly don't feel it's part of hospice care.” Another RN noted: “We're supposed to be focusing on the living and here we are offering this...option of opting out of living. Personally, I don't think it can align.”

Many participants believed that hospice care was able to reduce patient suffering to the point that MAID should not be needed for hospice patients. Some participants at Site 1 believed that MAID was only being used by those who were older, or had psychosocial issues that hospice care could have addressed rather than for uncontrolled physical suffering. One Site 1 participant felt that majority of participants at her hospice opposed MAID.

Importantly, some participants viewed the availability of MAID on-site as an opportunity for a hospice to improve the end-of-life experience for patients and families. They described that doing so would further the values of "compassion," "dignity," and the aim of furthering patient choice. That said, some of these participants still did not view MAID as a part of hospice care. Instead, they were separating the concept of hospice *as a place* into hospice spaces and hospice care. For example, a Site 2 nurse said: "I think there's room for AMM in the palliative care context. Like, with an understanding that they are two very different approaches." Another Site 2 participant noted:

> I see it more as an algorithm, you know, as [another participant] was saying, you've got, the palliative patient then you have palliative care. And then maybe you branch off, and then you've got medical aid in dying. So, I don't see it as a natural flow coming out of palliative care.

This separation helped participants avoid MAID's conflict with hospice care's commitment to living over dying. The aforementioned values and aims of "compassion," "dignity," and respect for patient choice, as well as improving patient comfort, allowed participants to see opportunities that offering MAID on-site could bring to hospice.

Participants believed that allowing MAID on-site would let patients choose their preferred death and dying experience. They felt that by doing so, patients and their families would not have to worry about whether a patient's death would be a good death. One participant felt that for the family, MAID is: "A relief because then the burden of: 'Was it a good death, a bad death, was it alone,' it's not there. It happens the way the person wanted it." Indeed, Site 1 participants described a family gaining peace from their relative's MAID death because they knew it was what their relative wanted. One participant felt that those in hospice were “good candidates” for MAID because they had the opportunity to consider hospice care and decided that it was not what they desired. As such, she believed that the patient’s request would arise from their preferences over a good death as opposed to unaddressed suffering.

Participants also believed that offering MAID on-site was an opportunity for symptom control. One nurse participant felt that despite a belief among the hospice community that hospice care provides an ideal death and dying experience, there were still deaths in hospice where patients experienced distressing symptomology, such as coughing or vomiting blood, or choking on one’s secretions. She said:

> I think in palliative care we've kind of deluded ourselves into thinking that the palliative care natural way is, you know, the epitome of a good death. I don't believe that … we've had beautiful deaths and we've had not beautiful deaths, right.

Another LPN participant believed that hospice care’s focus on living over dying leads to patients dying in an undignified manner. She noted that “the whole problem of the hospice approach” is:

> We want our patients to live until their body gives out, right…and I think that's the big thing with us, we think we should give that last bit of time with their families and keep them comfortable until that very last minute, but there's a lot of days, you know, people go on for days and days, you know, unresponsive, and it's not very dignifying.

This participant viewed MAID to “finish” or “stop” the dying process so that: “the family's at peace, you know, the body's at peace, everyone's at peace.” Participants at Site 2 also felt that offering MAID on-site could relieve some of the problems created by their hospice’s transfer system, and that the availability of MAID on-site would be a relief for existing hospice patients as they could make this request knowing that they would not have to leave. One nurse participant noted that:

> It would probably be a relief, for some patients to know that that's an option, and that they wouldn't have to leave. ‘Cause right now they have to leave to go to the hospital, they don't get to stay with us, which is sad. You know to have to go somewhere foreign like that, and I mean, the hospital is not really where you'd want to go to die, but it would be nice, it would be really nice if they could stay with us. And like I said I'm sure it would be a big relief, or just like, just to know that it’s an option … people would have the choice, you know, if it just becomes too much, and, you know their existential suffering, or their very real physical suffering is too much to bear, you know, that AMM could be done within their room, you know, within maybe a matter of days of making that request.

In a similar vein, a Site 2 participant believed that offering MAID on-site was an opportunity to improve the end-of-life experience for those looking to receive MAID, but who were only able to receive it in a hospital. She said she would be comfortable admitting these patients to hospice with the purpose of receiving MAID, so that they could receive MAID in a peaceful facility with skilled staff. She noted:

> I think I would be [comfortable in admitting these patients], in the kind of example that you say here, it's that if a person doesn't want to die at home, or is in the hospital and say: 'Well I want *l’aide medicale a mourir* but not here, with three other persons behind the curtains, and that I heard the other guy throwing up, or whatever,' you know, can we offer that in a beautiful setting, private, where people are trained and are compassionate and knows about death? And knows about end-of-life? … So, at that point I would be willing to say: 'Well, why don't we admit this person here?'”

The analysis of participant responses also identified several considerations that could streamline the introduction of MAID on-site, primarily by addressing some of the challenges of the on-site availability of MAID that were described in previous themes.

4.8.1- The impacts of MAID on staff, and the need for staff support, education, and engagement

As described in the previous themes, the legalization of MAID has created emotional and moral difficulties for hospice staff. Site 1 participants described the different coping members staff have developed to deal with these difficulties. A participant described that staff have created separation between themselves and situations that challenged their moral beliefs. This participant noted:

> All the conflicts that we have we're separating ourselves. So, if I'm doing anything, I'm saying: 'Well that's the patient's decision, that's not me deciding, well that has to be the family's decision, that's not me having to decide … you know, the MAID team is deciding all these things.' And we're just obliging by still doing our own job.

Other participants described how staff relied on colleagues for support, and a participant noted that management has let staff who were uncomfortable with MAID take the day of a procedure off. However, Site 1 participants felt that they needed more psychosocial support, a suggestion that Site 2 participants similarly echoed if MAID was to be allowed on-site.

Participants at both Sites also felt that engagement and education of staff could also help to streamline the introduction of MAID on-site. Participants at Site 1 felt that the decision to allow MAID in their hospice was taken by “higher ups” in the organization, and that the decision was "forced" onto staff. They wondered whether having had more "education" and "discussion" about MAID would have improved the transition of allowing it on-site.

Some Site 2 participants similarly felt that if MAID was to be introduced to their hospice, staff would need to be engaged throughout the implementation process. They believed that engagement should include education and the opportunity for them to voice their perspectives on the introduction of MAID, ask questions, and discuss how MAID would affect them. One participant specifically noted that hospice staff would need additional training on how to talk to families about MAID.

Some Site 2 participants felt that an engagement process could help staff view MAID as embodying many of the aims and values in hospice philosophy, such as compassion, dignity, and respecting patient autonomy. One participant felt that through:

> …open conversations kind of like what we're doing here, the transition may come slowly but, to show that we can still be compassionate [when a patient chooses MAID], they can still die with dignity, full autonomy in terms of choice, we'll take care of your family before and after.

Some Site 2 participants noted that there may be staff resistance in introducing MAID on-site. However, they believed that this does not mean that MAID should not be offered on site, even with an emphasis on staff engagement throughout the development and implementation of such a policy. That said, many Site 2 participants felt that if MAID was allowed on site, it would be important to respect how each staff member felt about the issue, including the protection that staff would not have to participate in MAID if they did not want to. A Site 2 participant discussed this consideration, stating:

> I mean as a nurse I don't want to participate, I don't wanna be the one starting the IV but, if we'll say [another participant] chose to do that, I'd be supportive of her. I wouldn't judge her, that's where our personal morals come in, and that's fine. 'Cause that's the one thing that I do hear from the staff where, they'll understand the patient's wish and even agree with it when you see some people suffering, but I don't wanna be there. And that's ok, if they don't wanna, they don't have to.

4.8.2- Patients should try hospice care first

Participants at both Sites insisted that hospice patients should try or at least consider hospice care before seeking MAID. Some felt that doing so could help overcome the challenge to hospice identity created by offering MAID on-site, including the worry that patients would "jump" to MAID without first considering or trying hospice care to see if it could address their suffering. One participant described that by not attempting to address the patients suffering first through hospice care, hospice workers would be "shortcutting" their jobs. She said:

> Maybe the desire of death comes from the fact [that] they have symptoms that are not well [controlled]. So the reflex shouldn't be 'oh well here's the form for [MAID] and then just sign it and we'll yeah'. That's not what we should do because this is, you know, shortcutting the job that we're doing. So we have as you say to address the exact the reason why deeply they want this … If it's because they ask, or they mention 'I can't take it anymore, I want it, I want to end', well what do you want to end? Your life, or your misery?

That said, some Site 2 participants emphasized the importance of leaving the "door" open for MAID. They believed that doing so lets patients and their families know what options are available, helping to relieve patient anxiety over when death will occur. One LPN believed that when she has seen hospice patients who are very anxious about the uncertainty of death, or believed that they were taking too long to die, conversations about the options of MAID or palliative sedation had not been had with the patient. She said that for these patients:

> …the doors weren't left open and they're not being explored. And so [the patient is] just kind of twittling his fingers waiting for death to come, and I think that's a huge thing of anxiety for a lot of our patients.

4.8.3- Community education and demystification of MAID

As discussed in theme 1, participants at both Sites acknowledged that the general community does not understand the work of hospices, and has misconceptions that hospices hasten the death of their patients. As such, Site 2 participants felt that if MAID was to be introduced at their hospice there would need to be education campaigns for both the lay and healthcare communities about hospice, and under what circumstances MAID would be available to patients at a hospice. One nurse participant said:

> There has to be like a clear understanding that when a patient or family comes to the residence, you know, we don't kill people quote on quote. ‘Cause people already have this idea that, you know, like they don't really know what's going on in palliative care. They think we kill people … they don't understand what we're doing. And so like, I would be worried about, if we started doing AMM because, then they do have like a logical worry, right, that ‘oh, well you do that here now', you know. So, I just feel like so much education would need to be done.

4.8.4- Space and staffing logistics of offering MAID on-site

Participants discussed considerations regarding space and staffing to improve the introduction of MAID in a hospice. Site 2 participants were opposed to having a special area designated for MAID, and felt that MAID could be provided in a patient's room much like palliative sedation. In terms of staffing, participants saw benefits and drawbacks to using either hospice staff or staff external to the institution to provide MAID. Participants felt that using hospice staff members would allow the patient and family to receive the procedure from staff members whom they knew and trusted. A Site 2 nurse participant, in discussing how MAID could be introduced to her hospice, stated that the downside of external providers is that:

> …it would be staff that…the patient and family would not be familiar with, which to me is like a huge con. If they're comfortable with us, and they know us, it seems like it would be a real shame, for the patient to have to die, you know, with, staff members they don't know.

Another Site 2 participant stated that an internal team would have a better rapport with the nursing staff. Other participants called bringing in an external team "counter-intuitive" and "clinical." Indeed, some Site 1 participants viewed MAID as "utilitarian" and "expedient," potentially resulting from the use of an external AHS MAID team that participants felt were engaging in secretive and disruptive activities in their hospice. That said, some Site 1 participants believed that the use of an external team could be streamlined through improved communication. For example, one LPN believed that doing so could help staff prepare emotionally for the MAID procedure. She said:

> You can sort of go 'okay this is gonna happen today, alright, I can, you know?'.. But to be told in the morning and then you have to deal with the family and the body of the patient that you've looked after for so many weeks it's like...

Site 2 participants also felt that the use of an internal team could create challenges. Some participants worried about how the families of other patients at the hospice would feel if a hospice physician provided MAID to one patient, and then that physician went to provide care to their relative. One participant stated that these family members would think: “He just did this, and now he's coming to my father.”

Another participant raised concerns that there would not be enough staff willing to participate. However, one participant stated that if staff members objected to participating in MAID, it would not affect the hospice’s ability to provide the procedure as the hospice staff work in a team, and even if half of staff objected, there would still be enough staff available to participate.

4.8.5- Increased supports for patient families

Participants at both Sites felt that current supports for families going through the MAID process were insufficient and needed to be increased, especially if Site 2 decided to allow MAID on-site. Site 2 participants felt that increased family support could help minimize the family conflict, stress, and anxiety described in theme 3. Some believed that this support would include a family assessment to determine whether all family members agreed with a patient’s decision, and to address any potential conflict. One participant noted:

> When everyone's on board and [MAID is] well planned out and the prep work is done prior to, then it, it's wonderful because they're part of it, and so the grieving its a normal grieving process. It's when they don't agree, right, or 'I shouldn't have let her do it' why did I let her do it?', or ‘I just went along with it because she felt she was a burden to me,’ and so it's all that, that starts to get

> unpackaged after. And that's why I said, I think if it was ever to be implemented, that that family assessment piece is so key, because then we prevent the complicated grief because we address it as we go along, we involve the family, yeah, so it's more preventative. It's when the family's not on board that we hit the grieving issues, but if they're all on board and part of the planning then it’s beautiful.

These participants also felt that part of this support would include helping families have conversations about MAID earlier in the disease process. One LPN participant noted:

> When you don't start the conversation early enough the anxiety towards the end is much more. And then that conversation is really hard to have when they say, you know, ' I want AM[M]', the family's much more resistant because they're like 'well why? you're not ready to die.'”

This theme has explored the opportunities the availability for MAID on-site could create for hospice. However, many participants did not view MAID as an extension of hospice care, but rather as a procedure that could co-exist alongside hospice care in a hospice. The analysis of participant responses also highlighted several considerations that could streamline the introduction of MAID to a hospice, including by minimizing many of the challenges described in themes 1-4.

4.9- Conclusion

Participants described how the legalization of MAID has created new challenges and opportunities for their hospices. Thematic analysis of the data constructed five themes that organized and synthesized similar challenges and opportunities. The first theme detailed how the availability of MAID on-site challenged the identity of a hospice. The second theme highlighted how hospice staff struggled to reconcile a patient’s decision to choose MAID given the abilities of hospice care. The third theme explored how the availability of MAID for patients whether on or off-site has led to challenging clinical situations involving hospice patients and their families. The fourth theme highlighted how differing hospice responses can create unique challenges. The last theme explored how the availability of MAID on-site provided opportunities for a hospice to improve the end-of-life experience of patients and their families. Together, these themes provided a rich description of the challenges and opportunities these hospice workers think MAID brings to a hospice, proving insight into the situations encountered by Canadian hospices as they navigate their new reality.

Chapter 5: Discussion

5.1- Introduction

This study provides insight into the perspectives of Canadian hospice workers on hospice, its relationship with MAID, and considerations for the implementation of MAID into hospice. This chapter will first describe the limitations of the study, and then discuss the results of this study in relation to the hospice and bioethical literature. It will then offer suggestions for Canadian hospices navigating their reality, and conclude with recommendations for further areas of research.

5.2- Limitations

As with all qualitative research, caution should be taken in transferring the results of this study to other contexts.[93] The two hospice sites included in this study each exist in their own unique social contexts, and as such readers should evaluate similarities between their contexts and the contexts of the study sites when looking to transfer the study's findings.[93]

Given that focus groups were the primary method of data generation in this study, it is possible that participants with minority or controversial beliefs were not comfortable sharing their perspectives. This limitation was partially addressed with the option of an individual interview, of which all participants were made aware through recruitment materials and the consent document that was read to them at the beginning of the focus groups.

5.3-MAID and hospice identity

This study's results provide insight into the identities of 'hospice,' 'hospice care,' and 'hospice community' through our concept of hospice as a place. Moreover, they highlight the impact of MAID on these identities and the related construct of the hospice 'good death.'

'Hospice' is a poorly defined concept in the literature, and there is considerable confusion as to whether it is a philosophy of care or a facility.[94] Our results help provide clarity to the term through the development of the concept of 'hospice as a place,' which highlights both a distinction and an interconnectedness between physical hospice facilities and the hospice philosophy of care. Through the influence of Tuan's Humanistic Perspective on Place, a hospice becomes conceptualized as a physical space wherein activities involving those in a hospice occur.[75] These activities create meaning for the hospice, turning it from a physical space to a place.[75] Participants described how the provision of hospice care is a prominent activity within hospice, which, as hospice as a moral practice dictates, requires the realization of certain internal goods, including goals, skills, values, and principles.[8] As such, hospice care and the internal goods that guide it substantially contribute to the meaning and identity of a hospice, all of which can be viewed through the lens of hospice as a place.

These results help to conceptualize and differentiate a Canadian hospice and the Canadian hospice community from those in the United States. In Canada, hospice care is provided in specialized stand-alone facilities, while in the United States, it is primarily delivered in a patient's private residence, nursing home, or in long term care.[1, 36] As such, while hospice as a place provides a conceptualization of Canadian hospices, or residential hospices in other jurisdictions, it does not describe hospice in the Unites States, which would need to consider the range of locations where hospice care is provided and the agencies that provide this care.

In the literature, assisted dying is described as threatening the identity of hospice communities by challenging their commitment to providing a hospice good death.[17, 20] Our results expand on the challenge MAID poses to hospice identity by highlighting three specific challenges to the identity of hospice as a place. Firstly, participants felt that the availability of MAID on-site posed a fundamental challenge to the purpose of a hospice. They believed that providing hospice care and the type of death it facilitated was a fundamental part of a hospice, and that MAID was not a part of hospice care. Moreover, they felt that MAID on-site could make it more difficult to provide hospice care and the benefits of both this care and the hospice good death as patients could simply choose MAID. Secondly, participants worried that allowing MAID on-site could change the role of a hospice in the healthcare system by becoming a ‘drop-in’ for MAID. Lastly, participants were concerned that allowing MAID on-site could negatively impact community perceptions of a hospice and its workers.

Yet, our results highlighted a willingness among participants to allow MAID in a hospice, with the understanding that MAID and hospice care are different end-of-life approaches. Participants believed that MAID was an opportunity for a hospice to further the values and aims of compassion, dignity, respect for patient choice, and improving patient comfort. This suggestion echoes Campbell et al.’s[51-53]argument that hospice responses to legalized assisted dying represent attempts to determine the constitution and boundaries of ‘hospice’ in the face of conflicting values and principles. Our analysis revealed that this suggestion was an attempt by participants to minimize conflict between MAID and the philosophy of hospice care while also furthering common goals and values between them, such as furthering patient choice and improving patient comfort and dignity.

5.4- Balancing the good death with paternalism

Participant suggestions on how their hospices should respond to the legalization of MAID, including potential strategies for introducing MAID to a hospice, attempted to balance the challenges and opportunities for a hospice that were created by the legalization of MAID. Many of these suggestions and strategies, such as prohibiting MAID on-site, not allowing patients to transfer to a hospice with the sole purpose of receiving MAID, and asking that patients first try or at least consider hospice care before MAID, attempted to maintain the hospice good death. While this attempt aimed to provide patients and their families with the benefits of hospice care and a hospice death, it also risked promoting paternalism regarding the content of an acceptable death and dying experience in a hospice. In the bioethical literature, paternalism refers to actions taken by healthcare providers to override patient requests or preferences with the aim of improving the patient's well-being.[95] Our results speak to the tension identified by Belanger et al.[67] that palliative care physicians feel the need to both explore a patient's suffering while respecting their wishes in responding to patient interest in MAID.

Many participants who advocated for patients to first try, or at least consider, hospice care before receiving MAID were concerned that patients were experiencing suffering that hospice care could address, thereby allowing the patient to continue living. There is evidence to support these concerns. A systematic review by Monforte Royo et al.[96] on patient reasons for requesting an assisted death found that these requests were in response to interrelated psychological, physical, and spiritual suffering, and at times could be the result of patients wishing not to end their life, but improve their quality of life.

However, there appears to be a limit to what hospice care and palliative care can do to satisfy the end-of-life needs and preferences of all patients. Existing research into why hospice and palliative care patients request MAID suggests that patients seek MAID to relieve suffering that hospice and palliative care could not address.[97-99] We similarly found that hospice care may be unable to address suffering to the satisfaction of all patients. This recognition was an aspect of the overarching finding that for some patients, hospice care and the good death it facilitated was simply different than what they wanted. Recognition of the limits of palliative is important for hospices in order to avoid a paternalistic response to the legalization of MAID, including to individual patient requests for MAID.

As bioethicist Franklin Miller[5] cautions, the hospice ideal of a good death creates a mold into which all hospice patients must fit, regardless of the patients' personal preferences for what it means to die well. He warns that "such a paternalistic stance abandons the patient-centered beneficence and respect for autonomy otherwise characteristic of the hospice philosophy" (p. 96).[5] Perhaps more concerning, he warns of the connection between paternalism and intolerance.[5] Indeed, sociologists Hart et al.[10] write that "exploration of the development of the good death concept exposes an ideology that constructs a socially approved form of dying and death with powerfully prescribed and normalized behaviours and choices" (p. 72). They argue that the good death concept thus creates stereotypes of good and bad patients.[10] Participant responses in our study highlight the early development of similar stereotypes as participants tried to re-assert the hospice ideal of a good death. For example, some participants believed that patients who wanted MAID should not be admitted to hospice facilities because they have no interest in hospice care.

The construction of MAID as a good death could also create similar expectations for patients on the content of an acceptable death and dying experience. Indeed, participants felt that MAID was co-opting the good death in societal discourse at the expense of Canada's hospice and palliative care communities. This finding resonates with Karsoho et al.'s[14] analysis of the *Carter* case, which found that proponents on either side of this debate portrayed their version of the good death as being superior to the other.

The impact of the normative expectations created by the construction of either hospice or MAID as a good death could limit the end-of-life options for patients. These restrictions could be created through government policy that increases or decreases the availability of either MAID or hospice for a population, or through the options that healthcare institutions and providers present and provide to their patients. A shift in end-of-life care is thus needed to change this adversarial relationship between assisted dying and hospice communities to a more collaborative one that recognizes the merits of each approach, a shift that has been historically advocated by some assisted dying advocates to frame the two as a mutually compatible alternatives.[17]

5.5-Obligations of hospices to their patients

Our results raise the question of what obligations a hospice has to patients who choose MAID. For example, Site 2 participants felt that the transfer system employed at their site created harms for patients. These results reflect debates in the hospice literature on the relationship between hospice's hesitancy to participate in MAID and its obligation of non-abandonment.[20, 51-53] The principle of non-abandonment refers to the obligation of healthcare workers to maintain a continuous relationship with their patient.[100] It is hoped that this relationship will both individualize the care given to the patient while providing continuous and un-wavering support and guidance to them throughout their health struggles.[100] The principle of non-abandonment integrates and applies four other bioethical principles: autonomy, beneficence, non-maleficence and justice.[100] When applied to the transfer system, the obligation of non-abandonment would be violated if a transfer disrupts this relationship to the point that it violates the integrated principle of non-maleficence by creating harms for the patient.

Proponents of the transfer system for MAID in the context of religious facilities argue that a smooth transfer system that does not place ‘undue’ harms or burdens on patients and maintains the unique identity of different healthcare facilities.[101] A similar argument could be made in the hospice context, while adding that offering MAID in a hospice makes healthcare workers complicit in the harms of MAID, violating their own commitments to non-maleficence.[7, 11, 16, 17]

However, our results indicate that even the smoothest transfer system could create harms for patients and families. Participants’ responses highlighted how transfers could pass judgement on a patient, and that transferring hospice patients from a facility in which they are comfortable and with staff whom they trust could create additional stress during an already difficult time for patients and their families. Other responses to the legalization of MAID, such as using an external healthcare team, may strike a better balance between maintaining the unique identity of hospices and hospice care while minimizing harms to patients. Moreover, evidence from Oregon and Ontario suggests that co-operation between hospice and palliative care and MAID does not decrease access to hospice or palliative care.[97, 98]

Critics of the transfer system also argue that Canadian hospices have an obligation to allow MAID on-site given the public funding they receive.[66] The question arises as to whether, in receiving public money, these privately operated facilities enter into a social contract, in which they must provide healthcare services that have been deemed by public institutions (Canadian legislatures, courts, and professional colleges) to be legal and clinically appropriate for some patients.[102] This social contract has already been recognized by the British Columbia government, which has mandated that any healthcare institution that receives more than 50% of its funding from provincial money must offer MAID.[66] Our findings of the potential harms to patients created by a transfer system strengthen the obligation for hospices to allow MAID, as this social contract would appear to be broken if hospice actions to prohibit a legal healthcare option creates harms for patients. However, given the importance of many Canadian hospices on community and corporate donations, hospices may find themselves in a *Catch 22* given our findings that allowing MAID on-site could exacerbate community misconceptions about hospice.

Our results also suggest that hospices may have an additional duty under the obligation of non-abandonment to introduce and discuss MAID as a treatment option for patients. Site 2 participants felt that it was important for hospice workers to introduce MAID as an option for patients to minimize patient anxiety over death. The obligation of non-abandonment holds that healthcare providers should engage in a partnership to resolve challenges relating to the patient's health and well-being.[100] Omitting from patients a treatment option that is both legal and determined by professional colleges to be clinically appropriate seems a violation of this partnership. Bioethicist and palliative care physician Timothy Quill writes that acknowledging the option of assisted dying with patients and their families will reassure and relieve patients and their families, as they would know that there are options should palliative care be unable to address their suffering.[103] For hospice staff, introducing the option of MAID to patients helps to further the collaborative relationship described in 5.4 so that patients may determine the best death and dying experience for themselves.

5.6-Recommendations for hospice response to the legalization of MAID

Our results, together with and existing literature, suggest that there are benefits to offering MAID in a hospice, with the understanding that MAID is not a part of hospice care. In this arrangement, patients would not only be able to receive MAID in their hospice room, but would be made aware of the option by hospice staff. Doing so could increase patient access to high quality end-of-life care, while also fulfilling a hospice's obligation of non-abandonment. These results echo the arguments of some proponents of assisted dying that co-operation between hospice and assisted dying could improve end-of-life care options for patients by framing the two as mutually inclusive options based on common values.[17] Moreover, by recognizing that MAID and hospice care are two separate approaches to care, hospices and hospice care would be able to largely maintain their intertwined identities. Separation between MAID and hospice care could be created through the use of an external team such as at Site 1, or by instituting a grace period that incoming patients must wait before receiving MAID, giving hospice staff the opportunity to inform the patient of hospice care options to address their end-of-life needs. While this 'separate but co-existing' approach provides an initial path forward for Canadian hospices, these benefits and the growing comfort with MAID that this study highlighted in the Canadian hospice community may provide future opportunities to integrate MAID within hospice care. That said, this community would need to reconcile conflicts between the commitments of hospice care and those of MAID.

Based on our results and existing literature, I have three recommendations to streamline the introduction of MAID to a hospice. Firstly, hospices considering the introduction of MAID on-site should increase psychosocial support for staff and the families of those who request MAID. Though further research should consider strategies for the content of this psychosocial support, respondents in Antonacci et al.'s study[68] noted a lack of debriefing sessions for staff on MAID.

Moral case deliberation (MCD) has been proposed as a method for healthcare staff to debrief after experiencing morally challenging or traumatic clinical situations.[104] In MCD, a facilitator guides participants in a group through a difficult clinical case, asking participants to reflect upon and discuss the moral issues presented in the case.[104] A systematic review by Haan et al.[104] found that the use of MCD in healthcare settings can help clinical staff feel relieved of moral burdens, increase confidence in their work and improve their understanding of the moral issues and perspectives at play. As such, MCD may be a method worth exploring for hospices looking to better support their staff surrounding MAID. Our findings also support Gamondi et al's[105] recommendation that family members be included in the clinical consults of those who have requested MAID, so as to identify and address their needs during the MAID process.

Secondly, hospice administrators and workers should practice 'reflective awareness' in crafting policy responses to the legalization of MAID, as well as in responding to patient requests for it. Nursing scholar David Wright[106] describes reflective awareness as a strategy for hospice nurses to reflect on their actions to support and guide end-of-life patients so as to develop an awareness of when these actions impose the providers' values on patients to the point of becoming paternalistic. Reflection on how different responses to the legalization of MAID, as well as to patients who ask for MAID, could help staff balance their beliefs about a hospice's purpose while also respecting patient views on what is an acceptable quality of life and an acceptable death and dying experience. Moreover, reflective awareness could help staff members struggling to understand patient requests for MAID to view these requests not as a failure of care, but rather as patients deciding to access a legal healthcare option in alignment with their preferences on death and dying. In response to individual requests, staff could start their reflection by asking themselves questions such as: Has the patient been made aware of all tried and untried alternatives to address their suffering?; and Has the patient been given the opportunity to pursue these alternatives?[107]

Thirdly, we recommend that hospices considering the introduction of MAID on-site take steps to educate and engage both their staff and the community they serve about any proposed policy changes, and about MAID itself. Our results resonate with Willis et al.'s[108] review on introducing and sustaining culture change in health systems, which found that policy changes are most successful in healthcare when staff are engaged through methods such as focus groups and brainstorming sessions, and that unengaged employees can develop anxieties and fears surrounding changes to their organization. They also note that changes are more successful when they are presented to employees as aligning with the organizations existing values.[108] Li et al.'s[109] description of the integration of MAID to a major Canadian hospital also stressed the importance of educating all staff members about MAID. They believed that staff fears surrounding MAID were assuaged by this education.[109] Moreover, community education and awareness of MAID could help address concerns raised by both Antonacci et al.[68] and our study that allowing MAID on-site could negatively impact community perceptions of hospice. This education could also help hospices address concerns over a reduction in community funding created by misconceptions about hospice. As such, I recommend that hospices considering a policy change to allow MAID on-site increase community education about hospice and MAID, and clarify the exact circumstances under which MAID is performed at the hospice.

5.7- Directions for future research

This study opens three areas for future research. Firstly, participants in our study described cases of MAID where there were concerns about the patient's capacity, where rules surrounding MAID were not applied, and where patients were in pain because they refused pain medication to ensure capacity to consent. A Site 2 participant also stated that she had heard of cases where things went wrong during the actual MAID procedure, such as where the medications did not work. Patients refusing pain medications to stay competent is an acknowledged consequence of Canadian and Quebecois MAID legislation.[25] I was unable to locate previous discussion or descriptions of the other situations in the literature, and as such these situations would be worthwhile avenues of future research.

Secondly, while our results have indicated the need for increased psychosocial support for staff and patient families, and provided some suggestions for the content of this support, there is limited literature on this topic. As MAID becomes increasingly introduced to hospice and other healthcare settings, demands for these supports will increase. As such, greater research is warranted to inform the development of these supports. This research could be intertwined with longitudinal research on the experiences of Canadian hospices that have allowed MAID on-site, thus allowing for the determination of best practices on the introduction of MAID to a hospice.

5.8-Conclusion

This study's participants have provided insight into three debates in the hospice literature: The impact of MAID on hospice identity, paternalism and the good death, and lastly, the obligations of hospice to patients who request MAID. Based on our results and existing literature, I suggest that for hospices navigating their new reality, there are benefits to offering MAID in a hospice, with the understanding that MAID is not a part of hospice care. Doing so would increase patient access to quality end-of-life care options, while allowing hospice to fulfill its obligation of non-abandonment. Moreover, creating some form of separation between MAID and hospice care, such as through the use of an external team to provide it, or a grace period on MAID that patients must respect after arriving in hospice, would allow hospice and hospice care to largely maintain their unique and intertwined identities. These benefits, as well as the growing comfort with MAID in the Canadian hospice community that was noted by this study, may provide future opportunities to integrate MAID within hospice care as hospices adjust to their new reality. However, Canadian hospices would need to reconcile the philosophical conflicts between hospice care and assisted dying before integrating MAID into hospice care.

Prior to this study, there had been little academic study on these subjects, and my results have laid the groundwork for further research. Specifically, our results and existing literature suggest that future research should focus on cases of MAID where procedures are not followed, or where there are problems during the actual procedure. Moreover, additional research should examine potential supports for staff in hospices that offer MAID, and for the families of hospice patients who have requested MAID.

Chapter 6: *Conclusion*

Since its inception in 1967, the modern hospice movement has sought to provide patients and their families with its version of the good death. [9, 10, 26, 28] The good death is a moral construct that specifies conditions of death and dying that are conducive to the well-being of the patient and their family.[9, 10] For modern hospice, a patient undergoes a good death when their end-of-life needs are addressed through holistic comfort care, allowing them to find meaning as they face their upcoming death alongside their family and friends.[5, 8] To protect, distinguish, and guide the care provided by hospice communities, and the good death this care facilitates, the modern hospice movement has adopted a commitment to neither hasten nor prolong death.[16, 17]

Assisted dying has been proposed by the right-to-die movement as an alternative good death for patients at the end of life.[11-15] The modern hospice movement has historically opposed assisted dying, arguing that it is both unnecessary as hospice care and the hospice good death already meet the needs of end-of-life patients, and that assisted dying is harmful to both patients and larger society.[7, 11, 16-19] Importantly, the good deaths provided by hospice communities and assisted dying share the same aim of providing patients with control over the dying process, and are rooted in values of patient autonomy and relief of suffering.[17, 23, 24] Given these shared aims and values, some proponents of assisted dying and end-of-life scholars have argued that co-operation between hospice communities and assisted dying could increase patient access to a dignified death.[17, 23]

For Canadian hospices, the 2016 legalization of MAID in Canada has created a new reality in which MAID is an option for hospice and other end-of-life patients, despite conflicting with the hospice conceptualization of a good death, and the principle of neither hastening nor prolonging death that was designed to protect it.[16, 17, 25] There had been no studies examining the impact of the legalization of MAID on Canadian hospices, including how they are reconciling hospice values that align and conflict with MAID, as well as the proposed benefits of co-operation with MAID, as they navigate their new reality.

This study aimed to fill this knowledge gap by answering the question: "What challenges and opportunities do hospice workers think MAID brings to a hospice?" In answering this question, this study adopted a qualitative description methodology, using *hospice as a place* as the theoretical framework. Working with my supervisor, I developed hospice as a place by integrating Timothy Kirk's Hospice as a Moral Practice and Yi-Fu Tuan's Humanistic Perspective as Place.[8, 75] Hospice as a place conceptualizes hospice institutions as places with meaning, and that this meaning is derived from the activities that occur within a hospice. The physical features of the hospice, in turn, influence these activities and the subsequent meaning and identity that these activities create for the hospice.

This study included four semi-structured focus groups and four semi-structured individual interviews across two Canadian hospice facilities. One of these hospices was located in Alberta and allows MAID on-site. The other hospice was located in Quebec and does not allow MAID on site. Twenty-four hospice workers from numerous disciplines took part in the study. We used thematic analysis to identify both descriptive and latent patterns in the data, leading to the development of five themes.[89] These results highlighted how the legalization of MAID has created challenges for the participating hospices, namely that the availability of MAID on-site challenged the identity of a hospice, and that staff struggled to understand a patient's interest in MAID given their beliefs in the abilities of hospice care. Moreover, these results showed that the legalization of MAID has led to challenging clinical situations involving hospice patients who have requested

MAID and their families, and that different hospice responses to legalization can create unique challenges. Despite these challenges, these results highlighted that the availability of MAID on-site provides opportunities for a hospice to improve the end-of-life experiences of patients and their families by creating another option for symptom control, allowing patients choose their version of a good death, and to avoid the harms of the transfer system. These opportunities were grounded in the values and aims of compassion, dignity, respect for patient choice, and improving patient comfort, which are shared by both assisted dying and the hospice community.

This study's results provided insight into how the legalization of MAID has impacted Canadian hospices, and contributed to debates in the literature on how MAID impacts the identity of hospice communities, the relationship between the good death and paternalism, and the obligations hospices have to patients who have requested MAID. Based on my results and existing literature, I suggested that for hospices attempting to navigate their new reality, there are benefits to offering MAID in a hospice with the understanding that MAID is not a part of hospice care. These benefits, and the growing comfort with MAID found by this study in the Canadian hospice community, may provide future opportunities to integrate MAID within hospice care. However, integration would require hospices to reconcile philosophical conflicts between hospice care and MAID. I also made suggestions to streamline the introduction of MAID in a hospice that focused on increasing psychosocial support for hospice staff and the families of patients who have requested MAID, the use of reflective awareness by staff, and the importance of engaging and educating hospice staff and the community on a policy change to allow MAID on-site. Based on our results and current gaps in the literature, I also suggested directions for future research. I hope that this thesis provided insight into the impacts of the legalization of MAID on Canadian hospices, and will provide these hospices with guidance as they navigate their new reality.

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Appendix A: Final guide for focus groups and interviews

Questions:

1.) What are the goals of the hospice approach to care?

2.) How could MAID align with the goals of the hospice approach to care?

3.) What challenges and concerns do you think MAID brings to the hospice approach to care?

4.) How do you think these challenges and concerns could be overcome?

5.) Do you think allowing MAID on-site could change the care received by patients?

6.) With regards to the staff and patient experience, the decision-making process to allow MAID at hospice, or anything you think relevant, what are your thoughts on hospices that do, OR do not, allow MAID on the premises?

7.) Is there a difference between the death of a patient through MAID vs. a natural death in terms of having a 'good death.'

*Please note that this guide was a starting point for focus groups and individual interviews. Questions were modified and added during focus groups and individual interviews to investigate novel topics raised during focus groups and interviews that the researcher thought were interesting and relevant to the research question.

Appendix B: Sample consent form for focus groups

Information and Consent Form [For Focus Group Interviews]

1. Title of the Study

A study of the perspectives of Canadian hospice workers regarding medical aid/assistance in dying

2. The student conducting the study

James Mellett, MSc. Candidate
Biomedical Ethics Unit, Palliative Care McGill,
McGill University
2001 McGill College, suite 500
Montreal, Quebec H3A 1G1
Tel: 403-988-5132
E-mail: james.mellett@mail.mcgill.ca

Supervisor:

Mary Ellen Macdonald, PhD
Division of Oral Health and Society
Faculty of Dentistry, McGill University
2001 McGill College, suite 500
Montreal, Quebec H3A 1G1
Tel: (514) 398-7203 ext. 089405
E-mail: mary.macdonald@mcgill.ca

3. *Introduction*

You are invited to participate in this study. Before deciding if you would like to take part in it, please carefully read the following information. This informed consent document may contain information or terms you are unfamiliar with. If anything is unclear, please feel free to ask the researchers any questions you may have.

4. Background Information: Medical Assistance in Dying in Canada

In 2015, the Supreme Court of Canada ruled that legal prohibitions on medical assistance in dying were unconstitutional. This decision led to the legalization of medical aid/assistance in dying (MAID) for certain patients with chronic and/or terminal patients. Some hospices within Canada have decided to offer MAID within their institutions, while others have made the decision to prohibit it. To our knowledge, there has been little research as to the impact of MAID on the work of hospice staff.

5. *Purpose of the study*

The purpose of this study is to identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care. The hospice approach to care refers to the hospice palliative care that is provided within freestanding hospices.

This study will answer the question: what challenges and opportunities for hospice workers does MAID bring to the hospice approach to care?

This study will primarily utilize focus groups with hospice workers to collect data. Focus groups are a moderated discussion amongst a small number of participants with the aim of creating a communal dialogue that provides insight into the perspectives and experiences of participants. Based on similar qualitative studies, we are aiming to hold approximately 4 focus groups, each containing approximately 5-7 participants. These focus groups will be held in two hospice sites.

Should you feel uncomfortable participating in a focus group, you may still participate in a private interview with the researchers

6 . Study procedures

The focus groups will be conducted within the participating hospices. Prior to the focus group, you will be informed about the project you are about to take part in, and we will ask you to provide verbal consent, as well as a signed consent form that we will have given you before the focus group. This form will then be returned to the researchers and the focus group interview will then begin. Each focus group will consist of an open discussion among you and your peers that will be moderated and facilitated by a researcher, James Mellett; it will last approximately 60-90 minutes. Each focus group will be audio- recorded to ensure that no information is lost. For this same reason, during focus group interviews, field notes will be taken by a second researcher. Field notes are a researcher's personal thoughts, ideas, and questions regarding their observations made during an interview. After each focus group, the audio-recording will be transcribed in preparation for data analysis.

Should you be uncomfortable participating in focus, including discomfort with being audio-recorded, you may still participate in a private interview with the researchers. The researchers will take written field notes to document your answers.

7. *Potential Risks or Benefits*

You will not directly benefit from this study; however, your participation will help identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care.

One of the risks of participating in a focus group is the sharing of information with the other participants. While we, the researchers, will keep the information you share private, we cannot guarantee that the other participants will keep the information confidential. You are encouraged to share only information that you are comfortable sharing. All participants will be reminded of the confidential nature of the discussion at the beginning and at the end of the focus group.

You may experience a variety of emotions due to the topic of discussion or in the case of an intense discussion; however, it is not expected that you will be exposed to any additional risks beyond those you encounter in your daily life. In addition, your participation is entirely voluntary. If needed, researchers are prepared to inform you of mental health supports affiliated with the organization from which you were recruited. Contact information for professional mental health supports can be found at the bottom of this document.

8. *Voluntary Participation and the Right to Withdraw*

Your participation in this focus group is entirely voluntary. During the focus group, if you feel uncomfortable for any reason at all, you have the right not to respond, and to leave the group if you prefer. Any information you share can be deleted at your request, up until the point of data analysis; after analysis, it can no longer be removed for the study.

9. Confidentiality

Researchers will use the collected study information with the sole intent of fulfilling the study's purpose: to identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care.

In order to maintain confidentiality, all data will be recorded using a pseudonym for individual participants. Hospice sites are recorded using the province in which they are located. Only the researchers and Institutional Review Board (an ethics review board) are aware of the identity of the participating hospices. All digital study data, including the audio-recordings, will be stored on a password protected McGill server to which only the researchers have access. Paper documents (transcribed audio-recordings, consent forms, and questionnaires) will be kept in a locked filing cabinet in the residence of James Mellett between July-August 2019, and in a locked filing cabinet in the office of Dr. Mary Ellen Macdonald at McGill University from September 2019 onwards. All data will be stored for a period of seven (7) years after the study results are published. The audio files and all data will be kept for seven years following the study's conclusion and will then be destroyed. Members of the McGill Institutional Review Board (an ethics review board), or persons designated by this Board may access the study data to verify the ethical conduct of this study.

The results of this study will be published as a thesis and/or in academic journals, and/or presented at academic conferences. Your identity will not be shared or published. If the researchers want to quote something you have said during the focus group, the information will only be referenced to the study code or pseudonym.

10. Funding of the research study

This study has not received any outside funding.

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11. Compensation

You will be offered a $10.00 gift certificate for your time.

12. Contact Information

If you have any question regarding to the study, you may in contact the investigators of the study at:

James Mellett, MSc. Candidate

Biomedical Ethics Unit, Palliative Care McGill,

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2001 McGill College, suite 500

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Mary Ellen Macdonald, PhD

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2001 McGill College, suite 500

Montreal, Quebec H3A 1G1

Tel: (514) 398-7203 ext. 089405

E-mail: mary.macdonald@mcgill.ca

If you have any questions about your rights as researcher participant, please contact Ms. Ilde Lepore, Ethics Officer of McGill's Institutional Review Board at 514-398-8302.

If you require professional mental health support please contact: [the exact contact details for professional mental health support will be added here after discussion with key informants at the two hospice sites, and the information provided will be tailored to each site.]

Consent Statement

I have read the information presented in this consent form, or I have had the purpose of the study, the study procedures, and risks and benefits of the study explained to me. Any questions that I had were answered. I am aware that I can withdraw from this study at any time. I agree to take part in this study. I do not give up any of my legal rights by signing this consent form. I can request a signed and dated copy of this consent form.

Do you agree to be audio-recorded during interviews? Yes ☐ No ☐

Signature:______________________________

Print name:_____________________________

Date:_________________________________

Person who obtained consent

I confirm that a copy of this signed consent form will be provided to the participant.

Name of person who obtained consent ______________________________

Signature of person who obtained consent (Date: day/month/year) _________

Appendix C: Sample consent form for individual interviews

Information and Consent Form [Individual Interviews]

1. *Title of the Study*

A study of the perspectives of Canadian hospice workers regarding medical aid/assistance in dying

2. *The student conducting the study*

James Mellett, MSc. Candidate

Biomedical Ethics Unit, Palliative Care McGill,

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Tel: (514) 398-7203 ext. 089405

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3. *Introduction*

You are invited to participate in this study. Before deciding if you would like to take part in it, please carefully read the following information. This informed consent document may contain information or terms you are unfamiliar with. If anything is unclear, please feel free to ask the researchers any questions you may have.

4. Background Information: Medical Assistance in Dying in Canada

In 2015, the Supreme Court of Canada ruled that legal prohibitions on medical assistance in dying were unconstitutional. This decision led to the legalization of medical aid/assistance in dying (MAID) for certain patients with chronic and/or terminal patients. Some hospices within Canada have decided to offer MAID within their institutions, while others have made the decision to prohibit it. To our knowledge, there has been little research as to the impact of MAID on the work of hospice staff.

5. *Purpose of the study*

The purpose of this study is to identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care. The hospice approach to care refers to the hospice palliative care that is provided within freestanding hospices.

This study will answer the question: what challenges and opportunities for hospice workers does MAID bring to the hospice approach to care?

6 . Study procedures

The individual interviews will be conducted within the participating hospices. Prior to the interview, you will be informed about the project you are about to take part in, and we will ask you to provide verbal consent, as well as a signed consent form that we will have been given to you before the interview. This form will then be returned to the researchers and the interview will then begin. The interview will involve a conversation facilitated by a researcher, James Mellett; it should last approximately 45-60 minutes. Each interview will be audio-recorded to ensure that no information is lost, though should you request that the interview not be recorded, your request will be honoured. For this same reason, during interviews, field notes will be taken by a second researcher. Field notes are a researcher's personal thoughts, ideas, and questions regarding their observations made during an interview. After each interview, the audio-recording will be transcribed in preparation for data analysis.

7. *Potential Risks or Benefits*

You will not directly benefit from this study; however, your participation will help identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care.

You may experience a variety of emotions due to the topic of discussion or in the case of an intense discussion; however, it is not expected that you will be exposed to any additional risks beyond those you encounter in your daily life. In addition, your participation is entirely voluntary. If needed, researchers are prepared to inform you of mental health supports affiliated with the organization from which you were recruited. Contact information for professional mental health supports can be found at the bottom of this document.

8. Voluntary Participation and the Right to Withdraw

Your participation in this interview is entirely voluntary. During the interview, if you feel uncomfortable for any reason at all, you have the right not to respond, and to terminate the interview if you prefer. Any information you share can be deleted at your request, up until the point of data analysis; after analysis, it can no longer be removed for the study.

9. Confidentiality

Researchers will use the collected study information with the sole intent of fulfilling the study's purpose:
to identify the challenges and opportunities for hospice workers that MAID brings to the hospice approach to care.

In order to maintain confidentiality, all data will be recorded using a pseudonym for individual participants. Hospice sites are recorded using the province in which they are located. Only the researchers and Institutional Review Board (an ethics review board) are aware of the identity of the participating hospices. All digital study data, including the audio-recordings, will be stored on a password protected McGill server to which only the researchers have access. Paper documents (transcribed audio-recordings, consent forms, and questionnaires) will be kept in a locked filing cabinet in the residence of James Mellett between July-August 2019, and in a locked filing cabinet in the office of Dr. Mary Ellen Macdonald at McGill University from September 2019 onwards. All data will be stored for a period of seven (7) years after the study results are published. The audio files and all data will be kept for seven years following the study's conclusion and will then be destroyed. Members of the McGill Institutional Review Board (an ethics review board), or persons designated by this Board may access the study data to verify the ethical conduct of this study.

The results of this study will be published as a thesis and/or in academic journals, and/or presented at academic conferences. Your identity will not be shared or published. If the researchers want to quote something you have said during the focus group, the information will only be referenced to the study code or pseudonym.

10. Funding of the research study

This study has not received any outside funding.

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11. Compensation

You will be offered a $10.00 gift certificate for your time.

12. Contact Information

If you have any question regarding to the study, you may in contact the investigators of the study at:

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If you have any questions about your rights as researcher participant, please contact Ms. Ilde Lepore, Ethics Officer of McGill's Institutional Review Board at 514-398-8302.

If you require professional mental health support please contact: [the exact contact details for professional mental health support will be added here after discussion with key informants at the two hospice sites, and the information provided will be tailored to each site.]

Consent Statement

I have read the information presented in this consent form, or I have had the purpose of the study, the study procedures, and risks and benefits of the study explained to me. Any questions that I had were answered. I am aware that I can withdraw from this study at any time. I agree to take part in this study. I do not give up any of my legal rights by signing this consent form. I can request a signed and dated copy of this consent form.

Do you agree to be audio-recorded during interviews? Yes ☐ No ☐

Signature:_______________________________

Print name:______________________________

Date:___________________________________

Person who obtained consent

I confirm that a copy of this signed consent form will be provided to the participant.

Name of person who obtained consent ______________________________

Signature of person who obtained consent (Date: day/month/year) _________

Appendix D: Report guide for focus groups and individual interviews (as developed by Dr. Macdonald)

Interview Report Form

Title of project:

Code/Interview #:

Name of interviewer:

Date / time of interview:

Location of interview:

Recruitment strategy:

Description of participant: [e.g., pertinent information such as gender, age, profession, relevance of participant to project, language of interview]

1- How did the interview unfold?
   a. Was the participant on time? Were you?
   b. Were you alone with the participant; if not, who else was there and why? What was the impact of any additional people on the encounter?
   c. How did the participant seem to you: e.g., At ease? Nervous? Anxious? Tired? Engaged? Did this change in any way as the interview progressed?

   d. How would you characterize the atmosphere of the conversation; why/how?: e.g., a chat or a debate? Was there anger? Suspicion? Laughter?

2- During the interview, were there events that upset the flow? (e.g., phonecalls, visitor arriving?) If yes, what happened and how did this affect the conversation?

3- Was there important information that was discussed when the audiorecorder was turned off? If yes, please describe.

4- Was the participant shy or intimidated by you? By the subject of the conversation? By the audio-recorder? How may this have affected the data?

5- Reflexivity: What strategies did you use to prompt the interviewee? How well did they work? Were there times when you felt the interview was going particularly well / not well? Why was this the case? What do you have in common with this interviewee? How might this have shaped the interaction?

6- What were the main issues or important questions that came up during the interview?

7- Summarize the information in each of the main domains of the interview guide.

8- What new ideas or hypothesis or intuitions were suggested by this encounter?

9- Methodological reflections: What did this encounter teach you about the strengths and limits of this tool (interviewing)? What/how might you change in future encounters?